



**Supporting young people whose parents use substances:  
A qualitative exploration and co-production approach**

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## Abstract

**Background:** Parental substance use is highly prevalent worldwide, presenting major child safeguarding and public health concerns, with young people often experiencing adverse impacts. Evidence-based interventions principally focus on the parent themselves aiming to reduce the risk to children or aim to affect change at the family level. Whereas interventions that are child- and young person-focused are limited and have low quality effectiveness.

**Aim:** To explore and develop a child- and young person-centred understanding of their lived experiences with parental substance use, perceived impacts, and coping strategies as well as young peoples' and practitioners' views on supporting young people whose parents use substances, to inform the development of future co-produced intervention(s) that address the needs of young people with experience of parental substance use.

**Methods:** A qualitative systematic review examined current published evidence on young people's experiences of parental substance use, their perceived impacts, and coping strategies. In-depth, semi-structured interviews and focus groups were conducted with young people whose parents use substances and health and social care practitioners. Data were analysed thematically to understand how experiences of parental substance use related to young people's support needs and how practitioners currently support young people. Co-production workshops with stakeholders were conducted online to prioritise intervention ideas for supporting young people whose parents use substances.

**Results:** Findings from the systematic review and qualitative interviews highlighted strategies children and young people used to manage and mitigate vulnerabilities and be resilient to unpredictable, adverse, isolating, and often stigmatising experiences. Three co-production workshops with young people and practitioners found that interventions that target loneliness, overcome stigma, and enhance agency are prioritised.

**Discussion:** Ensuring young people feel connected to other young people who experience parental substance use can help develop young people's resilience, reduce feelings of isolation and loneliness, and overcome stigma. Strategies within the school environment, including developing storybooks depicting common emotional and social experiences of children who experience parental substance use, as well as developing specialised training for practitioners to understand what it feels like to be a young person living with parental substance use could prove useful. Digital interventions may also support and develop agency amongst young people and empower them to engage in support earlier. Further co-production is necessary to develop intervention(s) that are acceptable, feasible, and effective.

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- Shortlisted within the top three most read blog posts of 2022 on the Fuse Blog for a post co-wrote with a young person, posted in December 2022.  
Blog post can be viewed here: <https://fuseopenscienceblog.blogspot.com/2022/12/what-support-do-children-and-young.html>
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## Table of Contents

Abstract.....	i
Acknowledgements .....	ii
Publications, Funding, and Awards Associated with this Thesis .....	iv
Table of Contents .....	v
List of Abbreviations .....	xi
List of Figures.....	xii
List of Tables.....	xiii
Chapter 1. Introduction.....	1
1.1    Overview .....	1
1.2    Background and Area of Study .....	1
1.2.1    Definition and prevalence of parental substance use.....	1
1.2.2    Impacts on children and young people .....	4
1.2.3    Interventions and support for children and young people .....	8
1.3    Aims and Objectives .....	13
1.4    Overview of Thesis .....	14
Chapter 2. Philosophical, Theoretical, and Methodological Positioning .....	15
2.1    Overview .....	15
2.2    Philosophical Orientation.....	15
2.3    Theoretical Stance .....	17
2.3.1    Ecological systems theory .....	17
2.3.2    Resilience: multi-system model .....	18
2.3.3    Stigma.....	20
2.3.4    Other constructs useful for this thesis .....	22
2.3.5    Summary of theories.....	24
2.4    Co-production Approach to this Research: Involvement and Engagement .....	25
2.5    My Reflexive Account .....	26

2.6	Chapter Summary .....	30
Chapter 3. Qualitative Systematic Review .....		32
3.1	Overview.....	32
3.2	Aims and Objectives.....	32
3.3	Methodology.....	32
3.3.1	Rationale for conducting a qualitative systematic review .....	32
3.3.2	Approach taken in identifying studies .....	33
3.3.3	Approach taken for quality appraisal .....	34
3.3.4	Approach taken for synthesis .....	35
3.3.5	Registered review protocol .....	36
3.4	Method.....	36
3.4.1	Review question and eligibility criteria .....	36
3.4.2	Scoping, searching, and selecting the literature .....	38
3.4.3	Data extraction .....	39
3.4.4	Quality appraisal .....	40
3.4.5	Data synthesis .....	40
3.4.6	Public and practice involvement in the synthesis .....	42
3.5	Findings: Description of Included Studies .....	44
3.6	Quality of Studies .....	47
3.7	Synthesis of Findings.....	51
3.7.1	Living with the unpredictable: insecurity within the family .....	51
3.7.2	Social and emotional impact of parental substance use .....	54
3.7.3	Controlling the uncontrollable: creating safety within the family .....	59
3.7.4	Coping with and resisting the emotional and social impacts .....	61
3.7.5	Formal and informal support.....	64
3.8	Identified Gaps and Needs for Further Research.....	67
3.9	Chapter Summary .....	69
Chapter 4. Qualitative Fieldwork with Young People & Practitioners.....		70

4.1	Overview .....	70
4.2	Aims and Objectives .....	70
4.3	Insights Informing the Methodology.....	70
4.3.1	Qualitative systematic review.....	70
4.3.2	Public and practice involvement.....	71
4.4	Methodological Approach to Fieldwork .....	71
4.4.1	Rationale for interviews and focus groups .....	71
4.4.2	Approach taken in conducting interviews and focus groups.....	73
4.4.3	Sampling strategy .....	76
4.4.4	Ethical considerations for young people .....	77
4.4.5	Approach to data analysis.....	81
4.5	Data Collection Methods.....	82
4.5.1	Ethical approval.....	82
4.5.2	Eligibility criteria.....	82
4.5.3	Recruitment strategy and sampling .....	83
4.5.4	Research process.....	85
4.6	Data Analysis .....	86
4.7	Findings: Participant Demographics .....	89
4.7.1	Young people sample characteristics .....	89
4.7.2	Health and social care practitioner sample characteristics .....	92
4.8	Overview of Themes: Supporting Young People Whose Parents Use Substances	93
4.9	Theme 1. Navigating Trauma and Safety Within the Family .....	93
4.9.1	Young people under stress: ‘a sprinkle of trauma’ .....	94
4.9.2	Needing space for themselves .....	99
4.9.3	Developing relationships and trust within support.....	103
4.10	Theme 2. Enhancing Young Peoples’ Agency.....	105
4.10.1	The pursuit for agency .....	105
4.10.2	Negotiating support together and building agency.....	108

4.11	Theme 3. Understanding Young Peoples' Experiences of Resilience and Stigma: The Role of Surviving or Thriving .....	112
4.11.1	Surviving is a lonely experience .....	112
4.11.2	Supporting young people to thrive emotionally and socially .....	119
4.12	Theme 4. Building Resilient and Non-stigmatising Systems around Young People 125	
4.12.1	The need for poverty informed services .....	125
4.12.2	Training and investment can help young people feel acknowledged .....	127
4.13	Chapter Summary .....	130
Chapter 5. Co-production Approach to Prioritisation .....		132
5.1	Chapter Overview .....	132
5.2	Aims and Objectives .....	132
5.3	Methodological Approach to Workshops .....	132
5.3.1	Rationale for prioritisation of interventions .....	132
5.3.2	Rationale for approach to prioritisation .....	133
5.3.3	Rationale for prioritisation criteria .....	135
5.3.4	Approach to developing prioritisation content and activities .....	136
5.3.5	Prioritisation outputs .....	137
5.4	Methods .....	138
5.4.1	Ethics and governance .....	138
5.4.2	Eligibility criteria .....	138
5.4.3	Recruitment strategy .....	138
5.4.4	Prioritisation process .....	139
5.5	Data Analysis .....	149
5.6	Findings: Demographics .....	149
5.6.1	Young people .....	149
5.6.2	Practitioners .....	149
5.7	Findings: Prioritised Intervention Ideas .....	149

5.7.1	Young people.....	150
5.7.2	Practitioners .....	153
5.7.3	Selection of intervention ideas .....	156
5.8	Findings: Intervention Principles .....	156
5.8.1	Creating connections amongst young people .....	156
5.8.2	Raising practitioner and public understanding and awareness.....	158
5.8.3	Allowing for flexibility, personalisation, and agency .....	160
5.9	Chapter Summary.....	161
Chapter 6. Discussion .....		163
6.1	Overview .....	163
6.2	Summary and Interpretation of Key Findings.....	163
6.2.1	A school-based approach to supporting children and young people .....	163
6.2.2	A direct approach to supporting young people.....	172
6.2.3	Macrosystem changes.....	177
6.3	Strengths and Limitations.....	179
6.3.1	Approach .....	179
6.3.2	Qualitative systematic review.....	182
6.3.3	Qualitative fieldwork.....	184
6.3.4	Prioritisation and workshops .....	189
6.3.5	Applicability to other adverse experiences.....	190
6.4	Implications for Policy, Practice, and Further Research .....	191
6.5	Conclusion.....	194
Appendix A. Prospero Registration for the Qualitative Systematic Review.....		197
Appendix B. Full Search Strategy for the Qualitative Systematic Review .....		202
Appendix C. Practitioner Involvement and Engagement Event Details for the Qualitative Systematic Review Findings .....		213
Appendix D. Summaries of Studies Included within the Qualitative Systematic Review.....		214
Appendix E. Full Quality Appraisal for the Qualitative Systematic Review.....		222

Appendix F. Included Studies within Each Theme of the Qualitative Systematic Review...	228
Appendix G. NHS Ethical Approval, HRA Approval, and COVID-19 Amendment .....	232
Appendix H. Interview Information Leaflet for Young People.....	245
Appendix I. Digital Advert for the SPRing Study .....	247
Appendix J. Interview/Focus Group Information Leaflet for Practitioners.....	248
Appendix K. Topic Guides .....	250
Appendix L. Example Coding of Transcript with Young Person Advisory Group.....	256
Appendix M. Initial Codes Identified with Young Person Advisory Group .....	257
Appendix N. Visual Representation of Ongoing Analysis .....	261
Appendix O. Visual Representation of Final Themes Before Write-up .....	262
Appendix P. Practitioner Workshop and Engagement Event Details for the Prioritisation of Intervention Ideas.....	263
Appendix Q. Practitioner Workshop and Engagement Event Programme .....	264
Appendix R. Example Personas.....	265
Appendix S. Interactive Jamboard Slides for the Intervention Ideas Grouped as ‘Nice if They Existed but Not Essential’ by Young People at the Group Consensus Workshop .....	266
Appendix T. Interactive Jamboard Slides for the Intervention Ideas Grouped as ‘Low Priority and Not Essential’ by Young People at the Group Consensus Workshop.....	267
Appendix U. OMBEA Response Live Graphs from the Practitioner Workshop for Low Priority Intervention ideas.....	268
Appendix V. OMBEA Response Live Word Cloud from the Practitioner Workshop for Low Priority Intervention Ideas .....	269
References.....	270



## **List of Abbreviations**

ACMD: Advisory Council on the Misuse of Dugs

CAMHS: Child and Adolescent Mental Health Service

CASP: Critical Appraisal Skills Programme

DI: Dyadic Interview

FG: Focus Group

IPVA: Intimate Partner Violence and Abuse

MRC: Medical Research Council

NHS: National Health Service

PPIE: Public and Practice Involvement and Engagement

UK: United Kingdom

USA: United States of America

VCSO: Voluntary and Community Sector Organisations

YPAG: Young Person Advisory Group

## List of Figures

Figure 2.1 Multi-systems model of resilience taken from a) Liu et al. (2017) and b) later adaptation and renaming in Liu et al. (2020) .....	20
Figure 3.1 A framework of the developing descriptive themes.....	41
Figure 3.2 A depiction of the descriptive themes within the review findings after public and practice involvement for the a) lived experiences, b) perceived impacts and c) coping strategies of children and young people whose parents use substances. ....	41
Figure 3.3 Flowchart of included studies.....	45
Figure 4.1 Depiction of the identified themes regarding supporting young people whose parents use substances.....	93
Figure 5.1 Three-stage approach to the intervention prioritisation process with multiple stakeholder groups .....	140
Figure 5.2 Two of the developed personas used in the consultations and workshops with young people to facilitate prioritisation of intervention ideas .....	145
Figure 5.3 Jamboard slides from the workshop with young people regarding their ‘absolutely essential’ and top prioritised intervention ideas.....	153
Figure 5.4 The OMBEA response live graphs produced during the practitioner workshop for prioritised intervention ideas.....	154
Figure 5.5 The OMBEA response word cloud produced during the practitioner workshop for the top priority intervention ideas .....	155
Figure 5.6 High-level logic model for children’s educational resources .....	158
Figure 5.7 High-level logic model for specialised training for teachers/school staff .....	159
Figure 5.8 High-level logic model for a digital application.....	161

## **List of Tables**

Table 3.1 Brief descriptive summaries of the thirty-five included studies with quality appraisal (Key paper: A/B; Satisfactory paper: C) .....	48
Table 4.1. Demographic details of young people whose parents use substances.....	90
Table 5.1 Twenty intervention ideas regarding how to support young people, proposed by young people and practitioners within the earlier stages of this thesis .....	142
Table 5.2 The intervention ideas in order of highest priority to lowest priority based on the young person group consensus workshop. Initial rankings and scores based upon the individual consultations are also shown in column three. ....	150

# Chapter 1. Introduction

## 1.1 Overview

This chapter presents the background and need for this research, focusing on the prevalence of parental substance use, the impacts to children and young people, and then detailing the interventions and support for young people whose parents use substances. The aims and objectives are then outlined. This chapter concludes with an overview of the chapters within this thesis.

## 1.2 Background and Area of Study

### *1.2.1 Definition and prevalence of parental substance use*

Globally and nationally, the use of substances, encompassing both illicit drugs such as heroin, licit drugs such as alcohol or prescribed drugs, and poly (multiple) drugs, is a major public health concern (WHO, 2018). Substance use contributes to over 200 health conditions, high morbidity rates and premature death (Degenhardt et al., 2018; WHO, 2018). Whilst there is extensive evidence that substance use poses a significant risk to the individual users, it also has harmful impacts on those around them, including partners, friends, or wider family members (Nutt, King, & Phillips, 2010). Children are particularly vulnerable to the impacts of parental substance use, which is a major child protection and public health concern (Canfield, Radcliffe, Marlow, Boreham, & Gilchrist, 2017).

When it comes to parental substance use, the level of alcohol or drug use at which parenting becomes impaired is unclear. A range of substance-related terminology are used interchangeably throughout studies, making comparisons between studies confusing and difficult. However, there is clear and consistent evidence for dependent levels of alcohol and/or drugs impacting upon children and emerging evidence that this is also true of problematic levels below the diagnostic threshold for dependency (Foster, Bryant, & Brown, 2017; McGovern et al., 2020). Substance use is on a continuum. Drug use can range from any illicit use to dependence, as well as the misuse of prescription drugs (WHO, 2006). For alcohol use, there is low-risk drinking, which is within legal and medical guidelines that is unlikely to result in alcohol-related problems (DHSC, 2016), to high-risk drinking and dependence that can result in alcohol-related problems (Kaner, 2007). Screening tools such as the Alcohol Use Disorders Identification Test can help measure and identify problematic or risky use, with ‘hazardous drinking’ defined as consumption of alcohol that increases an

individual's risk of physical (e.g., accident) or psychological (e.g., mood disturbance) consequences and 'harmful drinking' defined by the presence of adverse physical (e.g., liver cirrhosis) or psychological (e.g., depression) consequences (J. Saunders, Aasland, Babor, De La Fuente, & Grant, 1993). Hazardous and harmful drinking can also be referred together as excessive or heavy drinking. Moreover, diagnostic threshold for dependence (alcohol or drugs) is three or more of the following present together at some time during the previous year: a strong desire or sense of compulsion to take the substance; difficulties in controlling substance-taking (onset, termination, or levels of use); a physiological withdrawal state when substance use has ceased or has been reduced; evidence of tolerance; progressive neglect of alternative pleasures or interests; and/or persisting with substance use despite clear evidence of overtly harmful consequences (WHO, 2016).

For this thesis, the definition for parental substance use will include any substance use, including alcohol, illicit drugs, or the misuse of prescription drugs that has the potential to cause harm to a child in their care, with the focus being on the young person's interpretation of that impact/harm, rather than specific guidelines or thresholds being met. This is to ensure the research remains central to the young person's experience and does not exclude anyone based on whether they know if their parent's use is at dependent levels or otherwise.

Furthermore, the term "substance use" is used instead of "substance misuse" to acknowledge Adfam and Scottish Families' recommendations on reporting alcohol and drugs with dignity, respect, and non-stigmatising language in journalism (Adfam, 2022), which is also encouraging a shift in research reporting. Within the Children Act 1989, a parent is recognised as any adult who is responsible for providing care of a child over a significant period, either full time or part time, regardless of whether they are the child's biological parents (HM Government, 1989). This definition of parent will be used across the thesis, and where applicable, distinction will be made between substance use by mothers, fathers, or otherwise.

The prevalence of parental substance use is difficult to estimate due mainly to the hidden nature of the problem, with some families never coming into contact with services, for instance due to the illicit nature of drugs or the stigma and fear some families may experience (ACMD, 2003; Turning Point, 2006). Several studies have tried to provide estimates of the number of children and young people living with parental substance use, but estimates have primarily focused on parents whose use is of dependent levels, focusing on data from adult treatment populations. Underestimation of the number of parents whose substance use

impacts upon children is therefore likely, due to parents delaying seeking help (Phillips et al., 2007; Powis, Gossop, Bury, Payne, & Griffiths, 2000) or young people delaying seeking help (Houmøller, Bernays, Wilson, & Rhodes, 2011). Within the last two decades, the Advisory Council on the Misuse of Drugs (ACMD) published a first of its kind report providing an estimate of 200,000 – 300,000 children who had been exposed to parental drug use within the United Kingdom (UK) (ACMD, 2003). Whilst these initial estimates supported the political recognition of parental substance use as an area of need, the report had a limited definition of drug use which did not include alcohol, cannabis, polysubstance use, or new substances. Therefore, understanding on the actual prevalence was constrained. Manning, Best, Faulkner, and Titherington (2009) provided prevalence estimates inclusive of alcohol use based on national surveys within the UK, indicating that 22% (2.6 million) of children lived with ‘hazardous’ alcohol use, 6% (705,000) with dependent alcohol use, and 3% (335,000) with parental drug use. This study tried to account for both dependent and non-dependent patterns of use, outside of treatment populations. However, the reliance on survey data to self-report substance use, is likely to be skewed and under-representative of actual levels (Stockwell et al., 2004). Globally, estimates vary, suggesting that between 2 and potentially 37% of children live with at least one parent who uses substances problematically (European Monitoring Centre for Drugs and Drug Addiction, 2008; Galligan & Comiskey, 2019).

Most recently, in the UK, estimates have suggested that around 4% (478,000) of children lived with a parent who meets ‘dependency’ levels of alcohol or drug use in 2019 to 2020 (Children’s Commissioner’s Office, 2020). In addition, a recent rapid evidence assessment of prevalence rates for non-dependent parental substance use found that between 2-4% of parents in the UK were ‘harmful’ drinkers and between 12-29% of parents in the UK were hazardous drinkers (McGovern et al., 2018). Less was known about the prevalence of parental non-dependent illicit drug use but estimates suggested that 8% of children may have lived with a parent who had used an illicit substance in the past year. Prevalence estimates largely cover the ages of young people up to 16 years, without consideration of those who are older, who may still be living with their parents and impacted by parental substance use (Brook et al., 2010). Whilst an accurate estimate of the number of young people living with parental substance use is not available, these persistently high prevalence estimates have led to an increasing body of research exploring the impact of dependent and non-dependent parental substance use on a child’s health, wellbeing and development, and the need for interventions that address the impact upon the child.

### ***1.2.2 Impacts on children and young people***

Research has found that parental substance use can have many different impacts on children and young people. First, parental substance use can impact upon a child's physical health as they are more likely to suffer an injury (ACMD, 2003; Baker, Orton, Tata, & Kendrick, 2015; Bijur, Kurzon, Overpeck, & Scheidt, 1992), experience health problems, including ingestion of harmful substances (Horgan, 2011; Tyrrell, Orton, Tata, & Kendrick, 2012), and have inadequate diets, poor dental hygiene and low weight (Cleaver, Unell, & Aldgate, 2011; Jeffreys, 2009; Joya et al., 2009), often due to neglectful and inadequate parenting practices whilst intoxicated. Parental substance use can also impact a child's emotional, social, and behavioural development. It has been found that young children impacted by parental substance use may experience delayed cognitive and language development (Barnard, 2007) and begin to experience poor school attendance and concentration problems (Díaz et al., 2008; Kolar, Brown, Haertzen, & Michaelson, 1994; Torvik, Rognmo, Ask, Røysamb, & Tambs, 2011). This can then lead to low academic performance later in life (L. Berg, Bäck, Vinnerljung, & Hjern, 2016; Hogan & Higgins, 2001), and risk of truancy (Jennison, 2014), which can be due to living in a complex family environment with a lack of parental support. Furthermore, during adolescence, internalising or externalising problems may become dominant for those whose parents use substances (Velleman & Templeton, 2007). Internalising problems are inwardly directed and can cause distress within an individual including mental health difficulties like anxiety and depression, whereas externalising problems are outwardly directed and can cause discomfort or conflict within the environment including offending or aggressive behaviours (Forns, Abad, & Kirchner, 2011). Young people whose parents use substances are likely to experience anxiety (Lee & Cranford, 2008) and antisocial or conduct problems (Kendler et al., 2013; Molina, Donovan, & Belendiuk, 2010). Both maternal and paternal substance use have been found to be associated with increased odds of internalising and externalising problems (McGovern et al., 2023).

There is also an established literature base suggesting that parental substance use impacts on an adolescent's own substance using behaviours, including early initiation of alcohol and drugs and heavy problem drinking (Chassin, Pitts, & Prost, 2002; McGovern et al., 2020; Smith-McKeever & Gao, 2010; Velleman & Templeton, 2007). Furthermore, these early childhood experiences have a negative impact upon health and wellbeing that can endure into adulthood, leading to replication of risk factors within their own parenting practices in due course (DoH, 2013).

Few studies differentiate between maternal and paternal substance use, tending to use the term ‘parent’, with some longitudinal studies suggesting that maternal substance use has a greater impact on child outcomes (Chassin, Pitts, DeLucia, & Todd, 1999; Christoffersen & Soothill, 2003) while others have argued that paternal substance use is the greatest predictor of risk (Keller, Cummings, Davies, & Mitchell, 2008). However, a recent systematic review identified that both maternal and paternal substance use are associated with increased odds of a child’s drug and alcohol use (McGovern et al., 2023). Clearer distinction of what is meant by ‘parent’ would lead to ease of comparisons between studies.

Whilst the impacts of dependent parental substance use on the child has a more established evidence base than for non-dependent use, the literature (inclusive of the studies named above) is dominated by retrospective cohort studies, survey data, and correlational designs whereby causation cannot be determined as there is no ability to look for patterns or trends over time. Relatively few prospective longitudinal studies have addressed the impact of parental substance use on young people and mixed findings are present (Bayer et al., 2012; Girling, Huakau, Casswell, & Conway, 2006; Rossow, Felix, Keating, & McCambridge, 2016; Van der Zwaluw et al., 2008). Additional longitudinal studies would help to ascertain causation by identifying changes and patterns over time to explain to what extent parental substance use impacts a child’s health and development. There may be other factors, that most correlational studies do not consider, that may mediate or moderate the relationship between parental substance use and harm. It is difficult to isolate the effects of parental substance use from other adverse childhood experiences, including but not limited to, parental mental health (Smith-McKeever & Gao, 2010), domestic violence (Cox, Kotch, & Everson, 2003), experiencing abuse or neglect (Dube et al., 2001), or level of deprivation (Cleaver et al., 2011). Such adversities tend to co-occur or cluster and can have accumulative negative and persistent child and adult health outcomes (Felitti et al., 1998). In a recent study based on UK longitudinal data, Adjei et al. (2022) found that poverty can also amplify children’s experiences of adversities, including parental substance use, and is strongly associated with adverse child outcomes later in adolescence, including poor mental health.

Moreover, earlier studies in this field tended to explore parents’ views on the impacts of parental substance use on children, rather than asking the children themselves due to the parents’ expressed reluctance to involve their children directly in the research (Hogan & Higgins, 2001; Kolar et al., 1994). However, these types of studies do not consider the rich and detailed accounts that young people can provide of their perceptions of the impact on



them. Qualitative research eliciting children and young people's experiences of parental substance use has the potential to provide a deeper, child-centred understanding of what it is like for children and young people to live with parental substance use, how it impacts them, and how they cope with their experiences. This understanding can help inform practice and policy, as well as child-focused intervention development. A small number of non-systematic reviews have examined children's experiences of parental substance use (Adamson & Templeton, 2012; Kroll, 2004). However, these reviews were both limited by date and geographical restrictions (UK studies only) or only considered parental alcohol use (Adamson & Templeton, 2012). No thorough qualitative systematic review of children and young people's experiences of parental substance use had been published at the time of starting this doctoral work. Therefore, Chapter 3 within this thesis is based on my recently published qualitative systematic review on this topic (Muir, Adams, et al., 2022).

Many factors have been broadly theorised as possible mechanisms between parental substance use and child outcomes, one of which is the direct exposure to substance use, either during pregnancy (e.g., foetal alcohol spectrum disorder) or within the home (ACMD, 2003). Another possible mechanism may be ineffective parenting practices and a reduction in parenting capacity caused by the intoxicating effect of the substance and/or withdrawal from it (Kandel, 1990; Miller, Smyth, & Mudar, 1999). Childhood is a dynamic developmental period in which children experience considerable physical, cognitive, emotional, and social changes. Early- to mid-childhood can be categorised from birth to 9 years (WHO, 2019a). During this period, one of the most important factors affecting a child's psychosocial development is the environment in which they are raised (Bronfenbrenner, 1986), of which familial influences and parent-child relationships play a significant role (Park & Schepp, 2017). As children and young people depend on their families to meet many of their needs, this can be negatively influenced by parental substance use (NACD, 2011; Velleman & Orford, 1993; Velleman & Orford, 1999). Furthermore, a child's attachment to their parent or primary caregiver facilitates their social and emotional development, which again may be impacted by parental substance use (Parolin & Simonelli, 2016). Attachment Theory is one of the most accredited models for the conceptualisation of early relationships between the child and the parent (Bowlby, 1969), leading to secure or insecure relationships (Bowlby, 1973). For example, securely attached children experienced their parents' availability, sensitivity, and responsiveness to their needs, while insecurely attached children experienced unpredictable, rejecting, or unresponsive care. Studies have shown parenting practices to be jeopardised by

substance use and therefore affecting attachment, with a lack of parental emotional availability and warmth (Parolin & Simonelli, 2016).

Another possible mechanism is the greater likelihood of children experiencing trauma such as abuse or neglect (Dube et al., 2001). Some mothers who use substances have been found to ignore their child (Dore, 1998), experience and portray feelings of anger and intolerance (Eiden, Peterson, & Coleman, 1999), as well as displaying abusive behaviours such as neglect (Donohue, Romero, & Hill, 2006). Paternal alcohol use also impacts on father-child relationships and attachment (Kelley, Pearson, Trinh, Klostermann, & Krakowski, 2011; Salonen et al., 2023). In contrast, a non-using parent can act as a buffer against the effects associated with the substance using parent (Curran & Chassin, 1996). In support, a review found that the harm to a child increased when both parents use substances as opposed to only one parent, therefore the non-substance using parent can offer some protection to the adverse impacts on a child's development (McGovern et al., 2020).

Times of transition have also been identified as critically important times of social and emotional development in young people, which can be affected by parental substance use (AYPH, 2016). Adolescence is a time of rapid transitions physically, emotionally, and socially, in which parental substance use can have negative impacts (King et al., 2009; Mylant, Ide, Cuevas, & Meehan, 2002). Adolescents affected by parental substance use may lack the parental support and understanding to cope with developmental changes (Taylor, 2013); may be more likely to challenge their parent's behaviour leading to heightened levels of violence (Onyskiw, 2003); or neglect their own needs to care for their parents, restricting their social development (Moore, McArthur, & Noble-Carr, 2011). Adolescence has been conceptualised as including the ages between 10-19 years (WHO, 2017). However, it has been argued that adolescence should cover the ages of 10–24 years as neurocognitive maturation continues past 20 years (Sawyer, Azzopardi, Wickremarathne, & Patton, 2018). Moreover, the NHS long term plan acknowledges the need for children's services to go up to the age of 25 to ease transitions into adult services (NHS, 2019). When thinking about the impacts of parental substance use on young people, there have been a number of studies which have found impact on young people up to the age of 25 (Bailey, Hill, Oesterle, & Hawkins, 2006; Brook et al., 2010; Casswell, Pledger, & Pratap, 2002; Fergusson, Boden, & Horwood, 2008). Moreover, those over the age of 18 may be more open to discuss or disclose their experiences of parental substance use than those who are younger, who may fear stigmatisation or the involvement of social services (Phillips et al., 2007; Powis et al., 2000).

For this thesis, the stated age range for children and young people will therefore be up to 25 years to include young adulthood as an extension of adolescence, where young people may still live with parental substance use, be impacted by parental substance use, and in line with children's services extending to age 25 on a trial basis (NHS, 2019). The lower threshold for the qualitative systematic review will be those who have ability to speak for themselves, with a later focus during the qualitative fieldwork on those aged 11-25 years, covering adolescence to young adulthood.

### ***1.2.3 Interventions and support for children and young people***

Safeguarding and protecting a child against the impacts of parental substance use is of upmost importance (Department for Education, 2018b; TSO, 2004), with some children temporarily removed from parental care until the substance use is under control (Brown & Ward, 2012). Ideally, parents should be treated for their substance use to reduce risk upon the child. However, risk is on a continuum and many risks for the child do not meet safeguarding levels or if they do, the child is exposed to them whilst other work is being undertaken to reduce the parental risk (NSCB, 2018). While prevention of risk would be desirable, this is not always possible. Therefore, the child may also benefit from intervention focused specifically on their needs. This is especially important with regards to parents who may not be seeking treatment but the impacts to the child are prominent (McGovern et al., 2020).

Children and young people whose parents use substances can be supported directly or indirectly with most interventions being indirect, focussed on reducing parental substance use (McGovern, Newham, Addison, Hickman, & Kaner, 2021), or affecting change at a parent level (e.g., improving parenting skills) (Moreland & McRae-Clark, 2018; Peisch et al., 2018). These interventions have been found to show some effectiveness of indirectly improving outcomes for children, yet conclusions were made that child-targeted interventions were also needed to address the lasting impact of substance use. Two examples of parent-focused interventions are 'Focus on Families/Families Facing the Future' (Catalano, Gaine, Fleming, Haggerty, & Johnson, 1999) and 'Parents under Pressure' (Dawe, Harnett, Rendalls, & Staiger, 2003). Both interventions focus on parents who have been prescribed methadone to teach them effective parenting skills and prevent them from relapsing. Children are usually minimally involved, with the focus on enabling parents to practice their interactions with their children. These intensive interventions are thought to have an indirect impact on children's wellbeing by helping parents to create an optimal caregiving environment through reduced use. The Parents under Pressure programme was found to be highly cost-effective (£24,451

per case/£1.7 million net cost saving), which was also estimated to result in 20 fewer child abuse cases per 100 parents receiving the programme (Dalziel, Dawe, Harnett, & Segal, 2015). This programme is also currently being adapted and tested for fathers within the UK (Whittaker et al., 2022). The Focus on Families programme had little impact on child outcomes at twelve month follow up (Catalano et al., 1999) but longer term follow up showed medium effect sizes for reduced risk (odds ratio = 0.53) of their own substance use for male children but not for female children (Haggerty, Skinner, Fleming, Gainey, & Catalano, 2008). However, these interventions do not directly support children with the trauma or harm they may have already or continue to experience, they instead respond to the needs of the parents. They also focus solely on opiate dependent parents who are willing to receive treatment, excluding children of parents who use other substances and are not seeking treatment.

There have also been several reviews examining family-based interventions with inconclusive results (Calhoun, Conner, Miller, & Messina, 2015; Templeton, Velleman, & Russell, 2010). Family-based interventions can involve multiple family members and aim to effect change by strengthening family functioning to reduce negative childhood outcomes. Within adult legislation relating to substance use, the UK government published its Drug strategy, *'From Harm to Hope'* in 2022 (Home Office, 2022). This strategy highlights the importance of reducing parental substance use but also preventing vulnerable children, including those whose parents use substances, from using substance themselves. As such, the strategy does advocate for direct intervention with children, but it has a narrow focus on outcomes and what their needs for support are. This new strategy also introduced the 'Supporting Families Programme', focused on early intervention for families, which will support the government's levelling up mission for people to live longer, healthier lives, in safe and productive neighbourhoods. An example of a statutory intervention in the UK is the Family Drug and Alcohol Court, which aims to reduce the risk of child abuse by bringing together treatment professionals and children's social care (Gifford, Eldred, Vernerey, & Sloan, 2014). Whilst an initial study showed promising results (Harwin, Alrouh, Ryan, & Tunnard, 2013), a longitudinal study found that one-third of children who had gone through this system developed or continued to exhibit internalising (e.g., anxiety) and/or externalising (e.g., violence) behaviours (Harwin, Ryan, & Broadhurst, 2018). Such an intervention is adult treatment focused, which does not provide specific support to children directly.

Most of the family-based interventions targeting parental substance use are internationally developed, where the initial focus was on reducing the risk of substance use in children of

those whose parents use substances, again with a narrow focus on intended outcomes and support needs. Some examples include those from the United States of America (USA); ‘Strengthening Families Programme’, those from Australia; ‘Mirror Families Programme’, and from the UK; ‘Moving Parents and Children Together’ (M-PACT). These interventions are inclusive of different family members and provide specific support to parents and children both jointly and separately. The Strengthening Families Programme (Kumpfer, Alvarado, Tait, & Whiteside, 2007) and M-PACT (Templeton, 2014) were found to effectively improve family cohesion through consistent opportunities for positive parent-child interactions (Kumpfer, Whiteside, Greene, & Allen, 2010; Templeton, 2014; Usher, McShane, & Dwyer, 2015). For the M-PACT programme, whilst children liked having support in their own right, many families felt that the intervention needed to be longer to allow for the establishment of therapeutic and trusting relationships (Templeton, 2014). Both also target families where the parent is already engaging in treatment services or actively seeking support, excluding those children whose parents are not ready to receive support. To counter this criticism, a further iteration called M-PACT+ was delivered within a school setting, where children and their families could be referred into the programme without having a parent who was in treatment (Laing, McWhirter, Templeton, & Hannah-Russell, 2019). Whilst providing these services within a school setting rather than treatment service was seen as non-stigmatising for the parent, engagement was low due to the schools feeling like they had limited ownership over the programme for families. Mirror Families Programme is community based and aims to bring families without substance use together with vulnerable families, who can provide ongoing and sustained support, including both parents and children (Brunner & O’Neill, 2009). This support has proven useful in reducing the social isolation of families and providing consistent care for children (Tsantefski, Parkes, Tidyman, & Campion, 2013). However, for this programme to work, parents had to commit to maintaining relationships with the mirror families, which again placed the focus of the intervention on the needs of the parents rather than the wishes of the child.

Currently, there are no statutory requirements for providing support services that address emotional and social wellbeing directly to children and young people affected by parental substance use within England. The national guidance, ‘*Working together to safeguard children*’ notes that practitioners should be ‘alert’ to children living in a family that has ‘challenges such as drug and alcohol misuse, adult mental health issues, and domestic abuse’ but does not include obligations for commissioning services within local authorities to respond to the needs of children impacted by parental substance use (Department for

Education, 2018b). A systematic review undertaken by McGovern, Smart, et al. (2021) exploring psychosocial interventions for family members affected by substance use, identified a limited number of evidence-based interventions that were directly targeted towards children and young people whose parents use substances. Of those identified, most utilised cognitive behavioural therapy or self-help techniques, targeted towards adult children, and showed low-quality evidence of effect. Moreover, a recent review of reviews identified a gap in evidence for interventions that directly intervened with children of parents who use substances, calling for interventions to be developed and informed by those with lived experience (Barrett et al., 2023). An example of an intervention that directly supports young people is 'Trampoline', a German community-based psycho-educational preventive intervention for those aged 8-12 years whose parents use substances, which predominantly utilises play based learning within a safe environment. A randomised controlled trial identified that Trampoline reduced social-isolation and improved parent-child relationships with small effect sizes (Bröning et al., 2019). However, most of the centres involved in the trial were adult substance use services and therefore further work needs to be done on inclusive support for young people whose parents are not already in treatment.

Relatively few school-based interventions have been developed to intervene directly with young people to try and improve outcomes for those whose parents use substances. These have largely been developed within the USA, adopting a peer support model rather than involving family members. In a review of interventions for children, Bröning et al. (2012) identified that CHOICES (Children Having Opportunities in Courage, Esteem, and Success) was the superior school-based intervention for children, as it utilised multiple-components, included social and emotional support, and took a long-term approach to providing support. It also focused on multiple areas of risk and was not targeted to parental substance use only (Horn & Kolbo, 2000). Whereas another school-based intervention (e.g., Friends in Need), which targeted small groups of children whose parents had been identified as using drugs, found no change in the main outcome of isolation and loneliness (Dore, Nelson-Zlupko, & Kaufmann, 1999). Whilst the authors identified the limited number of sessions offered may be the cause, this could also be due to the targeted nature of the intervention, which could lead to further stigmatisation and isolation of this group of young people within the school as they are identified and targeted as 'different'.

A further example of an intervention that directly intervenes with the young person comes from Northern Ireland and is called 'Steps to Cope' (Templeton & Sipler, 2014). This model

is adapted from the adult-focused ‘5-step method’ developed in response to the ‘stress and strain’ experienced by adult family members whose loved ones use substances (Copello, Templeton, Orford, & Velleman, 2010). This is a structured approach that focuses on stress, strain, information, coping and support. Whilst the Steps to Cope model provided a structured framework for practitioners, a limitation of the model was its short-term nature impacting on practitioners’ ability to build trusting relationships with a young person and the lack of flexibility to engage with a child (Templeton & Sipler, 2014). As it was adapted from an adult focused model, the changes made may not be in line with the needs of young people.

Moreover, the Office for Health Improvement and Disparities (formerly known as Public Health England) commissioned a consultation activity with practitioners, commissioners, and managers working in substance use services. The published report identified that practitioners had difficulty implementing support in practice to parents and young people and clearer guidance was needed (Public Health England, 2018). Responsibility for children whose parents use substances crosses several governmental and local authority departments, spanning over adult treatment services and children's services (POST, 2018). Nationally, less than half of local authorities had a specific strategy to support children whose parents use substances, identifying a national ‘postcode lottery’ to service provision (POST, 2018; Templeton, Novak, & Wall, 2011). Moreover, current support tends to focus on the needs of children whose parents use alcohol rather than those of parental drug use (Children’s Commissioner’s Office, 2018). More research is needed to determine what support for children and young people is considered acceptable and feasible in practice by practitioners.

In summary, interventions tend to indirectly target children and young people with a focus on those whose parents are engaging with treatment services. Family-based interventions are a step closer to directly involving the young person but are often time-limited, put the parents needs first, or are based upon parental engagement in support. Despite high prevalence rates of young people experiencing parental substance use and the associated impacts and outcomes, there is a lack of evidence-based co-produced interventions specifically focused on directly intervening with children and young people whose parents use substances. Most interventions that are targeted directly for children and young people have been developed internationally, which may have different contextual issues than an intervention based in the UK. Likewise, these interventions tend to focus on young people’s own substance use, or they may possibly incite further stigma if the young person is singled out in school. There is a need for interventions that are developed exclusively for young people, regardless of whether their

parents are in treatment, and that are co-designed by young people to be relevant and acceptable to their needs. At the time of undertaking this thesis, there was a Cochrane review protocol aiming to explore the effectiveness of interventions to build resilience in children of parental alcohol use, which was due to publish findings (A. McLaughlin, Macdonald, Livingstone, & McCann, 2014). This was thought to identify most of the literature base, which would provide insight into effective strategies to directly support children and young people. I therefore decided not to undertake a systematic review for child focused interventions within both parental alcohol and drug use. Unfortunately, this review has not yet been published.

### **1.3 Aims and Objectives**

The aim of this research is to explore and develop a child- and young person-centred understanding of their experiences with parental substance use, perceived impacts, and coping strategies as well as views on supporting young people whose parents use substances, to inform the development of future co-produced intervention(s) that address the needs of young people with experience of parental substance use.

This aim encompassed three key research objectives:

1. To conduct a qualitative systematic review examining the experiences, perceived impacts, and coping strategies of young people whose parents use substances.
2. To examine the views of young people and health and social care practitioners on the support needs of young people whose parents use substances, exploring their views on past and current support provision, as well as future ideal support provision, through qualitative analysis of interviews and focus group data.
3. To identify, prioritise, and select, intervention ideas for young people whose parents use substances based on insights from young people who experience parental substance use and the practitioners who support them, using a co-production approach. Resulting in the development of guiding principles that underpin acceptable intervention(s) to support young people whose parents use substances.



## **1.4 Overview of Thesis**

Chapter 1: This chapter outlined the background and justification of the research, detailing the specific aims and objectives. This thesis consists of six chapters, and the contents of each additional chapter are outlined below.

Chapter 2: The philosophical, theoretical, and methodological orientation of this research is detailed. A reflexive account of my work is then provided.

Chapter 3: The methodological approach and specific methods of the qualitative systematic review are presented, followed by the thematic synthesis findings.

Chapter 4: The methodological approach and specific methods to the qualitative fieldwork are presented, including in-depth, semi-structured interviews and focus groups with young people and practitioners. The findings of the thematic analysis are then detailed.

Chapter 5: The methodological approach, specific methods, and findings are presented for the co-production approach to prioritisation of intervention ideas supporting young people whose parents use substances. The principles that underpin acceptable intervention(s) are outlined, depicted with high-level logic models of highly rated interventions.

Chapter 6: Each element of the thesis is integrated to discuss the overall contribution to supporting young people whose parents use substances with regards to the wider literature. The strengths and limitations of the research are detailed, followed by a discussion of the policy, practice, and future research implications, with conclusions.

## **Chapter 2. Philosophical, Theoretical, and Methodological Positioning**

### **2.1 Overview**

This chapter presents the philosophical orientation underpinning my research followed by an exploration of the theories that were applied to help interpret my findings. I then detail the co-production approach to this research, involving and engaging young people with lived experience as well as practitioners who support them. Finally, I detail my reflexive account to explore any potential influence my position had on the data and findings within this thesis as well as the research context, whereby the fieldwork was conducted during the COVID-19 pandemic.

### **2.2 Philosophical Orientation**

Researchers adopt different approaches to the study of phenomena, based on their underlying philosophical orientation. The issue of how the social world can be studied raises questions stemming from assumptions regarding ontology and epistemology. Ontology is concerned with the study of being and what constitutes reality, whilst epistemology is concerned with the study of knowledge and how we come to understand reality (Scotland, 2012). Both paradigms fall on a continuum, with ontology ranging from realism to idealism, and epistemology ranging from objectivism to subjectivism, with other positions falling in the middle (Fryer, 2022; Scotland, 2012). One philosophical position is of positivism, which takes a realist and objectivist stance (Scotland, 2012). Realism posits that a reality exists independent of an individual; with objectivist epistemology arguing that reality can be observed and discovered by empirical investigations. Therefore, positivism seeks to apply the scientific paradigm to the social world to identify objective facts and truths (Scotland, 2012). These principles tend to underpin quantitative methodologies, which use data in numerical form to explain a phenomenon or to make generalisations across groups of people, including correlational or experimental study designs. In opposition, another philosophical position is of constructivism, which takes an idealist and subjectivist stance (Scotland, 2012). Idealism posits that there is no reality that exists independent of the human mind; with subjectivist epistemology arguing that reality can only be measured through understanding an individual's social construction of the world and reality. Constructivism is therefore interested in understanding meanings and constructions, which can be interpreted differently between people (Scotland, 2012). These principles tend to underpin qualitative methodologies, which typically aim to explore people's lived experiences, views, and perceptions, including in-

depth interviews or observational studies. However, the philosophical position of critical realism (Bhaskar, 1975, 2008), which takes a realist and subjectivist stance, builds on both approaches to provide a more nuanced account of ontology and epistemology (Gorski, 2013). Critical realism argues that reality cannot be reduced or limited to what we know about reality, which is what positivism and constructivism have been critiqued for (Fletcher, 2017). This position acknowledges that there is an observable reality independent of individual perception but that knowledge about reality is fallible and can be constructed and interpreted in different ways. Critical realism functions as a general methodological framework for research but is not associated with any set of methods, meaning it is a flexible approach to take (Fletcher, 2017). This research has been conducted from a critical realist orientation.

Within critical realism, reality is argued to consist of three stratified domains (Bhaskar, 1975, 2008). First, the actual domain which includes those most closely associated with the observable world, such as actions or events, these occur regardless of human experience or perception. The real includes the underlying mechanisms, structures, or powers that cause events within the actual domain, and tend not to be perceived. Finally, the empirical domain represents our experiences and perceptions of events, through which all domains are viewed, understood, and constructed (Clark, Lissel, & Davis, 2008). These domains provide a useful framework for conceptualising social phenomena, including within this thesis of the experiences and support needs of young people whose parents use substances. It acknowledges that individuals have perceptions and experiences of events which they can speak about (the empirical level) e.g., young people/practitioners rich accounts of receiving or providing support or lack thereof, as well as recognising that there are invisible but altogether real determinants of these events and subsequent experiences (the real level) e.g., discrimination based on societal attitudes to addiction. Moreover, the ontological concept of emergence within critical realism also proves useful within this thesis, with the understanding that social phenomena can be understood at various levels of organisation with each level associated with its own causal powers, for instance across micro (e.g. biological and psychological) and macro (e.g., organisational and social) levels concurrently (Pratten, 2013). Placing an emphasis on uncovering and understanding these underlying mechanisms, especially through exploratory qualitative research can help inform recommendations and ways to intervene, across different micro and macro levels (Fletcher, 2017). Therefore, the focus of critical realism on identifying causal explanations matches the overall methods and aim of this research, to reveal, using a mixture of qualitative and co-production methods and

data collection techniques, the underlying mechanisms of acceptable and useful support for young people whose parents use substances and develop recommendations for intervening.

Critical realism also posits that the world is ‘theory-laden, rather than theory-determined’ and identifying relevant theories that may account for some of the underlying mechanisms of a social phenomenon is an important part of conducting social research (Fletcher, 2017). Applying different theories to data can therefore help to form a deeper and richer analysis. Throughout my research, I identified and considered various theories that might facilitate my interpretation, which were led by my developing findings across the qualitative systematic review and fieldwork. The theories selected to aid my analysis are outlined in the next section.

## **2.3 Theoretical Stance**

### **2.3.1 *Ecological systems theory***

The overarching theory applied throughout this thesis was the ecological systems theory. This is a theoretical framework that was developed to explain how individuals interact with their environment and how this interaction can then impact their development (Bronfenbrenner, 1979, 1986). Utilising the first two iterations of the theories development, the ecological systems theory proposes that individuals exist within a complex system of environmental factors, including family, school, community, and culture. Bronfenbrenner proposed that there are five different levels or systems that make up an individual's environment, and that each level has a unique influence on the individual. The following levels will be depicted in relation to young people. The first level includes the ‘microsystem’, which is the immediate environment that a young person interacts with on a regular basis, such as family, peers, and school. Next, is the ‘mesosystem’, this level refers to the connections between different microsystems, such as the interaction between family-life and school-life. Third, is the ‘exosystem’, including the social and cultural structures that indirectly impact a young person’s development through influencing their environment, such as mass media, educational systems, and health and social care systems. Next, is the ‘macrosystem’, referring to the broader cultural and societal context, including social norms and political and economic conditions that shape the environment in which young people exist. Finally, is the ‘chronosystem’, incorporating the changes that occur over time in a young person’s environment, including life transitions from childhood to adolescence and then into young adulthood, as well as historical events e.g., the COVID-19 pandemic, and cultural shifts.

Ecological systems theory emphasises a developmental perspective, identifying relevant and multi-layered social systems that can interact and influence the developing young person (Bronfenbrenner, 1979, 1986). Differences in individual outcomes can be explained by the way environmental factors affect people, depending on their beliefs and practices and the internal and external resources they have access to. According to this model, individuals' agency and self-development are not diminished, but the range of possibilities or outcomes may be limited and biased for some due to the influence of the broader interconnected systems. For example, poverty can lead to disparities in children's immediate and wider environments that affect young people's choices, which in turn affects children's health in various ways (Kramer et al., 2017). This theory can be applied to understand the many different interacting levels that shape the emotional and social wellbeing of young people whose parents use substances, and to identify at which level(s) support is needed. This contrasts with family systems theory, which tends to underpin current support and practice for interventions with young people whose parents use substances (Lander, Howsare, & Byrne, 2013) and which focuses exclusively on the parent-child relationship and family functioning to improve children's wellbeing (Rothbaum, Rosen, Ujiie, & Uchida, 2002).

### **2.3.2 Resilience: multi-system model**

The concept of resilience has also guided the analysis throughout this thesis, as not all children and young people subsequently develop social, emotional, or behavioural problems after experiencing parental substance use and are therefore considered resilient (Templeton, Zohhadi, Galvani, & Velleman, 2006). Resilience has been widely described as a 'dynamic process encompassing positive adaptation within the context of significant adversity' (Luthar, Cicchetti, & Becker, 2000, p. 543). However, the concept of resilience has been critiqued due to ambiguities in definition, terminology, and measurement between studies. Firstly, resilience was conceptualised as a personality construct, whereby it was viewed as a stable and enduring fixed trait (Funder & Block, 1989). However, this approach implies that children and young people cannot develop resilience or become more resilient with support. Rutter (2012) then argued that resilience is developmental, assuming it can be learned and developed over time in relation to adversity, arguing for a link between the individual and environment. Similarly, it has been found that exposure to low levels of manageable risk can promote positive development, compared to no exposure or high levels of risk (Khanlou & Wray, 2014; Seery, 2011). Moreover, research has also focused on the broader social-ecological factors that promote the development of wellbeing and resilience, as Ungar, Ghazinour, and Richter (2013) argued, 'changing the odds stacked against the individual

contributes far more to changes in outcomes than the capacity of individuals themselves to change' (p. 357). Measures of resilience also highlight the ambiguities in defining resilience, from single factor measures to scales that measure multiple domains (Klika & Herrenkohl, 2013). However, resilience is not thought to be a one-dimensional, dichotomous attribute, as people may be resilient in some areas but not others. Cross sectional and prospective studies have shown that children who seemed resilient in one area e.g., school performance, also possessed low social competence or emotional difficulties (Luthar, Doernberger, & Zigler, 1993).

Regarding the topic of this thesis, researchers have identified protective factors that contribute to resilience and risk factors that contribute to vulnerability in young people whose parents use substances (Park & Schepp, 2015; Wlodarczyk, Schwarze, Rumpf, Metzner, & Pawils, 2017). Protective factors and risk factors can be individual (e.g., having high esteem or low esteem), parental (e.g., positive, and consistent parenting or negative and inconsistent parenting), familial (e.g., no other comorbid psychopathology in parents or additional comorbidities), as well as social (e.g., positive social support or no social support). However, there was no further exploration of wider systems that may impact on resilience amongst young people whose parents use substances.

In response to ongoing debates about what constitutes 'resilience', whether as traits, psychological personality correlates, protective factors, and/or external social and community structures, a multi-system model of resilience has been proposed that conceptualises resilience as an interactive process between an individual, their environment, and adversity (Liu, Reed, & Fung, 2020; Liu, Reed, & Girard, 2017). This model consists of three systems, which have been adapted and refined based on further testing of the constructs (see Figure 2.1). First is the system of 'internal resilience', which includes relatively stable factors within a person such as biology and physical and mental health that can promote wellbeing. Next is the 'coping pursuits' system, which consists of coping strategies, knowledge, skills, and family relationships and social support that enable a person to respond to adversity. The outer system is 'external resilience', which consists of socio-ecological factors that promote resilience, such as access to support services, health and social care, education, as well as policies and norms. This model of resilience fits with ecological systems theory and allows resilience and young people's wellbeing to be understood as an interactive system that is not fixed in time or in situation, nor is it limited to the individual, as resilience can be addressed through broader

initiatives. This model has guided my understanding throughout data analysis, to explore resilience within supporting young people whose parents use substances.

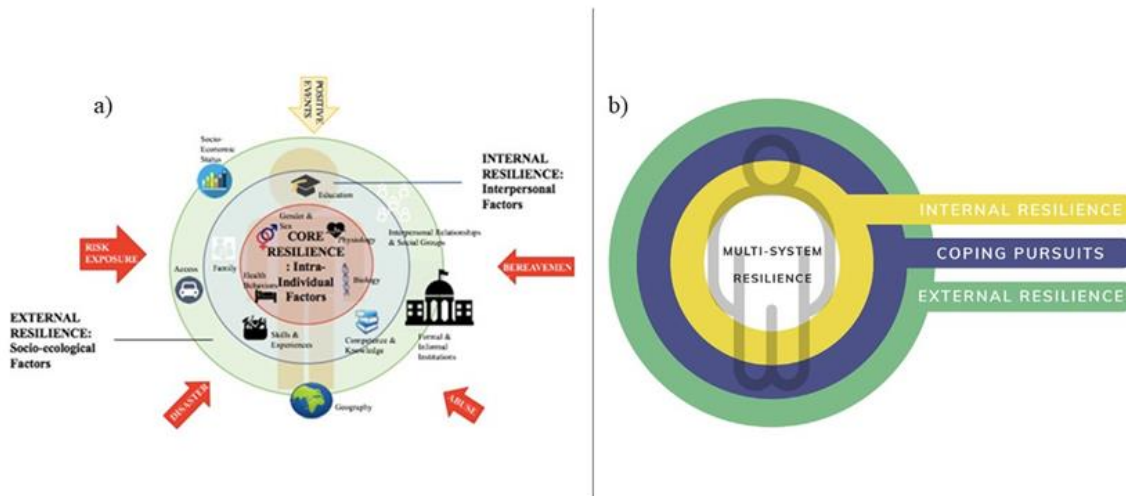


Figure 2.1 Multi-systems model of resilience taken from a) Liu et al. (2017) and b) later adaptation and renaming in Liu et al. (2020)

### 2.3.3 Stigma

Children and young people whose parents use substances can often feel stigmatised impacting their help-seeking behaviours (Adfam, 2012), which has guided the inclusion of stigma related theories within this thesis. This section is based upon a published book chapter I wrote as part of this doctoral work on ‘stigma and young people whose parents use substances’ (Muir, McGovern, & Kaner, 2022). The classic theorisation of stigma is provided by Goffman (1963) in his seminal work on the ‘spoiled identity’, in which he states stigma is a social process where certain groups or individuals possess ‘an attribute that is deeply discrediting’ reducing them ‘from a whole and usual person to a tainted, discounted one’ (p. 3). He also referred to non-stigmatised people as ‘normals’ and goes on to say that when an individual realises that they have failed to conform to or adopt the society’s norms and standards, they will be induced to feel shame and out of this stigma will arise. While Goffman’s work has been hugely influential to the study of how individuals experience living with stigma and stigmatised identities, this research has been critiqued as being too individualistically focused and failing to account for structures of power that inscribe some people with stigma and some as ‘normal’ (Link & Phelan, 2001).

Link and Phelan’s work on conceptualising stigma and ‘stigma power’ has been significant in attempting to focus on the socio-cultural structures of stigma, as well as linking them to individual experiences and interactions (Link & Phelan, 2001, 2014). They conceptualised

stigma as a social process involving labelling, stereotyping, separation, status loss, and discrimination, where unequal power is a necessity for stigma to occur (Link & Phelan, 2001). In this regard, discrimination can be individual, through interactions, as well as structural, occurring within institutional practices or government policies that disadvantage certain groups of people. Thinking about why people stigmatise, three functions have been proposed: (1) to keep people subservient or 'down' through exploitation and domination; (2) to keep people conforming or 'in' through enforcement of social norms; and (3) to keep people 'away' through avoidance (Phelan, Link, & Dovidio, 2008). The role stigma plays in achieving the aims of those who stigmatise and the functions of stigma regarding 'exploitation, management, control, and exclusion of others' is called 'stigma power' (Link & Phelan, 2014, p. 24). This concept has been further extended to understand stigma as a cultural and political economy that leads to social inequality and injustice, especially in thinking about the history of race and class (Tyler, 2020; Tyler & Slater, 2018).

Goffman (1963) also referred to associated others as being stigmatised, called 'courtesy stigma', otherwise known as 'associative stigma' (Mehta & Farina, 1988). Family members are particularly susceptible to associative stigma, due to close physical and/or relational proximity (Larson & Corrigan, 2008). Park and Park (2014) identified 'family stigma' as one key type of associative stigma, which arises from the 'unusualness' of the family, including factors such as parental substance use. Family stigma can be defined by three common attributes: negative attitudes towards a family and avoidance of them, the belief that association with the family could be harmful, and the belief that the entire family is contaminated by association with the stigmatised individual. Stigmatisation by others can have emotional, social, and interpersonal impacts on family members leading to a poorer quality of life (Park & Park, 2014).

Stigma can also operate from self to self, termed self-stigma (Goffman, 1963). Self-stigma essentially turns public stigma inwards on the self. Public stigma reflects the beliefs and attitudes that the public holds about a particular group of individuals or conditions (Corrigan et al., 2010). This can then become internalised self-stigma, where individuals come to make sense of themselves through public stigma and align themselves with the negative stereotypes and societal attitudes that may be ascribed to them, resulting in low self-esteem, shame, and fear (Corrigan et al., 2010; Corrigan, Watson, & Barr, 2006). This awareness of public stigma may also result in stereotype threat or social identity threat, where people believe and fear they will be stigmatised if labelled as different in the eyes of others (Steele & Aronson, 1995).



Research into these concepts as well as other similar concepts, highlights that the existence and knowledge of public stereotypes can harm stigmatised groups, even in the absence of direct stigma and discrimination from another person or institute (Aronson, Burgess, Phelan, & Juarez, 2013). However, for some individuals, living with a stigmatised identity can be an empowering experience (Shih, 2004). This model of thinking views stigmatised individuals as active participants in society who can create positive outcomes for themselves or others. The strength of overcoming and confronting such adversities of stigma lead to individuals perceiving that a situation has made them stronger or more resilient. However, this model places the management of stigma onto the individual and makes structures of inequality invisible when stigma and inequality are inherently linked.

To highlight and unravel these structures of inequality, it can be useful to consider the holistic environment surrounding an individual, especially using Bronfenbrenner's ecological systems theory as defined in section 2.3.1, which can also be applied to the experience of stigma. Kotova (2020) proposed a multi-faceted and cumulative model of stigmatisation that considers 'associative stigma' as well as stigma associated with class, race, and poverty for families of people in prison. They argued that not only do families experience stigma from their connection with a stigmatised individual, and their socially excluded backgrounds, but the stigma is amplified by current political, legal, and social views about value and worth, which can shape senses of identity and belonging. Thus, microsystem (e.g., bullying from peers) and macrosystem (e.g., Government policies) level factors become linked through social injustices and societal stereotypes, and it is through this model of stigma that I explored stigma within supporting young people whose parents use substances.

#### **2.3.4 Other constructs useful for this thesis**

##### ***Agency and resistance***

Alongside models of resilience, I also explored other constructs that were identified during my work through analysis of the data and discussions with public and practice partners. Two of these constructs were 'empowerment' (Christens & Peterson, 2012) and 'edgework' (Lyng, 1990), which position individuals as active and agentic within their environments and experiences rather than passive or only vulnerable. Agentic capacity within young people can be defined as the ability of young people to take an active rather than passive role in shaping their own lives, not only meeting their own needs but also influencing the choices of others (E. Katz, 2015), including a range of behaviours from resilience, resistance, protection, and planning (Callaghan, Fellin, Mavrou, Alexander, & Sixsmith, 2017). Moreover, Valentine

(2011) highlighted that agency is not always affirming of social norms but can be 'irrational' or potentially self-destructive, especially in the context of trauma. Empowerment theory is a framework that recognises the capacities that already exist in individuals, groups, organisations and communities and how societal barriers can impede growth (Christens & Peterson, 2012). For individuals, there are 'empowering processes' in which they attempt to gain control, acquire the resources they need, and understand their environment, and 'empowering outcomes' that are the consequences of attempts to gain control (Rappaport, 1987). Desired outcomes include greater perceived control, skills, and proactive behaviours. Researchers have found that high perceived control, a belief that you can influence the outcome, can reduce psychological stress (Fleming, Baum, & Weiss, 1987). The specific actions taken to achieve goals are not as important as the mere act of trying to exert control. Having awareness of an environment also includes knowing when to engage in conflict and when to avoid it (Kieffer, 1984).

For this research, the concept of 'edgework' further offers a framework to understand why young people who experience parental substance use may enact agency by taking risks within their environments (e.g., engage in conflict with their parents). Edgework is a form of resistance and involves the negotiation of the boundary between safety and risk (Lyng, 1990). Whilst originally used to describe activities like skydiving, it has been applied to instances of resistance in intimate partner violence and abuse (Rajah, 2007), as well as drug use (McGovern & McGovern, 2011). This framework posits that individuals intentionally and skilfully enter situations that may pose a significant threat to them, but they do so to try and control the uncontrollable and to exert agency that others might not be able to do (Lyng, 1990; Rajah, 2007). For this thesis, I explore how young people navigate a family or social environment that may fail to provide a normative and secure base, whether they develop context-specific expertise to establish order and control, and whether in doing so they put themselves at risk or experience rewards (e.g., safety, less conflict, or increased agency). Both constructs, alongside resilience, point to a strengths-based approach to support that goes beyond ameliorating the negative aspects of a situation by identifying the positive aspects and strengths of the individual, as well as understanding and building on their forms of agency and resistance.

### ***Risk and vulnerability***

The concept of 'vulnerability' is often used in the discussion of risk to describe individuals or groups who are considered to be in particular need due to a certain profile of risk factors,

socio-demographic characteristics, or exposure to sources of harm (ACMD, 2018). Labelling of those as ‘vulnerable’ can have benefits as well as disadvantages. Whilst it helps focus attention and resources to those in need, it can also lead to discrimination or stigma (Lloyd, 2013; Room, 2005). Within this research it was important to understand how young people whose parents use substances can be framed as vulnerable and ‘at-risk’ or ‘a risk to themselves or others’. Bancroft and Wilson (2007) argued that there is a constructed ‘risk gradient’ within the United Kingdom’s policy and practice for children whose parent’s use substances. This gradient means that within policy and practice it is assumed that responsibility for harm to the young person lies either with the parents or the young person. To summarise Bancroft and Wilson (2007) work, when children are young, parents are identified as responsible for any harm children and young people might experience, including injury or neglect (Baker et al., 2015). Young children are therefore viewed as vulnerable and in need of supporting. However, as young people grow into their late teens they are framed as ‘risk manifesting’, wherein they are no longer seen as being impacted by parental substance use but who can be held accountable, both legally and socially, for any harm they experience or inflict, including participating in substance use or offending behaviours (Kendler et al., 2013; Smith-McKeever & Gao, 2010). They are therefore deemed ‘risky’ and in need of punishment rather than support. This framing is explored within the data against experiences of stigma and resilience amongst young people whose parents use substances and how it may impact upon support.

### ***2.3.5 Summary of theories***

Within the introduction, I showed how young people have been found to be impacted by parental substance use through cross-sectional studies, highlighting their vulnerable position and need for support. Young people may also experience additional challenges or vulnerabilities by being stigmatised for their association with a parent who uses substances. However, I have also explored theories I have applied to my research that view young people as being resilient, resistant, and expressing agency despite their ‘vulnerable’ positioning. The ecological systems theory emphasises the importance of multiple levels of influence, from the microsystem (individual and immediate environment) to the macrosystem (larger cultural, social, and economic contexts). In the context of resilience, the ecological systems theory can be applied to understand how protective factors at different levels of the social ecology can buffer the negative impacts of parental substance use and stigma. For example, a supportive adult, positive school environment, and access to mental health resources may help a young person develop resilience despite exposure to parental substance use or stigma. Stigma can

also be understood through the lens of the ecological systems theory. The theory highlights the importance of social norms and beliefs that are shared by different systems, such as family, community, and society at large. Stigmatising attitudes and beliefs can impact individuals' self-concept and identity, as well as their relationships with others, which can in turn affect their mental health, wellbeing, and help-seeking behaviours. Overall, the ecological systems theory provides a useful framework for understanding the complex interplay between resilience, stigma, and the different systems in which young people are embedded. By considering the multiple levels of influence on young people's lives, interventions and support services can be designed to promote positive development and wellbeing.

#### **2.4 Co-production Approach to this Research: Involvement and Engagement**

Co-production is understood as a process by which 'citizens', including patients, public members and/or those within practice, take an active role in producing public services, interventions, or policies that have some consequence to them (Brandsen, Verschuere, & Steen, 2018). Building from this literature, co-production is also becoming more prominent within research (Involve, 2018). For research, it is about ensuring that people are involved in what gets researched, how it gets researched, and making decisions about things that may impact them. Within research, young people are being recognised as powerful contributors amplified by legislation specifying the right of a child to be heard on matters affecting them (United Nations, 1989). The National Institute for Health and Care Research co-created key principles and tips for involving and engaging young people in research (Involve, 2016). These principles included involving young people in as many parts of the research as possible and from as early as possible, building and developing relationships, sharing power, offering training and providing opportunity to develop new skills, respecting and valuing all contributions, and providing recognition for contributions. Involving young people in research, within a co-production approach, has been shown to positively impact them through the development of social skills, and when they feel valued as trusted equals it can improve self-esteem and self-efficacy (Mayer & McKenzie, 2017). Co-production also helps to create research that has the most potential to benefit the individual participants and others who share their characteristics or position (Involve, 2018). When co-production is used in the development of interventions it is also more likely to lead to interventions that are acceptable and relevant to the population it seeks to benefit (O'Cathain et al., 2019).

Defining the concept of co-production and how to do it ‘properly’ has been debated, with different academic disciplines and funding bodies using divergent methods and theories (Facer & Enright, 2016). However, this thesis adopts a definition of co-production as ‘an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge’ (Involve, 2018, p. 14). Drawing on critical realist principles, I believe that identifying underlying mechanisms of acceptable and useful support for young people whose parents use substances can be achieved and enriched through the co-production and sharing of different perceptions and understandings of a phenomena (Hodgkinson & Starkey, 2012). Throughout the next three chapters I detail fully how public and practice partners have been involved and engaged throughout my research. In brief, regarding young people, I initially engaged with a local service (i.e., PROPS Young Person’s Project) who support young people with lived experience of parental substance use, who facilitated the involvement of young people in this research. They helped shape the research questions, methods, materials, and early synthesis of qualitative review findings. Due to the COVID-19 pandemic and social distancing in place, I then set up a remote, national lived experience young person advisory group for the project, who supported the qualitative fieldwork analysis, prioritisation of interventions, and dissemination of findings. The project has also drawn on the experience of those in practice, with a practice advisor on the supervisory team helping shape decisions and making sure the research remains relevant within policy and practice. Throughout the project, I have also engaged and involved a wide range of practitioners who support young people with lived experience of parental substance use, at local and national forums and workshop events. Through this co-production approach to research, the project aims to develop recommendations for intervening that are acceptable and relevant to those who would be ‘end-users’ of an intervention (young people with experience of parental substance use) and those who would deliver or implement it (practitioners).

## **2.5 My Reflexive Account**

A reflexive account was kept throughout the research process in keeping with the critical realist orientation of this research. I explored how my own positionality as a researcher may impact and have influence on the data, findings, and subsequent interpretations as well as identified steps to guard against imposing my own world view on the research process and analysis (Berger, 2013; Pilgrim, 2014). My reflexivity was iterative throughout the research process, and I became more intuitive on my positionality the more I read and engaged with

the literature as well as synthesising and analysing the data. Within this research, I was both a researcher with participants during the qualitative fieldwork and a researcher aiming for shared power with practitioners and young people during the co-production and involvement and engagement activities. I therefore kept separate reflective journals on both positions to ensure I was able to move between roles swiftly and meaningfully, and to acknowledge the shift in my focus. Keeping a reflexive journal helped to explore my own views on the topic as well as how these may affect the conduct of my work and findings. Furthermore, regular supervisory and advisory group meetings provided a context where my plans, conduct of the study, and developing findings were discussed.

My academic and professional background is within psychology and health psychology, and I have worked as a peer mentor for young people and as an assistant psychologist in supportive and therapeutic roles. My views on appropriate responses to substance use include taking a preventative and harm reduction approach, as well as focusing on the health and social responses to substance use. Initially, my thinking and focus tended to lean towards individualistic psychological theories and health behaviour change models. But in studying the topic of parental substance use I quickly acknowledged the position of much more than individual behaviour, I was recognising the importance of family, society, and wider factors. I was not focusing on a reduction to the health behaviour of the parent but rather how to support those who are impacted by it across multiple different levels or systems. Due to working within a clinical setting, I originally wanted to screen for parental substance use using clinical thresholds of problematic use, which I believed would make the study robust. However, through public and practice involvement and engagement I learnt that imposing such criteria may result in young people not taking part who are impacted but who were not experiencing parental substance use at a dependent level. Moreover, imposing thresholds would have meant possibly seeking this information from the parent, as the young person may not know. This could have further resulted in young people not wanting to take part because they did not want their parents to know about the study. It would have placed further restrictions on an already hard to engage population group. I moved to a much more child- and young person-centred description of parental substance use, which reflected the nature of my study and subsequent support that may be developed. Furthermore, as I was used to working within supportive roles, I initially found it difficult to switch to the role of the researcher, where I was not there to provide ongoing support. Often, the interviews were an opportunity for young people to talk about their experiences in depth, which could lead to emotionally charged interviews. In these instances, I would want to be able to provide

support. After discussions with my supervisory team, I acknowledged that providing a safe space for young people to talk about their experiences without stigma, judgment, or fear of repercussions could be beneficial for young people. However, to allow myself to feel comfortable within the interviews, I made sure the young person knew I was not there to offer mental health support but could signpost them to appropriate services if they needed. I do believe, however, that my previous training in supportive roles with young people allowed me to remain sensitive and attuned to young people within the interviews, helping to build rapport.

My personal experiences have also shaped my analysis and interpretations. I have experienced family substance use, both within the immediate family and wider family networks when I was a child and adolescent. Whilst I do not have experience of parental/caregiver substance use, I know of the hidden nature of substance use within families and the resulting shame and stigma this may cause. However, from my perspective there is more to family substance use than the negative impacts on young people often reported in research and news reports. It was this awareness that drove me to want to explore how to develop support for young people, and through conversations with lived experience experts and practice partners, I came to understand and acknowledge the young person as both vulnerable but agentic, as someone who needs support but also wants to be empowered. Whilst I could relate to young people about the impacts of substance use, which may place me as an ‘insider’ (Berger, 2013), my experiences were also different as I had experienced loving and stable parents. A sense of needing to have ‘control over the uncontrollable’ and finding agency was not something that I had personally experienced, as my situation was perhaps a little more in control due to my parents’ role within the family. If asked by young people, I would disclose my personal experiences, which facilitated trust and rapport building, with a sense of ‘shared knowledge’. However, I made sure not to make assumptions on what childhood, adolescence, or young adulthood was like for the young people I interviewed and how they were impacted by parental substance use. I acknowledged throughout that young people’s experiences were unique to each child and I made sure to be directed by the topics during data collection and the data during analysis. If a young person assumed I would know something, I tried to encourage them to explain what they meant or how they felt. My experiences provided depth and richness to the interpretations alongside my supervisory team and public and practice advisors. At times I was emotionally affected by young people’s accounts as well as my own reflections on personal experiences. However, through open conversations with my supervisory team, taking regular breaks between interviews, undertaking personal activities

such as yoga, and attending training on researcher resilience, I managed these emotions, and allowed them to motivate me to progress this research. I hope to continue working within this field and co-producing interventions for young people and families.

Other wider levels of influence on the research process included my gender, age, ethnicity, and socioeconomic status. I am female (cisgender), White British, and of a high socioeconomic status. During the interviews and workshops, I was in my late 20s/early 30s meaning I could easily relate to the pressures of adolescence and young adulthood. However, I was aware not to make assumptions about the pressures young people were under and how they may be impacted by parental substance use. I acknowledge these different factors have shaped my experiences, understanding, and presentation to others. I endeavoured to conduct meaningful research with all, but specifically reflected on my ability to access spaces, understand experiences, and analyse data about men and transgender people, those from minority ethnicities, and those of a low socioeconomic status. I kept a reflexive journal, spoke with supervisors, and ensured the advisory groups had a mix of representation to help enrich my research and thinking. For instance, across the young person advisory groups, there were males, a transgender young person, those from minority ethnicities, and those from a low socioeconomic status alongside females, White British young people, and those from a high socioeconomic status. I also ensured when I was visible on camera during video calls with young people that I did not dress in a way that made me look too professional or of a higher socioeconomic status. I also made sure to not have any personal items or objects that could indicate a high socioeconomic status in my background. With practitioners, I tried to dress more professionally when visible on camera. These choices were made to help facilitate a relationship between myself and the participant(s), advisory group members, and stakeholders.

Furthermore, my age was recognised as a positive by both young people and their practitioners who considered me relatable and someone who could understand more easily. This helped reduce some of the power imbalances within the interview for young people. In opposition, this meant that within practitioner interviews and focus groups I felt pressure to present myself as knowledgeable and skilled as a researcher. Due to this insecurity, within the first focus group I tended to contribute my own understandings to the discussions. Upon reflection and after initial transcribing of the audio file I became aware of my behaviour, and realised it may constrain or direct topics, so I sought to portray my confidence in the subject either before or after the focus group/interview with practitioners. As I undertook more data



collection with young people and practitioners in unison, I felt more comfortable changing between different styles and approaches to data collection and how I perceived myself in those interactions.

This research was undertaken during the COVID-19 pandemic, with social-distancing in place during most of the data collection, impacting both myself and participants. This was a unique situation wherein each participant and I had a shared experience that we could reflect on and bond upon. Such a shared experience helped to build rapport quickly during the data collection phase. I also acknowledged that this was a sensitive and emotional time for a lot of people and ensured my study was not putting participants at increased risk, with changes to my study design and inclusion criteria, discussed in more detail in Chapter 4. I also had to ensure I was taking time for myself as the data collection, including emotionally charged conversations, were happening within my home, over the telephone or on video call software. I ensured as best as I could that I worked in a separate space to where I ‘lived’. I would build in time after each interview or focus group to debrief with a supervisor if needed and have time away from my workspace to relax.

I also reflected on the co-production approach, seeking feedback from young people and practitioners on the conduct of the research and their involvement. Where applicable, I would present these findings in a ‘you said, we did’ style at meetings or over email. For instance, some of the feedback I received from young people was that they wanted to choose their own vouchers for their involvement, so this was amended to allow for autonomy and flexibility. Practitioners wanted to be provided with enough time to offer meaningful feedback, which was not always possible with conflicting schedules. To ensure meaningful involvement and to acknowledge time constraints, I often worked with practice advisors separately rather than as a group.

## **2.6 Chapter Summary**

This chapter detailed the philosophical positioning of critical realism applied to this research, which underpinned the methodology of the research. Following this, the justification and rationale of theories that frame the thesis were provided including, ecological systems theory, and constructs related to resilience, stigma, empowerment, and resistance. The critical realism orientation and the selected theories informed understanding of some of the underlying mechanisms of acceptable and useful support for young people whose parents use substances,

explored through a mixture of qualitative and co-production methods and data collection techniques. I then described and justified the co-production approach to this research. Finally, I provided a reflexive account of how my positioning may have influenced the data and findings as well as my methods for trying to address these biases. The next chapter will present the methodology, methods, and findings of the qualitative systematic review exploring the experiences, perceived impacts, and coping strategies of children and young people whose parents use substances.

## **Chapter 3. Qualitative Systematic Review**

### **3.1 Overview**

This chapter presents the methods and findings of the qualitative systematic review exploring children and young people's experiences of parental substance use. First, the aims and objectives are stated, followed by the methodology and rationale to the approach taken. The methods used to identify relevant studies, as well as for data extraction, quality appraisal and analysis are described. Public and practice involvement and engagement in guiding this review is detailed. Studies identified for inclusion within the qualitative systematic review are summarised and the results of the thematic synthesis are presented.

### **3.2 Aims and Objectives**

The primary aim was to conduct a qualitative systematic review exploring children and young people's experiences of parental substance use. Additionally, this review aimed to produce a child- and young person-focused account of their perceived impacts, and strategies implemented to manage the adverse impacts of parental substance use. The main objectives were to identify, appraise, and synthesise qualitative literature on young people's experiences of parental substance use using a systematic search strategy.

### **3.3 Methodology**

#### ***3.3.1 Rationale for conducting a qualitative systematic review***

Systematic reviews aim to summarise and present the current understanding on a given topic, by identifying, combining, and evaluating relevant individual studies (CRD York, 2013). Through transparent, predefined, and rigorous methods, this process can allow for more accessible evidence for practitioners and can guide future research decisions. Initially, systematic reviews were applied to evaluate evidence for the effectiveness of specific interventions using relevant quantitative studies. However, over time, the importance of establishing a more detailed understanding of a phenomenon, through utilising qualitative insights has increased (Noyes, Booth, Cargo, et al., 2018). Such a systematic approach and method can be drawn upon to review qualitative studies as well, which analyse narrative forms of data. Systematic reviews combining multiple qualitative studies can offer new and more comprehensive understandings of a phenomenon across various health and social care contexts (Tong, Palmer, Craig, & Strippoli, 2016).

It has been commonly argued that qualitative research cannot be generalised and is specific to a particular context, time, and group of participants and therefore combining individual studies can be seen as inappropriate and problematic as the reviewer may decontextualise the findings (Campbell et al., 2003; Dixon-Woods, Fitzpatrick, & Roberts, 2001). However, there is a powerful argument for qualitative research to be valued for its potential to inform policy and practice, wherein combining individual studies can lead to greater insights (Newman, Thompson, & Roberts, 2006; Popay, 2006). By examining diversities within a body of literature, such contextual information can be utilised to enhance the understanding of the topic and explore for similarities or differences across studies.

### ***3.3.2 Approach taken in identifying studies***

Search strategies are formal methodological processes used within systematic reviews to ensure transparent, rigorous, and replicable results by others (Higgins & Green, 2011). There is a balance between developing search strategies that are ‘sensitive’ enough to identify a comprehensive literature base and ‘specific’ enough to identify relevant literature accurately and efficiently (The Cochrane Collaboration, 2011). The Population-Intervention-Comparison-Outcome (PICO) tool developed for quantitative review types to aid the design of search strategies has been modified for qualitative reviews with a range of variants (Booth, 2016). The modified PICoS (Population-Phenomena of Interest-Context of study-Type of Study) tool was selected to aid the development of search strategies for this thesis due to findings that it can identify specific and sensitive searches (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014). Identifying qualitative literature across databases can be problematic (Shaw et al., 2004). These difficulties relate to the unreliable nature of indexing of qualitative studies across databases and the lack of keywords in titles and abstracts relevant to identifying such studies (Evans, 2002). Validated search filters, using a combination of predetermined terms, have been designed to maximise the identification of qualitative research within topic-specific searches (Flemming & Briggs, 2007) or specific databases (McKibbin, Wilczynski, & Haynes, 2006). DeJean, Giacomini, Simeonov, and Smith (2016) developed a validated search filter to identify qualitative literature across different health and social science databases. The search strategy used within this thesis drew upon this filter. To maximise sensitivity to relevant articles, key words and database-specific indexing terms were combined with the validated search strategy. Published guidelines for conducting systematic search strategies were consulted to ensure a consistent and rigorous approach was taken (Bramer, de Jonge, Rethlefsen, Mast, & Kleijnen, 2018; McGowan et al., 2016).

Parental substance use from a young person's perspective intersects a range of disciplines across health and social sciences. Therefore, multiple appropriate databases were chosen to encompass relevant fields. Additionally, grey literature sources were searched, for further relevant articles, as publication biases mean qualitative studies can sometimes not be published and voluntary and community sector organisations commonly publish their research outputs as reports on their websites (Dixon-Woods et al., 2001). Backward citation searching (e.g., checking included study reference lists) and forward citation searching (e.g., checking for citations of the included study) were also utilised to identify studies missed by other forms of searching (Briscoe, Bethel, & Rogers, 2020).

### ***3.3.3 Approach taken for quality appraisal***

Whilst quality appraisal is an essential component of quantitative systematic review methodology, the issue of why and how to judge the quality and methodological strengths and limitations of qualitative studies is a controversial topic (Hannes, Lockwood, & Pearson, 2010; Noyes, Booth, Flemming, et al., 2018). The opinion on the value of quality assessment in qualitative systematic reviews remains divided. Some suggest that quality assessment can help determine to what extent the included studies, both singly and collectively, can inform findings or practice recommendations (Britten et al., 2011). Likewise, utilising quality assessment can promote reflection on the appropriateness of the qualitative approach taken and can highlight any issues with transparency, adding to the credibility of findings (Saini & Shlonsky, 2012). In contrast, a primary concern is regarding to the philosophical and epistemological diversity of qualitative research, wherein combining such research would impede meaningful appraisal. Some suggest that assessing qualitative research against specific criteria and applying quantitative paradigms and approaches are not appropriate as they neglect the flexibility needed in interpretative synthesis (Dixon-Woods, Shaw, Agarwal, & Smith, 2004).

Instead of assessing risk of bias like within quantitative studies, reviewers often assess the qualitative rigor of included studies to establish the authenticity of the findings and conclusions. However, there appears to be disagreement over what criteria should be used to appraise quality (Hannes & Macaitis, 2012). There are numerous tools that have been developed to aid researchers and guidance suggests that a tool should be chosen that has multiple components to assess quality in research (Carroll & Booth, 2015). The Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist evaluates studies on multiple criteria including clarity, appropriateness, rigour, and overall value (Critical

Appraisal Skills Programme, 2018). The CASP tool is the most used tool for quality appraisal in qualitative evidence synthesis and can be applied to a wide range of qualitative methodology making it a flexible and robust approach (Noyes, Booth, Flemming, et al., 2018). This is the tool I adopted in this review. Moreover, there is controversy over how critical appraisal findings should be used in a synthesis (Carroll & Booth, 2015). At times, appraisals are used to exclude low quality quantitative studies from the synthesis. However, this causes issues when assessing qualitative studies as there is no consensus over a threshold for exclusion as well as whether the final synthesis benefits from the exclusion of poorer quality studies. Low quality assessment can likely be due to reporting biases within journals wherein authors do not have the space to include full methodological information, rather than a flaw to the study. Some tools also use a numerical scoring system to establish quality, but this approach is criticised for giving weight to issues in methodological quality while simultaneously denying the strength of the findings insights (Dixon-Woods et al., 2004). Rather than to decide whether to exclude lower quality studies or to score numerically, another approach is that studies could be appraised for both their quality and relevance to the review (Malpass et al., 2009). This was the approach taken for this review, utilising a two-stage process adapted from Britten and Pope (2012). Firstly, quality was assessed using the CASP criteria, wherein narrative summaries of the CASP quality appraisal were produced based on reviewers' responses to each of the checklist items. Studies were not excluded based on quality, but a modified rating scale based on Dixon-Woods et al. (2007) and Malpass et al. (2009) was used to aid the synthesis process and decide the relevance of studies to the review. This allowed for a form of 'sensitivity analysis' (Carroll & Booth, 2015), wherein the lowest rated studies based on relevance and quality, were gradually added to the synthesis to explore their contribution to developing themes.

### ***3.3.4 Approach taken for synthesis***

There are two main approaches to qualitative systematic review methods: aggregative and interpretative. Aggregative methods aim to comprehensively summarise data and identify practice and policy applications from qualitative studies. They tend to adopt a realist or pragmatist epistemological framework (Drisko, 2020). An example of which is meta-aggregative synthesis (The Joanna Briggs Institute, 2008). Whilst these approaches can accommodate for 'thin' data with relatively little depth to support understanding (e.g., open-ended responses to surveys), they can be criticised for missing or omitting useful interpretations of the data with a strong focus on practical application (Drisko, 2020). In contrast, interpretive methods aim to generate or enhance prior conceptualisation and theory.

They tend to adopt interpretivist or constructivist epistemological frameworks. An example of which is meta-ethnography (Noblit & Hare, 1988). Whilst these approaches primarily focus on the combining of ‘rich’ data with detailed and nuanced accounts of lived experiences, they can be critiqued for often limiting the inclusion to studies from a single paradigm (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). Thematic synthesis tends to sit between the two approaches, taking a critical realist approach (Barnett-Page & Thomas, 2009). Thomas and Harden (2008) developed this systematic and iterative approach, which shares characteristics of meta-ethnography in that it aims to reinterpret the data from individual studies whilst also aiming to be accessible for practice and policy application. This approach can accommodate for both conceptually ‘thick’ and ‘thin’ data (Flemming, Booth, Garside, Tunçalp, & Noyes, 2019). This thesis adopts a thematic synthesis approach, aiming to reconceptualise the current data on children and young people’s experiences of parental substance use, whilst working with practitioners to ensure the themes presented remain applicable to practice and policy.

### **3.3.5 *Registered review protocol***

The review protocol was registered at inception in June 2019 with PROSPERO, the international prospective register of systematic reviews (CRD42019137486) (Muir et al., 2019). Protocol registration intends to reduce bias in reporting by enabling readers to compare the completed review with the planned approach as well as prevent duplicated work (CRD York, 2013). The registered protocol reports the proposed research questions, search strategy, data extraction and synthesis process (provided in Appendix A).

## **3.4 Method**

### **3.4.1 Review question and eligibility criteria**

Public involvement and engagement activities, including a workshop of four young people (aged 11-17 years) with lived experience of parental substance use, and regular meetings with a practice advisor, initially established what the focus of the systematic review should be so that the outcomes would be relevant to both young people and practitioners (Harris, 2015). Alongside experiences of parental substance use, there was also a need to focus on the perceived impacts of parental substance use and young people’s coping strategies. Review questions and search strategies were then developed using the PICoS mnemonic to help define the material of interest. Inclusion and exclusion criteria defined the population,

phenomena of interest, context of study, and types of study. This is consistent with the registered protocol and to ensure the synthesis included appropriate sources of data.

### ***Population***

Studies with participants who were children and young people aged below 25 years (or where the mean age was less than or equal to 25 years) whose parent(s) used substances were included. Three studies (reported across eight papers) reported analysis of data from young people with an age range spanning beyond 25 years (Backett-Milburn, Wilson, Bancroft, & Cunningham-Burley, 2008; Bancroft, Wilson, Cunningham-Burley, Backett-Milburn, & Masters, 2004; Park & Schepp, 2017, 2018; Park, Schepp, & Park, 2016; Wangensteen, Bramness, & Halså, 2019a; Wangensteen, Halså, & Bramness, 2020; Wangensteen & Westby, 2019b). These studies were included, but accounts from those aged under 25 were prioritised. Studies that included multiple perspectives on children and young people's experiences where the reporting meant the young person's views were indistinguishable from other populations were excluded.

### ***Phenomena of interest***

Studies reporting views and perspectives of lived experiences, perceived impacts, and/or coping strategies of children and young people whose parents' used substances were included. Parental substance use was defined as the overall definition for this thesis as described in section 1.2.1, therefore, included any use that had the potential to cause harm to a child or young person. This could range from frequent or heavy alcohol use to any use of illicit drugs, including the misuse of legally prescribed drugs. Parent refers to anyone who has had a parenting role (e.g., biological, step, adoptive parent/carer, or kin care). Studies were excluded if they only focused on parental tobacco and/or caffeine use. Studies were also excluded if they mainly reported findings from looked after children or those in custodial criminal justice settings (or other similar situations) where the focus was not on living with parental substance use. For instance, young people were identified for having parental substance use but exploration was on their experience of being looked after.

### ***Context of study***

Studies were not excluded based on language, date, or geography to ensure all applicable evidence was incorporated into the synthesis.



### ***Types of studies***

This review included studies that focused on qualitative data collection, analysis, and reporting. Studies including only quantitative methods, analysis and reporting were excluded. Reviews, process evaluations, case studies, and theses were also excluded but primary study publications were specifically searched for if identified via this latter route.

### ***3.4.2 Scoping, searching, and selecting the literature***

#### ***Scoping the literature***

I initially undertook a scoping exercise to determine whether there was relevant qualitative literature on the topic and whether the proposed review was feasible. Keywords relating to children and young people, parental substance use, and qualitative study were entered into two databases, Medline (OVID) and Scopus, to identify appropriate studies. Through scoping, I identified seven key studies, which responded to the review question, establishing that an adequate amount of literature existed and was feasible for a meaningful synthesis. The identified qualitative literature included mainly adolescents' experiences, with most of the study participants ranging from 11-18 years. With the help of an information scientist at Newcastle University Library Service, I developed the search terms for 'child' sufficiently to help identify studies with younger children for full review. I also examined the identified studies by title, abstract, keywords and database-specific headings to help identify further search terms that were relevant. During the scoping process, key studies were identified that included retrospective accounts of young people up to the age of 27, therefore it was decided to include young people where the mean age was below 25 in the full review, refining the detail of inclusion criteria. I used the key studies initially to develop my search strategy and then to test the search strategy in the databases to see how many of the key studies were retrievable in the database.

#### ***Searching the literature***

A search strategy was developed combining, where applicable, key words and database-specific headings relating to the concepts, 'children and young people' and 'parental substance use' (see Appendix B for full search strategy). Due to the difficulty of identifying relevant qualitative research (Shaw et al., 2004), a validated search filter designed to identify qualitative research was applied and adapted across the databases (DeJean et al., 2016). Using a qualitative search filter also meant I did not have to include additional terms for 'experiences, impacts and coping strategies' as these were identified at screening. Keywords and database-specific headings were combined for each concept using the Boolean operator

‘OR’. Search terms for the three concepts were combined using the Boolean operator ‘AND’. To ensure maximum sensitivity and specificity of relevant articles, the search strategy was amended with the help of an information scientist at Newcastle University Library Service and a supervisor (RM). Where registered on the database, the searches were tested for their recognition of key studies that had been identified during the scoping phase.

The international literature was primarily searched with the use of electronic databases. To select electronic databases that would include relevant journals from health and social sciences, I consulted with information scientists within Newcastle University Library Service. The databases I searched from inception to February 2022 were Medline (OVID), PsycINFO (OVID), Cumulative Index to Nursing and Allied Health Literature (EBSCOhost), International Bibliography of the Social Sciences (ProQuest), Social Science Database (ProQuest), Sociology Collection (ProQuest), including, Applied Social Sciences Index and Abstracts, Sociology Database, and Sociological Abstracts, as well as Scopus. These selected databases allowed for complete coverage of the key papers identified in the scoping phase. Such searches were supplemented with key term searching on Google Scholar, and grey literature sources e.g., Open Grey and Dissertation Abstracts International as well Children’s Society and other voluntary and community sector organisation’s websites covering the topic of interest. Additional relevant studies were identified through hand-searching reference lists and citations of included studies, as well as journals relevant to this topic area.

### ***Selecting the literature***

Two reviewers (CM and another reviewer) independently screened all titles and abstracts using Rayyan, against the specified inclusion and exclusion criteria. Non-English titles/abstracts were translated online to assess eligibility. Full papers for all potentially eligible studies were retrieved and evaluated in full text by two independent reviewers. For non-English papers, the methods were initially translated online to assess eligibility and if included or uncertain, they were translated by individual’s bilingual in the language and English. Discrepancies at each stage were resolved by discussion or by consulting a third researcher if consensus could not be reached.

### ***3.4.3 Data extraction***

Forms and spreadsheets were developed and initially piloted to extract data from included studies. Relevant data were extracted independently by two reviewers (CM and another reviewer) including: study aim, design, and methodology; sample characteristics; nature of

parental substance use; findings relevant to the review; and limitations (both from author and reviewer). Authors were contacted when articles were irretrievable online, or data were missing. Any discrepancies in decisions were resolved through discussion.

#### **3.4.4 *Quality appraisal***

Included papers were quality assessed, simultaneously to data extraction, by two independent reviewers (CM and another reviewer). This approach was guided by a two-stage process (Britten & Pope, 2012) of assessing for quality using the CASP Qualitative Studies Checklist and then reviewing for relevance (Dixon-Woods et al., 2007; Malpass et al., 2009). Studies were rated as: (A) a key paper that was most relevant and conceptually rich, with no or few quality issues, (B) a secondary key paper, that was relevant but with limited themes and data, and/or some quality issues; or (C) satisfactory, that was less relevant to the review and/or the CASP appraisal highlighted major limitations related to the quality of reporting. Narrative summaries of the CASP quality appraisal and relevance rating were produced. Any discrepancies in decisions were resolved through discussion.

#### **3.4.5 *Data synthesis***

Synthesis was based on Thomas and Harden (2008) three-stage thematic method that moves iteratively between coding, identification of descriptive themes, and generation of analytic themes. The first stage involved familiarisation of findings of each study during full text screening and immersion through repeated reading. During data extraction and quality appraisal, I listed initial ideas from the main findings and potential codes. I then inductively generated line-by-line codes from the study findings and author interpretations using NVivo 12 management software (QSR International Pty Ltd, 2018). Analytical notes (memos) were recorded throughout the synthesis process, detailing explanations, and patterns across the data. The second stage consisted of developing descriptive themes. Recurring codes explaining findings across the studies, were developed into a descriptive framework, with an overarching theme of unpredictability and uncertainty, and four themes: (1) the family environment; (2) challenges and impacts; (3) coping; and (4) looking forward, each with different sub-themes (see Figure 3.1). This framework remained close to the original findings of included studies. This framework was then explored with the wider research team and public and practice advisors (see section 3.4.6) who provided feedback on the themes and suggested areas that could be explored within the findings. To capture these discussions alongside the emerging review findings, three further depictions of the main research

questions: (1) lived experiences; (2) impacts; and (3) coping strategies were also developed (see Figure 3.2). These discussions began to highlight possible interpretations (e.g., the experience and impact of stigma).

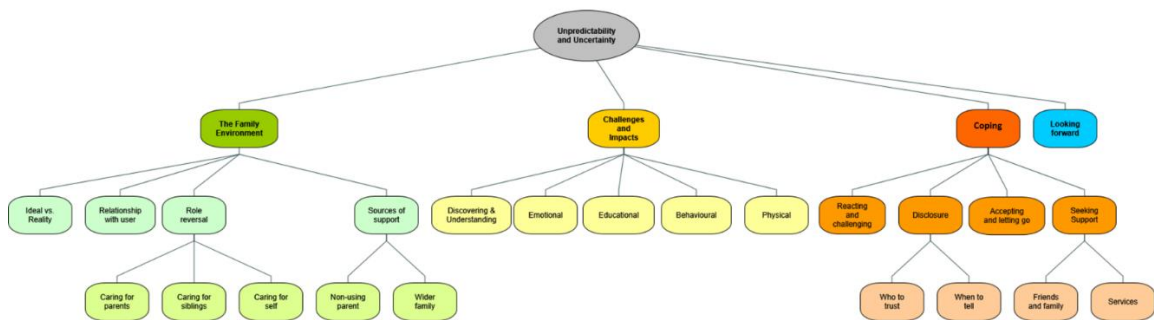


Figure 3.1 A framework of the developing descriptive themes.



Figure 3.2 A depiction of the descriptive themes within the review findings after public and practice involvement for the a) lived experiences, b) perceived impacts and c) coping strategies of children and young people whose parents use substances.

The third stage of synthesis involved identifying and mapping links between the descriptive framework and descriptive themes, to generate analytical themes that, together, made sense of children and young people’s experiences of parental substance use. Quotations from the included studies were identified to support and illustrate the review findings. Theoretical

constructs were also identified that shaped the understanding and development of the presented findings, as detailed in section 2.3. These themes were presented to and further refined with practice involvement, to ensure emerging interpretations and themes were relevant and applicable to practice and policy.

#### ***3.4.6 Public and practice involvement in the synthesis***

Throughout the synthesis process, developing themes were discussed and refined with a practice advisor from Adfam, practice and policy practitioners during a dissemination and structured discussion workshop, as well as with young people who had experienced parental substance use, and their support workers during a workshop.

##### ***Practice advisor***

From inception, Vivienne Evans from Adfam (<https://adfam.org.uk/>), a national charity focusing on tackling the negative effects of drugs and alcohol on family members and friends, was a practice advisor throughout this PhD. She attended monthly advisory group sessions to support the development of key themes. This involvement ensured that the findings would be relevant to practice and policy practitioners. After being presented with the descriptive framework (Figure 3.1) the practice advisor informed the team that the topic of stigma could be explored further within the synthesis of children and young people's views of parental substance use as it did not seem to be explored across the included studies. This further guided the inclusion of stigma related theories in addition to resilience theories as discussed in section 2.3.3.

##### ***Young people***

PROPS Young Person's Project, a North East based service for young people who experience someone else's drug or alcohol use, facilitated the involvement of young people in the synthesis of data. I was invited to run a workshop with four young people, aged 11-17 years, who had experienced parental substance use, as well as with two of their support workers, in January 2020. These young people already knew each other as they had attended group support with one another within the service. I discussed the findings from stage two of the synthesis, presenting the descriptive framework (Figure 3.1). Young people were invited to discuss these themes as a group, or they could write and draw their thoughts on paper with coloured pens and pencils. The young people chose to discuss the themes as I captured their responses on paper. Young people felt that children and young people are usually seen as being impacted negatively by their parent's alcohol or drug use, but they felt they had also

done things to help themselves or others which should not be seen negatively. From this insight, children and young people's agency was further explored in the synthesis. An additional area that young people identified as being missing and where I should focus my synthesis was around how young people can feel different to their peers, and how they can feel isolated and like they had to keep everything hidden from others for fear of being judged. This was similar to the practice advisor's feedback around exploring stigma. Both discussions guided the inclusion of stigma related theories as discussed in section 2.3.3.

Whilst I had planned to continue to involve this group of young people in later iterations of the theme development and synthesis, unfortunately the COVID-19 pandemic impacted this proposed work. PROPS Young Person's Project suspended group work with young people due to social distancing rules and they were prioritising the safety of their young people in a supportive role rather than involving them in research during this time.

### ***Practice and policy practitioners***

Adfam invited me to present my early systematic review findings at an online national forum in December 2020 (see Appendix C for event details). This event was attended by 24 practice and policy professionals, within the field of study across England. I held a structured discussion session after the presentation where practitioners could provide feedback on the findings. Adfam facilitated this discussion and co-produced minutes for the event focused on guidance for the synthesis process. These guiding notes, as below, supported further refinements of the themes and can be seen throughout the findings section.

Notes from the online event with practitioners:

- The emphasis of the research is on building resilience, not making children into better carers for their substance using parents, which is a positive. Consensus that attendees also liked the focus on children and young people's agency not just negative impacts.
- Alcohol use is more normalised, which is a barrier to engagement with services for children, but the stigma around drug use also prevents children from disclosing their parents use. Can stigma be explored regarding type of substance within the literature?
- Barriers preventing children from seeking support (mainly stigma but also fear of being taken from parents/getting their parents into trouble) must be removed. The interpretations on stigma and shame are original and needed within this field.
- Young people want support for their parents, and they want to know more about addiction and the effect it has on families. But children can also be harmed by parent's

substance use even if they do not live with the substance using parent or they have stopped using substances. Findings reflected this but could bring out more clearly that support for children and young people in their own right is essential and needs to be ongoing (perhaps implication of findings).

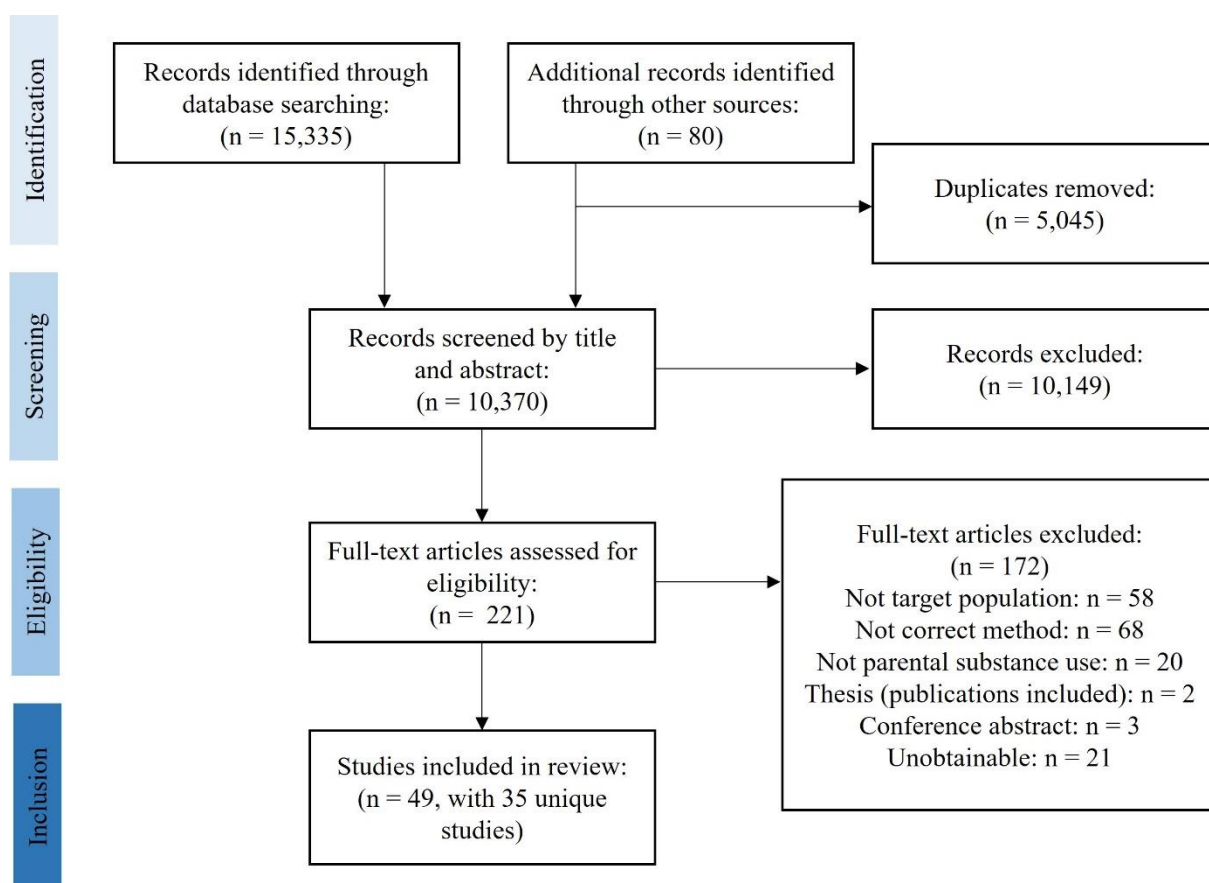
- ‘Unpredictability’ is important, this could be a theme in and of itself (for clarity), across the different areas discussed – e.g., relationships.
- Presentation of themes: to follow (loosely) the review questions with interpretations explored throughout the theme/across sub-themes.

Additionally, Vivienne Evans, Adfam and Claire Hayward, National Hidden Harm Lead for Change Grow Live, provided guiding comments on practice and policy recommendations and implications based on the synthesis findings for the publication of this systematic review in Trauma, Violence and Abuse.

### **3.5 Findings: Description of Included Studies**

After deduplication the search identified 10,370 papers of which 10,149 were excluded at title and abstract screening and a further 172 were excluded at full paper screening. Figure 3.3 depicts the flow of papers through the selection process. Reasons for exclusion at full paper screening were, wrong population (e.g., adult children), wrong method (e.g., quantitative study), did not cover parental substance use (e.g., focus on parental smoking), identified thesis or conference abstract (of which publications were identified), or they were unobtainable after contacting the author.

This process resulted in the inclusion of thirty-five unique studies, reported across 49 papers. Where studies were reported across multiple papers, each addressed different research questions or aims and presented distinct or additional findings.



*Figure 3.3 Flowchart of included studies*

Brief descriptive summary characteristics of the included studies are presented in Table 3.1, with more extensive details provided in Appendix D. Studies included data collected from 1996 onwards. The synthesis of findings involved over 737 children and young people (aged 4-30 years) whose parents use(d) substances. Most studies included both male and female participants. Only one study had all female participants (Ahuja, Orford, & Copello, 2003). Where reported, there were 417 female and 250 male participants. Authors variably reported ethnicity, with most reporting predominantly White-European participants. Two studies (four papers) explored black African and American young people's experiences (Johnson, 2013; Lewis, Smith, Offiong, Prioleau, & Powell, 2021; Offiong, Powell, Lewis, Smith, & Prioleau, 2020; Powell, Willis, Smith, Lewis, & Offiong, 2021), while Ahuja et al. (2003) explored Sikh daughter's perspectives. Studies recruited samples from across twenty countries, with the majority from Europe (n=21), then North America (n=5), Asia (n=5), Oceania (n=2), South America (n=1) and Africa (n=1).

Four studies (six papers) reported on parental illicit drug use only (Barnard & Barlow, 2003; Lewis et al., 2021; McGuire, 2002; Offiong et al., 2020; Powell et al., 2021; Yusay & Canoy,



2019). Ten studies (nineteen papers) focused on parental alcohol and/or drug use (Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bancroft et al., 2004; Bernays & Houmøller, 2011; Houmøller et al., 2011; Johnson, 2013; Moore et al., 2011; Moore, Noble-Carr, & McArthur, 2010; O'Connor, Forrester, Holland, & Williams, 2014; Reupert, Goodyear, & Maybery, 2012; Ronel & Haimoff-Ayali, 2010; Ronel & Levy-Cahana, 2011; Templeton, Velleman, Hardy, & Boon, 2009; Velleman, Templeton, Reuber, Klein, & Moesgen, 2008; Wangensteen et al., 2019a; Wangensteen et al., 2020; Wangensteen & Westby, 2019b; Wilson, Cunningham-Burley, Bancroft, & Backett-Milburn, 2008, 2012). The remaining 21 studies (24 papers) primarily examined parental alcohol use. Four studies (five papers) focused on fathers' use (Ahuja et al., 2003; Nattala et al., 2020; Park & Schepp, 2017; Park et al., 2016; Ramírez Dávila, Naal, Salinas, & Pérez, 2014), one focused on mothers' use (Johnson, 2013), while all remaining studies focused on substance use in either or both parents. Ten studies (11 papers) reported that all young people were living with the parent who uses substances at the time of data collection (Ahuja et al., 2003; D'Costa & Lavalekar, 2021; Dundas, 2000; M. Hill, Laybourn, & Brown, 1996; Johnson, 2013; Mudau, 2018; Ramírez Dávila et al., 2014; Reupert et al., 2012; Templeton et al., 2009; Tinnfält, Fröding, Larsson, & Dalal, 2018; Velleman et al., 2008). All other studies reported varied living arrangements for young people.

Data were mainly collected through in-depth and semi-structured interviews. Three studies used a longitudinal approach, where two studies conducted two interviews, one over 4 months (Murray, 1998), and another over 20 months (Bernays & Houmøller, 2011; Houmøller et al., 2011). The other study conducted three interviews over a 13-year time period (Hagström & Forinder, 2019). Co-production workshops (A. McLaughlin et al., 2015), focus groups (L. Hill, 2015; Tinnfält, Eriksson, & Brunnberg, 2011), online open-ended qualitative survey (Holmila, Itäpuisto, & Ilva, 2011), and a standardised qualitative questionnaire interview with open ended questions (Templeton et al., 2009; Velleman et al., 2008) were also methods for data collection. Where reported, a range of theories and approaches were applied to qualitative analyses, including thematic analysis, grounded theory, interpretative phenomenological analysis, narrative analysis, and content analysis. Most studies recruited from a variety of services and organisations due to difficulties with identifying participants.

### **3.6 Quality of Studies**

Based on quality and relevance, twenty-three studies were rated as key papers (A=8 and B=15), and 12 studies were rated as satisfactory (see Table 3.1). Detailed accounts of the issues regarding the quality of each study are presented in Appendix E. For the studies rated as key paper A authors reported detailed accounts of their methods and analysis with rich findings relating to young people's experiences, perceived impacts, and coping strategies. For key paper B, most authors tended to be clear and explicit in their reporting of methods and analysis, but some of the findings may have lacked depth or breadth (e.g., focusing on one or two of the areas of study rather than all three). For satisfactory papers, there was generally a lack of clarity and transparency with the reporting of methods, with limited findings. Reflexive methods or considerations were rarely reported across all studies. As key papers tended to provide thicker and more conceptually rich descriptions of findings than other studies, they contributed more to the developed themes.

Table 3.1 Brief descriptive summaries of the thirty-five included studies with quality appraisal (Key paper: A/B; Satisfactory paper: C)

First Author (Year) and Country	Sample size (Female), Ages	Parental substance use	Data collection; recruitment; and analysis	Quality appraisal
<b>Ahuja (2003)</b> <i>England</i>	<i>N</i> = 7 (7F), 17-23	Father's alcohol use	Semi-structured interviews; Specialist addiction treatment service for parents; Grounded theory	C
<b>Alexanderson (2017)</b> <i>Sweden</i>	<i>N</i> = 23, 6-19	Parental substance use	Semi-structured interviews; Social services/support groups for children; Grounded theory	C
<b>Bancroft (2004)</b> <i>Scotland</i> (Backett-Milburn, 2008; Wilson, 2008; Wilson, 2012)	<i>N</i> = 38 (20F), 15-27	Parental substance use	Semi-structured interviews with life grid; Multiple services, organisations, and universities	A
<b>Barnard (2003)</b> <i>Scotland</i>	<i>N</i> = 36 (20F), 8-22	Parental drug use	Semi-structured interviews; Treatment services/secure unit/rehabilitation unit; Analysis unknown	B
<b>Bickelhaupt (2021)</b> <i>USA</i>	<i>N</i> = 13 (9F), 21-25	Parental alcohol use	Semi-structured interviews; Local state University; Constant comparative analysis	A
<b>Christensen (1997)</b> <i>Denmark</i>	<i>N</i> = 32 (14F), 5-16	Parental alcohol use	Interviews; Alcohol treatment institution for parents; Analysis unknown	C
<b>D'Costa (2021)</b> <i>India</i>	<i>N</i> = 15 (11F), 17-19	Parental alcohol use	Semi-structured interviews; Treatment services for parents; Thematic analysis	B
<b>Dundas (2000)</b> <i>Norway</i>	<i>N</i> = 17 (8F), 10-21	Parental alcohol use	Semi-structured interviews; Out-patient clinic for parents' alcohol use; Analysis unknown	C
<b>Fraser (2009)</b> <i>England</i>	<i>N</i> = 8 (4F), 4-14	Parental alcohol use	Draw & write semi-structured interviews; Social services; Phenomenological perspective	B
<b>Hagström (2019)</b> <i>Sweden</i>	<i>N</i> = 19 (8F), 6-24	Parental alcohol use	Longitudinal, three interviews over 13 years; Children are People Too programme; Narrative methods	A
<b>Hill (1996)</b> <i>Scotland</i>	<i>N</i> = 27, 5-12+	Parental alcohol use	Interviews; Multiple agencies and services; Analysis unknown	C
<b>Hill (2015)</b> <i>Scotland</i>	<i>N</i> = 30 (16F), 9-20	Parental alcohol use	Group work, interviews, task-based activities; Voluntary organisations; Thematic analysis	C

<b>Holmila (2011)</b> <i>Finland</i>	<i>N</i> = 70 (58F), 12-18	Parental alcohol use	Online survey with open-ended questions; Two websites for children with parental substance use; Content analysis	C
<b>Houmøller (2011)</b> <i>England</i> <i>(Bernays, 2011)</i>	<i>N</i> = 50 (30F), 10-18	Parental substance use	Semi-structured interviews (16 young people had follow-up interviews over 20 months); Specialist services for young people; Thematic analysis	A
<b>Johnson (2013)</b> <i>USA</i>	<i>N</i> = 14 (6F), 14-17	Mother's substance use	Semi-structured interviews; Social services and schools; Content analysis	B
<b>McGuire (2002)</b> <i>Scotland</i>	<i>N</i> = 7, Adolescence	Parental drug use	Semi-structured interviews; Social work services and addiction treatment services; Analysis unknown	B
<b>McLaughlin (2015)</b> <i>Northern Ireland</i>	<i>N</i> = 23 (14F), 7-14	Parental alcohol use	Co-production participatory workshops; Pharos service at Barnardo's; Thematic analysis	B
<b>Moore (2010)</b> <i>Australia</i> <i>(Moore, 2011)</i>	<i>N</i> = 15 (8F), 11-17	Parental substance use	Semi-structured interviews with activities for engagement; Services and organisations for young people; Grounded theory	A
<b>Mudau (2018)</b> <i>South Africa</i>	<i>N</i> = 8 (4F), 14-25	Parental alcohol use	Interviews; Local village and schools; Thematic narrative analysis	C
<b>Murray (1998)</b> <i>Canada</i>	<i>N</i> = 5 (3F), 13-19	Parental alcohol use	Three interviews over 4 months; Al-Anon, school, personal contact; Constant comparative analysis	A
<b>Nattala (2020)</b> <i>India</i>	<i>N</i> = 15 (10F), 10-19	Father's alcohol use	Semi-structured interviews; Outpatients for fathers in treatment and snowball sampling; Analysis unknown	A
<b>O'Connor (2014)</b> <i>Wales</i>	<i>N</i> = 13, 13-21	Parental substance use	Interviews; Crisis intervention service (child protection register); Thematic analysis	B
<b>Offiong (2020)</b> <i>USA</i> <i>(Lewis, 2021; Powell, 2021)</i>	<i>N</i> = 14 (6F), 18 – 24	Parental drug use	Semi-structured interviews; Local organisations; Content analysis	B
<b>Park (2016)</b> <i>South Korea</i> <i>(Park, 2017; Park 2018)</i>	<i>N</i> = 22 (14F), 19-30	Mainly father's alcohol use	Two semi-structured interviews; Two universities, one college, online self-help groups, siblings; Thematic analysis	B
<b>Ramirez (2014)</b> <i>Mexico</i>	<i>N</i> = 4 (3F), 20-22	Father's alcohol use	Life Stories method with interview; One University; Content analysis	C

<b>Reupert (2012)</b> <i>Australia</i>	<i>N</i> = 12 (6F), 8-15	Parental substance use	Semi-structured interviews; Service for dual diagnosis families; Interpretative phenomenological analysis	B
<b>Ronel (2010)</b> <i>Israel</i> (Ronel, 2011)	<i>N</i> = 19 (7F), 13-22	Parental substance use	Semi-structured interviews; Treatment services for parents and services for young people; Qualitative constructivist method	B
<b>Silva (2013a)</b> <i>Brazil</i> (Silva, 2013b)	<i>N</i> = 40 (30F), 15-20	Parental alcohol use	Life history- semi-structured interviews; Urban Tribes Project; Thematic analysis	C
<b>Tamutiené (2019)</b> <i>Lithuania</i>	<i>N</i> = 23 (18F), 8-18	Parental alcohol use	Semi-structured interviews; Social services; Thematic analysis	C
<b>Tinnfält (2011)</b> <i>Sweden</i>	<i>N</i> = 27 (24F), 12-19	Parental alcohol use	Interviews/focus groups; Support groups; Content analysis	B
<b>Tinnfält (2018)</b> <i>Sweden</i>	<i>N</i> = 18 (8F), 7-9	Parental alcohol use	Interviews; Treatment center for parents' addiction; Content analysis	A
<b>Turning Point (2006)</b> <i>England/Wales</i>	12-18	Parental alcohol use	Interviews; Turning Point services; Analysis unknown	B
<b>Velleman (2008)</b> <i>England, Germany, Poland, Spain, and Malta</i> (Templeton, 2009)	<i>N</i> = 48 (31F), 12-18	Parental alcohol use	Mixed method interview- standardised questionnaire with open ended questions (Alcohol Violence Teenager Version); Treatment services for parents, support services for the young person; Thematic analysis	C
<b>Wangensteen (2019a)</b> <i>Norway</i> (Wangensteen, 2019b; Wangenstein, 2020)	<i>N</i> = 12 (9F), 13-26	Parental substance use	Semi-structured interviews; Treatment services for parents; Interpretative phenomenological analysis	B
<b>Yusay (2019)</b> <i>Philippines</i>	<i>N</i> = 13 (10F), 13-19	Parental drug use	Interviews; Community-based intervention program for parent's substance use; Narrative analysis	B

### **3.7 Synthesis of Findings**

Synthesis of 35 studies (49 papers) identified five overarching themes: (1) living with the unpredictable: insecurity within the family, (2) social and emotional impact of parental substance use, (3) controlling the uncontrollable: creating safety within the family, (4) coping with and resisting the emotional and social impacts, and (5) formal and informal support. For a table documenting the included studies that informed each theme and sub-themes, please refer to Appendix F.

#### ***3.7.1 Living with the unpredictable: insecurity within the family***

Children and young people reported experience of a great deal of uncertainty across many different aspects of their everyday life while living alongside and growing up with parental substance use. The issue of unpredictability was found across young people's relationships with their parent(s), roles and responsibilities within the family, and their living arrangements. Uncertainty often resulted from fluctuation in parental substance use that could alter parent's behaviour and mood towards the child and within the home. Such uncertainty and unpredictability, for young people, could feel uncontrollable and difficult to cope with. In Nattala et al. (2020), a 17-year-old female stated that, *'life is out of control'* (p. 11).

#### ***Relationship with parent***

The relationship between the child and parent who uses substances was often reported as unpredictable, described as a *'never ending roller coaster'* (Bickelhaupt, Lohman, & Neppl, 2021, p. 7), with fluctuations in the levels of love and affection shown from the parent to the child. A minority voice within some studies included children and young people who reflected that their relationship with a parent who uses substances was not affected (Alexanderson & Näsman, 2017; Bancroft et al., 2004; Bernays & Houmøller, 2011; Fraser, McIntyre, & Manby, 2009; M. Hill et al., 1996; Johnson, 2013; McGuire, 2002; Moore et al., 2011; Reupert et al., 2012; Silva, Padilha, & Araujo, 2013b; Tinnfält et al., 2018; Wilson et al., 2012), or even that they enjoyed the affection and generosity from their parents when they had been drinking alcohol as opposed to when they had not (M. Hill et al., 1996). Yet most deemed such affection as *'meaningless'* (Bancroft et al., 2004, p. 12), and often described these relationships as being hostile and manipulative, with frequent arguments, tension, and conflict or less frequently reported as a *'[roommate] kind of relationship'* (Moore et al., 2010, p. 23). Relationships with the parent who does not use substances could also cause insecurity, with young people feeling anger towards them because they view this parent as lacking in

care and support for their children (Ahuja et al., 2003; Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bancroft et al., 2004; D'Costa & Lavalekar, 2021; Johnson, 2013; Ramírez Dávila et al., 2014; Ronel & Haimoff-Ayali, 2010). Bancroft et al. (2004) found that children and young people viewed non-using mothers more harshly than they viewed non-using fathers due to the perception that mothers should provide them with safety and comfort. Regardless of their parent's substance use and subsequent insecurity, many children perceived family as important, felt a strong loyalty to their parents, and wanted to belong to a family (Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bernays & Houmøller, 2011; Dundas, 2000; Houmøller et al., 2011; Moore et al., 2011; Reupert et al., 2012; Tinnfält et al., 2018; Turning Point, 2006; Wangensteen & Westby, 2019b; Wilson et al., 2012). Where young people did not have close family relationships, they spoke about developing family-like relationships with others, including friends, social workers, or teachers (Backett-Milburn et al., 2008; Bancroft et al., 2004; A. McLaughlin et al., 2015; O'Connor et al., 2014; Offiong et al., 2020; Wilson et al., 2012).

### *Cycle of use*

A common experience for the young people was the feeling of uncertainty that resulted from substance use fluctuation from abstinence to heavy use. Such fluctuation was reported to impact the unpredictable and chaotic nature of their parent's behaviour and mood, leading to inconsistent parenting. Periods of substance use were viewed as stressful and scary, leading to issues of unsupervised care, neglect, and creating unsafe environments for children and young people. During periods of abstinence most studies reported that young people experienced this as good and happy times, where they felt loved and cared for. However, the unpredictable nature of not knowing when or if their parents would use substances again seemed to affect children and young people's emotional wellbeing. During periods of lower use, young people could become anxious or worried about when their parent would begin or resume drinking or use drugs (Bancroft et al., 2004; Bernays & Houmøller, 2011; Fraser et al., 2009; Hagström & Forinder, 2019; L. Hill, 2015; Houmøller et al., 2011; Moore et al., 2011; Nattala et al., 2020; Park & Schepp, 2017; Tinnfält et al., 2018; Wangensteen et al., 2019a; Wangensteen et al., 2020). In Moore et al. (2011), a 17-year-old male stated that,

*“there were the frantic times, when there were weeks when it was worse, or weeks when it seemed completely normal. I would start looking out for stuff during these good times” (p.167).*

For some young people even those ‘good times’, during periods of reduced use (due in part to their parents receiving treatment), can feel unsafe and stressful. Younger children were described as having hope that their parents had stopped for good while older children recalled ‘losing hope’ after witnessing several failed attempts by their parents to stop. However, these children reported beginning to predict the unpredictable, and were better able to find a path through the insecurity (Alexanderson & Näsman, 2017; Bancroft et al., 2004; Christensen, 1997; D’Costa & Lavalekar, 2021; Moore et al., 2010; Silva & Padilha, 2013a; Yusay & Canoy, 2019).

### ***Roles and responsibilities***

A further common theme within the literature was the caring responsibilities that children and young people had taken on for other members of their family, which felt unpredictable when parents stopped use and either took back the parental role from children or started ‘acting like a parent’ (Ahuja et al., 2003; Backett-Milburn et al., 2008; Bancroft et al., 2004; Bernays & Houmøller, 2011; D’Costa & Lavalekar, 2021; Fraser et al., 2009; Hagström & Forinder, 2019; M. Hill et al., 1996; Holmila et al., 2011; Houmøller et al., 2011; Johnson, 2013; Lewis et al., 2021; McGuire, 2002; A. McLaughlin et al., 2015; Moore et al., 2011; Moore et al., 2010; Murray, 1998; Nattala et al., 2020; O’Connor et al., 2014; Offiong et al., 2020; Park et al., 2016; Ramírez Dávila et al., 2014; Reupert et al., 2012; Ronel & Haimoff-Ayali, 2010; Ronel & Levy-Cahana, 2011; Templeton et al., 2009; Turning Point, 2006). These relationships often resulted in the blurring of roles and repeated exchanges of responsibility between being a child, sister or brother and being a parent to siblings or parents. Such unpredictability led to confusion, tension, and arguments within the family, with young people viewing family members as lacking in care and support or finding it hard to relinquish these roles (Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bancroft et al., 2004; Hagström & Forinder, 2019; Holmila et al., 2011; Johnson, 2013; Moore et al., 2011; Murray, 1998; Park et al., 2016; Ramírez Dávila et al., 2014; Ronel & Haimoff-Ayali, 2010; Turning Point, 2006). In Bancroft et al. (2004), a 17-year-old female reflected on this experience,

*“I’m used tae daen [to doing] all the tidying and the cooking and like telling [siblings] when tae be in... And my mum’s started daen that and... it’s like a kind of conflict between us now” (p. 10).*



### ***Living arrangements***

The lack of stability within their living arrangements and home environment played into the experience of insecurity for children and young people. Young people recalled having transient lifestyles, with frequent moves, often described as chaotic, leading to young people feeling unsettled (Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bancroft et al., 2004; Fraser et al., 2009; L. Hill, 2015; Houmøller et al., 2011; Lewis et al., 2021; McGuire, 2002; Moore et al., 2011; Moore et al., 2010; O'Connor et al., 2014; Offiong et al., 2020; Park et al., 2016; Reupert et al., 2012; Ronel & Haimoff-Ayali, 2010; Tamutienė & Jogaitė, 2019; Templeton et al., 2009; Turning Point, 2006; Wangensteen & Westby, 2019b; Wilson et al., 2008). In L. Hill (2015), a 10-year-old female recalled her experience of such transience,

*“I use to live with my mum, but she got a bit ill, so we moved into Gran’s house. Then she got better (sighs), so we moved back down, and then she got a bit ill again, and then she got better... That was a big breath! Phew” (p. 348).*

Furthermore, some young people also experienced the stress and insecurity of the often-present threat that they would be forced to leave the family home by a parent (Ahuja et al., 2003; Backett-Milburn et al., 2008; Johnson, 2013; Lewis et al., 2021; Nattala et al., 2020; Wilson et al., 2008). For other young people, parental substance use affected parent’s abilities to pay rent, prompting many housing moves, and feelings of insecurity (Lewis et al., 2021). When recalling the home environment, some children and young people described it as untidy, unstable and one in which ‘*unsafe adults*’ frequently visited (Backett-Milburn et al., 2008; Bancroft et al., 2004; Hagström & Forinder, 2019; Houmøller et al., 2011; McGuire, 2002; Moore et al., 2010; Murray, 1998; Park & Schepp, 2018; Park et al., 2016; Reupert et al., 2012; Wangensteen & Westby, 2019b).

### ***3.7.2 Social and emotional impact of parental substance use***

For many children and young people whose parents use substances the combination of unpredictable and stigmatising situations with often adverse experiences reportedly impacted them both emotionally and socially. Realisation that their families were not the same as others and the subsequent unfair treatment of them by other people perpetuated young people’s feelings of difference, isolation, and self-shame as well as received shame from others. Moreover, issues of social deprivation often reportedly worsened young people’s experiences, as they were made to feel different.

### ***Family adversity***

Children and young people commonly recounted experiencing interrelating and compounding factors beyond parental substance use, which contributed to the complexity, insecurity, and trauma within children and young people's lives. These cumulative factors led to one 23-year-old male recounting his experiences as, "*the most hellish experience that you could ever imagine*" (Backett-Milburn et al., 2008, p. 466). Across most studies, many young people were additionally exposed to parental intimate partner violence and abuse (IPVA), violence and abuse against them directly, siblings or pets, as well as parental mental health problems, intergenerational substance use, or family imprisonment. A minority of young people also recalled incidents when parents either encouraged or forced them to use substances (Alexanderson & Näsman, 2017; Hagström & Forinder, 2019; Nattala et al., 2020). IPVA compounded their difficult situation and was associated with feelings of abandonment and a lack of protection (Alexanderson & Näsman, 2017). However, some children and young people spoke more about the harmful impact of parental alcohol use than violence in their families (Templeton et al., 2009), while others perceived parental mental health problems to have a particularly detrimental impact on them (Bancroft et al., 2004). Bancroft et al. (2004) also found that young people reported violence as more likely with parental alcohol use than with parental drug use. In Ahuja et al. (2003), a young female recalled of her father who drank alcohol, "*my father got a broom and hit me over the head with it. I needed stitches*" (p. 858). Whilst some young people spoke of the traumatic incidents of physical or sexual abuse towards them directly, the majority spoke of the emotional turmoil they experienced.

### ***Emotional impacts***

The emotional impacts of living with parental substance use and compounding family adversities were reported in all studies. Children and young people reported experiencing mental health problems and feeling "*hurt in the inside*" (M. Hill et al., 1996, p. 163), including feelings of sadness and depression, fear, anxiety and worry, as well as describing externalised feelings of anger that "*erupt like a volcano building up inside*" (A. McLaughlin et al., 2015, p. 46). The emotional impact of parental substance use was often reported to be complex and enduring, in Velleman et al. (2008) a young person commented, "*even if my mum stops drinking, I'll always be worried*" (p. 41). A minority of young people experienced guilt or blame for their parent's substance use at a young age, before realising they were not to blame, or feeling disdain for their parent(s) (Bickelhaupt et al., 2021; Christensen, 1997; M. Hill et al., 1996; Mudau, 2018; Murray, 1998; Park & Schepp, 2017; Turning Point, 2006). Additionally, it was often reported that caring responsibilities within the family felt

burdensome, whereby young people expressed a sense of loss at not having a normative childhood, missed opportunities for family bonding, and decreased self-esteem and confidence as they abandoned their own needs for the needs of their families. Yet, a minority of young people described such roles as improving their self-esteem (Backett-Milburn et al., 2008; Bancroft et al., 2004; D'Costa & Lavalekar, 2021; O'Connor et al., 2014; Ronel & Haimoff-Ayali, 2010). Siblings also tended to experience and be impacted by parental substance use differently, depending on birth order. Younger siblings often reported being protected or shielded by their older siblings but became more vulnerable if their older siblings subsequently left home. This could be due to decreased opportunities to express agency and develop their own coping strategies early on. Older siblings had increased exposure and advanced understandings of parental substance use but had greater opportunity for independence and space. However, they may also tend to externalise their problems due to limited support (Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bancroft et al., 2004; Bernays & Houmøller, 2011; Houmøller et al., 2011; Templeton et al., 2009). Children and young people also reported experiencing low confidence, poor self-esteem, and limited hope for the future (Moore et al., 2011; Moore et al., 2010; Murray, 1998; Nattala et al., 2020; Park et al., 2016; Ronel & Levy-Cahana, 2011). Such emotional distress was also described as affecting some children and young people's physical health, sleep, and diet (Bickelhaupt et al., 2021; Hagström & Forinder, 2019; Holmila et al., 2011; Houmøller et al., 2011; Nattala et al., 2020; Templeton et al., 2009; Velleman et al., 2008). In Bickelhaupt et al. (2021), a young adult female stated:

*“I was really struggling . . . I internalized a lot of things . . . so a lot of it took stress out on my body . . . I just kept it in . . . I build up so many walls . . . I was hospitalized for almost two weeks because I had ulcers . . . I was vomiting blood” (p. 8).*

### ***Stigma and shame***

Young people were often impacted by the secrecy of substance use within the family, wherein parents' continued efforts to hide, disguise, or deny their substance use established the topic as taboo, and created the perception that substance use is embarrassing, shameful, and to be hidden (Backett-Milburn et al., 2008; Barnard & Barlow, 2003; Houmøller et al., 2011). Experiencing shame and stigma within the family, especially from a parent who may be seen as the protective non-using parent, could have damaging lasting impacts on young people's self-worth and wellbeing (Nattala et al., 2020). However, where families were open, honest, and acknowledged substance use, young people felt less internalised shame and stigma

(Tinnfält et al., 2011). Young people also reported feeling great shame and embarrassment when they realised that their families were unlike other families, and that their parent's behaviour was not perceived as 'normal' within society. In Houmøller et al. (2011), an 18-year-old female reflected:

*"It's embarrassing because all your friends have got normal parents and you haven't... It's horrible, it really is" (p. 28).*

Labelling and stereotyping of young people whose parents use substances were reported across studies, wherein some young people felt they were labelled with derogatory terms and were perceived to use drugs like their parents, even if they did not (McGuire, 2002). Additionally, some young people were discriminated against due to other people's perception that the young person would turn out like their parents (Tamutienė & Jogaitė, 2019). Such labelling, induced shame, and awareness of difference, due to the association with parental substance use led to fear of being treated unfairly (Bancroft et al., 2004; Barnard & Barlow, 2003; Bernays & Houmøller, 2011; Christensen, 1997; Dundas, 2000; Holmila et al., 2011; Houmøller et al., 2011; McGuire, 2002; Park et al., 2016) or judged and rejected by others regardless of enacted discrimination (Backett-Milburn et al., 2008; Bancroft et al., 2004; Holmila et al., 2011; Houmøller et al., 2011; McGuire, 2002; Moore et al., 2010; Mudau, 2018; Murray, 1998; Yusay & Canoy, 2019). Fear of being stigmatised could be a powerful experience for most young people; with such fear signalling how these young people demonstrate a greater sensitivity to how they think they are perceived by others and society more broadly, regardless of any concrete discrimination.

Nonetheless, if others found out about parental substance use, due to a parents behaviours in public or by a friend telling other people, stigma, bullying, and discrimination towards the young person often ensued (Backett-Milburn et al., 2008; Bancroft et al., 2004; Barnard & Barlow, 2003; Bernays & Houmøller, 2011; Fraser et al., 2009; Hagström & Forinder, 2019; M. Hill et al., 1996; Houmøller et al., 2011; McGuire, 2002; Moore et al., 2010; Nattala et al., 2020; O'Connor et al., 2014; Tamutienė & Jogaitė, 2019; Tinnfält et al., 2018; Wangenstein et al., 2020). In Hagström and Forinder (2019), a 24-year-old female recalled the stigmatising behaviour of adults:

*“Often parents didn’t want me to play with their kids. As if something was wrong with me...I was ashamed...and then I was sad. You feel so strange...a strange person, not like others” (p. 17).*

Interactions between young people’s family and others that led to discrimination could reinforce young people’s internalised stigma and low self-esteem (Moore et al., 2010). However, some young people experienced positive interactions including receiving empathy and support from those who had witnessed their parent’s substance use, which improved their self-esteem, reduced internalised stigma, and improved their resilience (Houmøller et al., 2011; McGuire, 2002). Yet, for most young people, experiencing shame, stigma, and discrimination impacted on their emotional development, their ability to trust and develop social relationships, and perpetuated the isolation felt by many young people (Bancroft et al., 2004; Hagström & Forinder, 2019; Houmøller et al., 2011; McGuire, 2002; Moore et al., 2011; Mudau, 2018; Nattala et al., 2020; Offiong et al., 2020; Reupert et al., 2012; Tamutienė & Jogaitė, 2019; Turning Point, 2006; Yusay & Canoy, 2019).

### ***Poverty and financial impact***

Many young people reported that they had been exposed to poverty throughout their lives, with resources further diminished by parental substance use. Exposure to poverty and the financial impact of parental substance use left little money for things such as food, clean clothes, or school fees (Houmøller et al., 2011; McGuire, 2002; Moore et al., 2010; Mudau, 2018; Nattala et al., 2020; Ramírez Dávila et al., 2014; Yusay & Canoy, 2019), and reportedly resulted in some young people feeling shame as well as being bullied by peers or singled out by teachers (Houmøller et al., 2011; McGuire, 2002; Park & Schepp, 2018; Tamutienė & Jogaitė, 2019). Whilst one study found that children of substance using parents experienced stigma regardless of their socio-economic status (Hagström & Forinder, 2019), other studies reported a socio-economic advantage from belonging to a higher social class or lack of exposure to poverty (Bancroft et al., 2004; McGuire, 2002; Ronel & Levy-Cahana, 2011). Within these families, parents could purchase lifestyles which were relatively free of discrimination and stigma relating to their alcohol or drug use, as they could more easily hide it from others. For instance, a young person recalled their reasons for not being bullied was because their parents could afford to pay for, *“the best of gear [clothes]”* (McGuire, 2002, p. 26).

### ***3.7.3 Controlling the uncontrollable: creating safety within the family***

Whilst children and young people were generally negatively impacted by parental substance use, they were not passive within these experiences and often reported trying to “*control the situation*” at home or within their family (D’Costa & Lavalekar, 2021, p. 20). Young people reported finding and trying many ways to express agency to create safety for themselves and others. Young people often controlled the uncontrollable by adapting to their environment and trying to change and manage their parent’s substance use and any consequent conflict.

#### ***Adapting to their environment***

With growing awareness of parental substance use, children and young people quickly learned to adapt. Hypervigilance allowed children and young people to notice signs and clues that better prepared them for escalating substance use, imminent conflict, violence, or abuse (Backett-Milburn et al., 2008; Barnard & Barlow, 2003; Bernays & Houmøller, 2011; Bickelhaupt et al., 2021; Christensen, 1997; Fraser et al., 2009; Hagström & Forinder, 2019; L. Hill, 2015; M. Hill et al., 1996; Houmøller et al., 2011; McGuire, 2002; Moore et al., 2011; Tinnfält et al., 2018; Velleman et al., 2008). Being able to identify potentially risky situations allowed young people to mediate, control, or avoid such escalating situations, keeping them safe and able to survive. Children and young people spoke of enacting agency by taking control of their environment and creating safe spaces for themselves and siblings to escape within an otherwise unsafe home (Ahuja et al., 2003; Backett-Milburn et al., 2008; Bancroft et al., 2004; Bickelhaupt et al., 2021; Christensen, 1997; D’Costa & Lavalekar, 2021; Dundas, 2000; Hagström & Forinder, 2019; M. Hill et al., 1996; Holmila et al., 2011; Houmøller et al., 2011; Johnson, 2013; Nattala et al., 2020; Park & Schepp, 2017, 2018; Park et al., 2016; Ramírez Dávila et al., 2014; Templeton et al., 2009; Tinnfält et al., 2018; Turning Point, 2006; Velleman et al., 2008; Wangensteen et al., 2019a; Yusay & Canoy, 2019). In Hagström and Forinder (2019), a 6-year-old boy would, “*hide in a small space under the house with a torch*” as it was “*a scary dark place where no one else dares to go*” (p. 16). This allowed children and young people to resist their parents’ threatening and controlling behaviours by finding ways to minimise contact with the parent, in addition to taking up hobbies or spending extended periods of time at the homes of others. They also constantly monitored their parent’s reactions, trying to understand their parent’s emotions, and adapted their response to the perceived mood (Bernays & Houmøller, 2011; D’Costa & Lavalekar, 2021; Dundas, 2000; Hagström & Forinder, 2019; Park & Schepp, 2017; Park et al., 2016; Reupert et al., 2012; Tinnfält et al., 2018; Yusay & Canoy, 2019). In Reupert et al. (2012), an 8-year-old boy recalled, “*It’s important that I am good and [do] not make dad angry*” (p. 157). Additionally,

gaining independence from the family allowed young people a sense of control over their relationships and to put their needs first (Backett-Milburn et al., 2008; Bancroft et al., 2004; Bernays & Houmøller, 2011; Bickelhaupt et al., 2021; Hagström & Forinder, 2019; Houmøller et al., 2011; Park & Schepp, 2017; Ramírez Dávila et al., 2014; Ronel & Haimoff-Ayali, 2010; Wangensteen et al., 2019a; Wilson et al., 2012). However, it was difficult for some children and young people to fully gain independence from these relationships (Ahuja et al., 2003; Backett-Milburn et al., 2008; Bancroft et al., 2004; Houmøller et al., 2011; Wilson et al., 2012), even more so for young people living in collectivist societies where cultural norms expected children to support their aging parents e.g., Confucianism in South Korea that considers family more important than an individual family member (Park et al., 2016).

### ***Controlling parental substance use and conflict***

When younger, children described trying to control their parent's substance use by hiding or throwing away substances or hiding money to stop their parents from buying alcohol or drugs (Ahuja et al., 2003; Backett-Milburn et al., 2008; Bancroft et al., 2004; D'Costa & Lavalekar, 2021; Fraser et al., 2009; Hagström & Forinder, 2019; M. Hill et al., 1996; Moore et al., 2011; Nattala et al., 2020; Tinnfält et al., 2018). Some young people tried talking to their parents and felt that if they "*could find the right words*" to tell their parents how they were impacted then their parents would stop using substances (Christensen, 1997, p. 29). Young people also described trying to confront their parent(s) about substance use or sometimes gave ultimatums (Backett-Milburn et al., 2008; Bancroft et al., 2004; Christensen, 1997; Hagström & Forinder, 2019; Holmila et al., 2011; Johnson, 2013; McGuire, 2002; A. McLaughlin et al., 2015; Nattala et al., 2020; Park & Schepp, 2017; Templeton et al., 2009; Turning Point, 2006; Yusay & Canoy, 2019). As they aged and gained power, in terms of physical, relational, and emotional strength, young people also reported mediating conflict, by putting themselves in harm's way to protect their non-using parent or siblings and to defuse escalating arguments within the home (Ahuja et al., 2003; Alexanderson & Näsman, 2017; Bancroft et al., 2004; Barnard & Barlow, 2003; Bernays & Houmøller, 2011; D'Costa & Lavalekar, 2021; Hagström & Forinder, 2019; M. Hill et al., 1996; Holmila et al., 2011; Houmøller et al., 2011; Johnson, 2013; McGuire, 2002; Moore et al., 2011; Nattala et al., 2020; Park & Schepp, 2018; Park et al., 2016; Ramírez Dávila et al., 2014; Ronel & Haimoff-Ayali, 2010; Silva & Padilha, 2013a; Templeton et al., 2009; Tinnfält et al., 2018; Velleman et al., 2008).

To avoid or manage conflict between their parents, some young people recalled withholding information from their non-using parent about their experiences with a substance using parent

(Alexanderson & Näsman, 2017; Dundas, 2000; Hagström & Forinder, 2019; Johnson, 2013; Park et al., 2016; Turning Point, 2006), or more rarely, by contacting services e.g., police or social care, to help defuse situations (Holmila et al., 2011; Tamutienė & Jogaitė, 2019).

Where they could, young people reported trying to avoid putting themselves into danger when they lived between separated parents, by calling to see if their parent was sober before returning home (Alexanderson & Näsman, 2017; Hagström & Forinder, 2019). Trying to control escalating situations between their parents with context-specific expertise, and negotiating the boundaries between risk and safety, were intended to get themselves or others out of harm's way. However, some young people experienced repercussions, in terms of violence towards them or their family (Ahuja et al., 2003; Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bancroft et al., 2004; M. Hill et al., 1996; Moore et al., 2010; Mudau, 2018; Nattala et al., 2020; Powell et al., 2021; Ramírez Dávila et al., 2014).

#### ***3.7.4 Coping with and resisting the emotional and social impacts***

Children and young people reported trying different strategies to cope with the emotional impacts of parental substance use by themselves, often either by internalising or externalising their emotions. Additionally, one of the main strategies to manage and resist the social impacts of parental substance use, particularly stigma, was to keep the substance use private or 'hidden' from others.

##### ***Coping with the emotional impacts***

Children and young people reported seeking to resist the emotional impacts of parental substance use through choosing to write in journals, practicing mindfulness, or taking part in fun activities like watching tv, reading a book, or playing games (D'Costa & Lavalekar, 2021; Dundas, 2000; Hagström & Forinder, 2019; Holmila et al., 2011; Tinnfält et al., 2018; Velleman et al., 2008). These strategies allowed young people to make sense of their emotions or helped them to detach emotionally from their experiences. More passive strategies used to cope, for example avoiding thinking about their circumstances, reportedly had negative consequences on their mental health (Backett-Milburn et al., 2008; Bickelhaupt et al., 2021). Another way young people learned to cope was to gain knowledge and awareness around substance use and addiction, as well as talking to their parents about their childhood. Understanding that addiction is a disease and not something that was their fault, young people were likely to accept their parents' behaviour, and start to forgive them, for example in Park and Schepp (2017) a young adult reflecting on his father's alcohol use reported:



*“I learned somewhere that alcoholism is not cured by just having a strong will to quit, since alcohol addiction is actually a brain disease...I understand that his tough life might have made him become like that” (p. 1883).*

Other young people externalised their emotions through anti-social behaviours including violence and bullying, offending, or substance use (Ahuja et al., 2003; Alexanderson & Näsman, 2017; Backett-Milburn et al., 2008; Bancroft et al., 2004; Barnard & Barlow, 2003; Bickelhaupt et al., 2021; Fraser et al., 2009; Hagström & Forinder, 2019; L. Hill, 2015; Holmila et al., 2011; Lewis et al., 2021; Moore et al., 2010; Murray, 1998; O'Connor et al., 2014; Offiong et al., 2020; Park et al., 2016; Ronel & Haimoff-Ayali, 2010; Ronel & Levy-Cahana, 2011; Tamutienė & Jogaitė, 2019; Templeton et al., 2009; Tinnfält et al., 2011; Tinnfält et al., 2018; Turning Point, 2006; Wilson et al., 2008). Such behaviours as well as the young person were seen as a problem within society, where the young person was excluded and/or punished. Some young people also reported self-harming behaviours to cope with the emotional impact (Bickelhaupt et al., 2021; Holmila et al., 2011; Nattala et al., 2020; Tamutienė & Jogaitė, 2019; Velleman et al., 2008). In Tamutienė and Jogaitė (2019), a 17-year-old female reflected on her experiences of how her externalised behaviours showed emotional impact as well as a call for help that she did not receive:

*“I stopped attending classes, started talking to teachers harshly and later started self-harming. I was showing how bad it was for me, and later, I started consuming alcohol and drugs at school” (p. 215).*

### ***Resisting the social impacts***

The majority of children and young people made efforts to hide their parents substance use in order to reportedly resist the social impacts of parental substance use, including stigma, embarrassment, and fear of endangering social relationships (Backett-Milburn et al., 2008; Bancroft et al., 2004; Barnard & Barlow, 2003; Bernays & Houmøller, 2011; Christensen, 1997; D'Costa & Lavalekar, 2021; Hagström & Forinder, 2019; M. Hill et al., 1996; Holmila et al., 2011; Houmøller et al., 2011; McGuire, 2002; Moore et al., 2010; Murray, 1998; Nattala et al., 2020; Park & Schepp, 2018; Park et al., 2016; Reupert et al., 2012; Tamutienė & Jogaitė, 2019; Templeton et al., 2009; Tinnfält et al., 2011; Tinnfält et al., 2018; Turning Point, 2006; Velleman et al., 2008; Wangensteen et al., 2020; Wilson et al., 2008; Yusay &

Canoy, 2019). In Turning Point (2006), an 18-year-old female recounted her reasons for non-disclosure,

*“I didn’t really like to talk to my friends about it...it was embarrassing, who wants to admit their families are alkies” (p. 12).*

Instead of talking about their experiences to someone else, some young people also chose to write down their thoughts as a way to resist social stigma. In D’Costa and Lavalekar (2021), a young person recalled;

*“I feel safe when I put my thoughts down on paper because no one is judging me” (p. 22).*

For some young people, the experience of parental drug use was seen as more stigmatising and embarrassing to disclose than parental alcohol use, due to the illegal status of classified drug use and the social acceptance of alcohol use. A young person reported preferring to tell other people that her mother drank alcohol rather than used drugs, as she was ashamed to be associated with illicit drug use (Barnard & Barlow, 2003). Additionally, young people whose parents used alcohol tended to identify more open use in front of them but when parents were confronted, denied their use was problematic due, in part, to societal perceptions of those whose use is seen as problematic within society (Houmøller et al., 2011; Park & Schepp, 2018). Other less-cited reasons for choosing not to disclose included fear of removal from the family, fear of repercussions for the parent or being disloyal, and fear of violent repercussions. Over time, many young people did eventually choose to tell someone about their parent’s substance use, mainly due to reaching a crisis point, with sometimes but not always favourable supportive outcomes. Telling the wrong person resulted in increased stigma, discrimination, and isolation for young people, therefore it was hard to decide and navigate who to trust. Younger children did not always choose to speak to people due to the fear and shame they experienced but enacted small gestures of defiance to their parents’ hidden use by talking to pets or toys (Hagström & Forinder, 2019; Holmila et al., 2011; A. McLaughlin et al., 2015). For example, in Hagström and Forinder (2019), a 6-year-old-boy stated, *“I talk to the bird. She’s a friend. I tell my secret to the bird. I only whisper it to her” (p. 17)*. In Holmila et al. (2011), a young person also reflected: *“I gather all my soft toys in the bed, turn off the lights and tell them my worries” (p. 182)*. Whilst young people were

finding ways to show resistance and cope with the emotional and social impacts of parental substance use, it also tended to place them in a further isolated and lonely position.

### ***3.7.5 Formal and informal support***

Children and young people reflected on formal and informal forms of support they had received that were often conditional, providing both help and hindrance to children and young people. Most often, they spoke of the informal support they had received from friends or an extended family member rather than receiving formal support. School was often reported as a place that could provide comfort for some young people but also isolation for others.

#### ***Sources of support***

Emotional and social support were mainly cited as being provided by older siblings, a non-using parent, an extended family member, friend, or neighbour. However, these forms of informal support were not always accessible, long-lasting, or safe, as some of these relationships were seen as inducing further risk to the young person, especially friends who encouraged substance use and offending behaviours or caregivers who experienced mental health problems (Backett-Milburn et al., 2008; Bancroft et al., 2004; McGuire, 2002; Ronel & Haimoff-Ayali, 2010; Ronel & Levy-Cahana, 2011; Tamutienė & Jogaitė, 2019; Wilson et al., 2008). Less often, young people reflected on the formal support they had received from within the healthcare, social care, and education systems that reportedly provided both help and hindrance (Backett-Milburn et al., 2008; Bancroft et al., 2004; Bernays & Houmøller, 2011; Fraser et al., 2009; Houmøller et al., 2011; Johnson, 2013; McGuire, 2002; A. McLaughlin et al., 2015; Moore et al., 2010; O'Connor et al., 2014; Offiong et al., 2020; Powell et al., 2021; Tamutienė & Jogaitė, 2019; Tinnfält et al., 2011; Turning Point, 2006; Wangenstein & Westby, 2019b; Wilson et al., 2008, 2012). Within A. McLaughlin et al. (2015), an 11-year-old female reflected on the fragile nature of receiving support from a practitioner: *“Talking to my counsellor helped me, but then my counsellor left (p. 113).”* Such formal forms of support were also mainly reported to be targeted towards improving young people’s emotional wellbeing.

Within both formal and informal forms of support, children and young people viewed interactions that were genuine, caring, compassionate, and non-stigmatising, as helping them to feel safe and trust the other person. To build these relationships, young people spoke of needing time, consistency, flexibility, and *“the need for someone stable”* (Offiong et al., 2020, p. 4). Within formal forms of support provision, it was the informal approach that was

often seen as most useful, for instance a headteacher who allowed a young person who was having a difficult day to “*sit in a corner on a beanbag and work in her office*” and to “*have a cup of tea and a biscuit*” (Houmøller et al., 2011, p. 59). However, children and young people also reflected that the quality of the relationship could be detrimental to support provision when the opposite occurred, including lack of trust, lack of consistency due to high turnover of staff, rigidity in the support provided, and feelings of being pressured for information. Further, some young people had experienced stigma and prejudice from professionals within education (Backett-Milburn et al., 2008; Bancroft et al., 2004; McGuire, 2002; Nattala et al., 2020; Tamutienė & Jogaitė, 2019; Wilson et al., 2008), social care (McGuire, 2002), healthcare (Hagström & Forinder, 2019), or from a range of practitioners in the health, care, and education system (Wangensteen et al., 2020), impacting the support they received. Young people stated that the lack of action or adequate action when disclosure occurred left them feeling abandoned and less likely to seek further support (Bancroft et al., 2004; Hagström & Forinder, 2019; Houmøller et al., 2011; Tamutienė & Jogaitė, 2019; Templeton et al., 2009; Tinnfält et al., 2011; Turning Point, 2006; Velleman et al., 2008; Wangensteen et al., 2019a). Some young people also recalled times when they did not meet the eligibility criteria or age restrictions for support, leaving them further isolated (Moore et al., 2010; Offiong et al., 2020; Wilson et al., 2008). In Moore et al. (2010), a 14-year-old male spoke of his distrust in drug and alcohol services:

*“I’m sick of them saying, ‘We can’t help, our support’s not for you’. Who is here for us? Am I not worthy of help? We’re the ones doing the right thing, so why doesn’t anyone give a shit?” (p.24).*

### ***School environment***

School was frequently cited within studies, often viewed by young people as a place of safety and support, but not without risk. Primary school was reported as a place for young people to see friends, explore hobbies, and have time for themselves away from home (D’Costa & Lavalekar, 2021; A. McLaughlin et al., 2015). However, problems tended to arise at secondary school where it became a place to worry about home, often leading to young people skipping school (Backett-Milburn et al., 2008; Barnard & Barlow, 2003; Dundas, 2000; Hagström & Forinder, 2019; L. Hill, 2015; Lewis et al., 2021; Moore et al., 2010; Nattala et al., 2020; O’Connor et al., 2014; Turning Point, 2006) or struggling to keep up with their schoolwork (Holmila et al., 2011; Moore et al., 2010; Mudau, 2018; Nattala et al., 2020; Park & Schepp, 2017; Templeton et al., 2009; Turning Point, 2006). Achieving and doing

well at school was viewed as a useful strategy to lead a successful life and teachers were often reported as providing support and encouragement with their goals and aspirations (Ahuja et al., 2003; Bancroft et al., 2004; Bickelhaupt et al., 2021; D'Costa & Lavalekar, 2021; Hagström & Forinder, 2019; M. Hill et al., 1996; Houmøller et al., 2011; Nattala et al., 2020; Park & Schepp, 2017, 2018; Ramírez Dávila et al., 2014; Ronel & Haimoff-Ayali, 2010; Turning Point, 2006; Wangensteen & Westby, 2019b; Wilson et al., 2008). However, this was not always easy, due to some young people being excluded or suspended for their unacceptable behaviour, further isolating them from social and professional support (Bancroft et al., 2004; Tamutienė & Jogaitė, 2019; Turning Point, 2006; Wilson et al., 2008). Young people reported wanting school staff to recognise the impacts of parental substance use on children, to improve referral and early access to support (Hagström & Forinder, 2019; Holmila et al., 2011; Moore et al., 2011; Tamutienė & Jogaitė, 2019; Tinnfält et al., 2011; Turning Point, 2006). Whilst externalised behaviours were reported as being easier to identify, this was not always the case for internalised feelings such as anxiety or fear, due to some pretending that everything was okay, to not incur social stigma (Bernays & Houmøller, 2011; D'Costa & Lavalekar, 2021; Houmøller et al., 2011; Tinnfält et al., 2011). In Houmøller et al. (2011), a young person reflected,

*“Even though I was having them problems at home I didn’t let it show in school. I’d still come in and do my work and act like a normal kid” (p. 28).*

### ***(Un)helpful helping***

Different forms of support were reported to be both helpful and unhelpful for young people across studies, highlighting the requirement for support to consider the range of needs of children and young people. The focus of services on supporting the parent and ignoring the needs of the child was reportedly experienced negatively by young people as they wanted support for themselves (Alexanderson & Näsman, 2017; Moore et al., 2010; Tamutienė & Jogaitė, 2019). In Wangensteen et al. (2019a), a 21-year-old male expressed:

*“People keep talking about my mother: “Your mum is on drugs, your mum is off drugs, your mum is in treatment...” I do understand it, but we never talked much about me” (p. 205).*

However, substance use support for their parents alongside their own emotional support could be considered by services who support adults (Christensen, 1997; Holmila et al., 2011;

McGuire, 2002; Moore et al., 2010; Reupert et al., 2012). Support that included the whole family was viewed as useful when it alleviated family stress and conflict or improved family connectedness (Moore et al., 2011; Moore et al., 2010; Reupert et al., 2012; Tinnfält et al., 2018) but it was hard for some young people to talk openly in front of parents (Bancroft et al., 2004). Other young people wanted to have family support that focused on members of the family separately but at the same time instead of together in the same room or place (Moore et al., 2010). Kinship care was usually viewed positively (Bancroft et al., 2004; Fraser et al., 2009; L. Hill, 2015; Lewis et al., 2021), but did not always solve the emotional impact of young people's previous experiences of parental substance use (Christensen, 1997). Young people wanted practical and financial aid to support the family yet rarely received this (Moore et al., 2011; Moore et al., 2010; Park & Schepp, 2018; Powell et al., 2021; Reupert et al., 2012; Tamutienė & Jogaitė, 2019; Templeton et al., 2009; Velleman et al., 2008). Understanding more about substance use was viewed as useful and was sometimes searched for online, which did not always return helpful results (Bernays & Houmøller, 2011; Bickelhaupt et al., 2021; D'Costa & Lavalekar, 2021; Houmøller et al., 2011; Johnson, 2013; Murray, 1998; O'Connor et al., 2014; Park & Schepp, 2017; Turning Point, 2006; Velleman et al., 2008; Wangenstein et al., 2019a; Wangenstein et al., 2020). Being involved in religious communities (D'Costa & Lavalekar, 2021; M. Hill et al., 1996; A. McLaughlin et al., 2015; Nattala et al., 2020), or meeting with those in similar situations and having a peer role model (Bancroft et al., 2004; L. Hill, 2015; M. Hill et al., 1996; Holmila et al., 2011; A. McLaughlin et al., 2015; Moore et al., 2011; Moore et al., 2010; Mudau, 2018; Powell et al., 2021; Reupert et al., 2012; Tinnfält et al., 2011; Turning Point, 2006; Velleman et al., 2008) were also sources of useful support for those who had been provided with the opportunity, however these were usually only on rare occasions.

### **3.8 Identified Gaps and Needs for Further Research**

Gaps in the existing knowledge base that do not address the aims of this thesis are explored below. Principally, understanding how best to support the varying needs and preferences of young people regarding their parents' substance use needs further exploration. Firstly, this review has highlighted the perceived impacts that young people experience, including the social impacts of stigma and loneliness, yet there is limited indication of how young people manage or are supported with these impacts within formal support. Whilst young people tried to resist the stigma of parental substance use, they also sometimes inadvertently isolated themselves further. When formal support was discussed, studies mainly reported that

emotional support was provided with limited mention of formal support aiming to improve social wellbeing. As perceived impacts to social wellbeing was a main finding within this review, the subsequent chapters will directly explore this area further to understand stigma, isolation, and young people's social wellbeing support needs. Next, the systematic review identified that despite the negative impacts young people may experience, they often try to actively manage and mitigate the risks. This was interpreted as the young person expressing their agency in such situations, whereas most included studies positioned and described young people as vulnerable or passively coping with parental substance use. A deeper understanding of how agency could be fostered in support is required and further explored within the chapters to follow. Finally, most children and young people reported relying on informal forms of support rather than formal support. Yet, extended family members, siblings or peers were not always accessible or reliable due to the temporary or fluctuating nature of such relationships and may not be the best option for young people to provide ongoing support. It also places the burden of support on those who may also be exposed to substance use. As there was limited discussion in the literature around experiences of formal support, with mainly contradictory accounts of support being both helpful and unhelpful, with little around how support could be improved, following chapters will explore this further, aiming to identify how support can meet the needs of young people whose parents use substances. This will be explored from the views of young people who experience parental substance use and the different practitioners who provide them with support.

The majority of the studies included from the United Kingdom were conducted in Scotland. In comparison to England, Scotland has a different political context and support provision for young people whose parents use substances (The Scottish Government, 2022). Of those studies conducted in England, all were conducted over 10 years ago with some two decades ago, mainly around the time of the publication of the reports from the Advisory Council on the Misuse of Drugs (ACMD, 2003, 2007). Since, policies for supporting young people and families where there is parental substance use have been updated. The next chapter will provide an updated account of young people's experiences of parental substance use in relation to their support needs, from those across England, to understand need on a national level.

### **3.9 Chapter Summary**

This chapter detailed the methodology and methods for the qualitative systematic review and the findings of the thematic synthesis. The review aimed to explore published evidence of children and young people's lived experiences of parental substance use, with additional focus on their perceived impacts and coping strategies. A discussion was provided regarding the different approaches to systematically reviewing qualitative studies and the specific methods used were presented. A two-stage process to quality appraisal was applied wherein studies were rated on quality and relevance to the review. The involvement of public and practice members in guiding this review was described. Thirty-five studies covered the perspectives of over 700 children and young people whose parents use substances from across twenty countries. Findings of the thematic synthesis were discussed in terms of five themes: living with the unpredictable: insecurity within the family; social and emotional impact of parental substance use; controlling the uncontrollable: creating safety within the family; coping with and resisting the emotional and social impacts; and formal and informal support. Identified gaps and needs for further research were detailed. Practice and policy implications from this review will be explored in relation to the findings from the following chapters, in Chapter 6. The next chapter will detail the qualitative fieldwork with young people whose parents use substances and the practitioners who support them, exploring the support needs of young people whose parents use substances.



## **Chapter 4. Qualitative Fieldwork with Young People & Practitioners**

### **4.1 Overview**

This chapter presents the methods and findings of the qualitative fieldwork with young people whose parents use substances and the practitioners who support them. The justification and implications of the chosen methodology for the approach to the fieldwork and analysis will then be discussed. Next, will be a detailed account of the methods, including recruitment strategy, process of data collection, and approach to analysis. Following this, the findings will be presented exploring the support needs of young people whose parents use substances. The demographic details of participants will be detailed first, with exploration of the four identified themes afterwards. The main themes include: (1) navigating trauma and safety within the family; (2) enhancing young peoples' agency; (3) understanding young peoples' experiences of resilience and stigma: the role of surviving or thriving; and (4) building resilient and non-stigmatising systems around young people. Each theme is detailed in turn, with quotations provided to illustrate the theme's content.

### **4.2 Aims and Objectives**

The objective of this fieldwork was to examine the views of young people and health and social care practitioners on the support needs of young people whose parents use substances, exploring their views on past and current support provision, as well as future ideal support provision. Additionally, this fieldwork aimed to explore how young people's lived experiences and impacts of parental substance use related to their support needs and help-seeking behaviours. These objectives were met through qualitative analysis of interviews and focus group data generated on the topic.

### **4.3 Insights Informing the Methodology**

#### **4.3.1 *Qualitative systematic review***

The research methodologies of included studies in the earlier systematic review were considered during formulation of this study and influenced the approach taken for this work, especially regarding conducting individual interviews with young people. I also reflected on the included studies' limitations regarding recruitment and/or methodology. From this it was apparent that I should establish and build strong relationships with gatekeeping organisations for successful recruitment of young people. I endeavoured from as early as possible to develop professional relationships with services and organisations, both locally and

nationally. I attended practitioner events and networked with those in attendance, discussing my research, and involving practitioners in meaningful ways throughout the study process. Moreover, the initial themes that were generated during the qualitative reviewing phase helped shape the topic guides and direction of this research. I wanted to address the gaps identified from the review in understanding how formal approaches of support could help young people with their experiences and impacts of parental substance use and therefore I structured the topic guide to allow me to explore these areas. The qualitative systematic review identified that most young people relied on informal networks of support, so I wanted to recruit young people who had experienced formal support from a range of different services including healthcare, social care, or voluntary and community sector organisations, and not just focus on one area (e.g., social care). This insight strengthened my rationale for using gatekeeping organisations to access young people. Specific decisions influenced by insights from the qualitative systematic review are highlighted throughout the methodology section described within this chapter.

#### ***4.3.2 Public and practice involvement***

Public and practice involvement and engagement (PPIE) activities were drawn upon to inform the methodology employed within this study. This included young people with lived experience of parental substance use as well as the practitioners who support them. To inform the qualitative interviews with young people, I consulted a local service for young people who experience someone else's drug or alcohol use (PROPS Young Person's Project) as well as a family that I knew, where there was parental substance use. I was invited to run a workshop with four young people from PROPS, aged 11-17 years, who had experienced parental substance use, as well as with two of their support workers. The family consisted of three female siblings aged 14-23 years. I also attended two local forums hosted by Adfam, which were attended by eight and ten practitioners respectively, supporting families with substance use. Across these sessions, public and practice members helped shape the recruitment strategies, methodology, topic guides, and recruitment materials. The way in which PPIE consultations informed the methodology will be discussed throughout this chapter.

### **4.4 Methodological Approach to Fieldwork**

#### ***4.4.1 Rationale for interviews and focus groups***

Qualitative exploration has been found to provide an in-depth understanding of participants views, needs, and experiences, and can be a useful approach used alongside PPIE methods

when developing interventions (Muller et al., 2019). Semi-structured interviews, including both individual and dyadic interviews, in addition to focus groups were selected as methods for data generation within this study. Individual interviews can be thought to produce richer, more detailed accounts of a phenomenon, allowing deeper insight into a participant's personal thoughts, feeling, and views (Guest, Namey, Taylor, Eley, & McKenna, 2017). Whilst focus groups, usually ranging in size from 4-12 individuals, can benefit from group dynamics, interaction, and the stimulation of discussion that can produce data not otherwise generated in individual interviews as well as a wider range of views and ideas (Guest et al., 2017). Focus groups therefore provide opportunity for participants to share, refine, and dispute views through discussion in a socially oriented environment that can reflect everyday interactions. Dyadic interviews allow for interaction and the generation of new discussions whilst also allowing each participant more time to delve deeper into their own personal views than in a focus group (Morgan, Ataie, Carder, & Hoffman, 2013). Interviews (including individual and dyadic) and focus groups produce rich complimentary data that can be triangulated for a more comprehensive understanding of a topic (Patton, 1999).

### ***Young people***

Young people participated in individual interviews only, instead of focus groups, which facilitated the sharing of detailed personal narratives on a sensitive research topic. This decision was informed by several factors. First, the qualitative systematic review had found that young people may feel shame or embarrassment discussing personal experiences of parental substance use in front of others, as such focus groups may not be an appropriate approach. Focus groups were also infrequently used as a data collection method within the included studies of the review. Moreover, in a study comparing the use of interviews or focus groups when conducting qualitative research with young people, it was found that individual interviews were preferred by young people when discussing their lived experiences as it was more confidential (Punch, 2002; Punch & Graham, 2017). Whereas focus groups were preferred when there were more informal and impersonal topics to discuss which could appropriately include others. Finally, this decision was further informed by PPIE, where young people with experience of parental substance use reflected that the topic would be most suitable within a one-to-one approach, as young people could talk openly and privately.

### ***Practitioners***

Practitioners participated across the three different approaches. Initially, focus groups were considered for this participant group because they are considered a method of choice when the

purpose of the research is to study processes, interaction, and behaviour (Barbour, 2007; Bloor, Frankland, Thomas, & Robson, 2001). The aim was to recruit those with substantive experience of working with young people impacted by parental substance use and to facilitate discussion amongst those who normally work together or are expected to work together in practice. Research in a similar area exploring practitioners' views of supporting parents who use substances had also utilised focus groups to encourage authentic discussion amongst practitioners (Whittaker et al., 2016). However, during discussions with practice advisors on this thesis, they suggested that preferences between practitioners and services may differ for style of participation within the study. Therefore, practitioners were offered the choice of taking part in a focus group or interview, with some also requesting dyadic interviews. Lambert and Loisele (2008) found that the integration of focus group and interview data allowed for an iterative approach to data collection wherein focus groups generated additional discussion topics, and interviews contributed to the depth and understanding. For this thesis, focus groups were therefore conducted first with interviews conducted later to explore the emerging themes from different perspectives. It was important to understand how power dynamics may influence the discussion in focus groups or dyadic interviews where practitioners were from the same service but had hierarchical positions e.g., a manager, team leader, and frontline worker. Such provisions (e.g., dyadic interviews) were made to accommodate practitioners' participation where they felt that the perspectives that they held may have an impact on their role if discussed in front of senior staff in a larger focus group.

#### ***4.4.2 Approach taken in conducting interviews and focus groups***

Qualitative interviews and focus groups vary on a continuum from free-ranging exploratory discussions (e.g., an unstructured ethnography interview) to highly structured interviews (e.g., standardised interviews or surveys). In the middle, is a hybrid approach, including the semi-structured approach. This approach utilises a topic guide, which provides a framework of open-ended questions to be discussed with each participant whilst also allowing opportunity to probe around emerging ideas and views (Magaldi & Berler, 2020). Semi-structured interviews and focus groups are therefore social interactions that are seen as a 'conversation with a purpose' (T. Berg, 1989). Being able to build rapport with participants, including putting them at ease in a relaxed, engaging, and cooperative manner, is seen as an important factor in conducting qualitative research and thus the skills and qualities of the researcher can help with the richness of the data collected (Yeo, Legard, Keegan, & Ward, 2014). To establish rapport, I would often meet or talk to the participant(s) prior to the interview or focus group and during the recruitment process, to answer questions or explain the study.

During PPIE consultations, young people reflected that it was important for young people to have the opportunity to meet with me before the interview. Within the interview, I endeavoured to create a trusting environment, where participants felt understood, respected, and did not feel stigmatised. Where relevant or asked, I reciprocated an appropriate level of self-disclosure (e.g., experience of family substance use) which can facilitate trust, encourage deeper disclosure on the part of participants and aims to avoid power imbalances that may create discomfort (Karnieli-Miller, Strier, & Pessach, 2009). Regarding focus groups, I aimed to form groups of practitioners with commonality (e.g., peer networks) to harness existing rapport between participants, facilitating interaction and discussion. I met with and discussed my research with these existing groups prior to the focus group taking place to build trust and respect.

As this research was disrupted by the COVID-19 pandemic and there were social restrictions in place, all interviews and focus groups were adapted to be conducted remotely instead of in person. Remote data collection can facilitate the inclusion of participants from a wide range of geographical locations (Oltmann, 2016) and therefore the study was opened up to those from across England, instead of only the North East of England. Moreover, research has found that remote data collection can aid the discussion of traumatic or sensitive topics, resulting in rich data as participants can take part in the comfort of their own environment as well as an added layer of anonymity if conducted over the telephone (Trier-Bieniek, 2012; Whale, 2017). However, for some young people this meant that they were in the house with their parent who uses substances. For safeguarding purposes, I collaborated closely with gatekeepers to identify young people where these conversations would be appropriate and safe to take place. To protect participants privacy and safety I took considerations during the interview including advising them of the potentially sensitive nature of the study and that they should seek a private space before commencing, and to use an agreed 'code word' if their privacy was compromised in which we could stop or pause the interview (Hensen et al., 2021). Further ethical considerations are explored in section 4.4.4.

Topic guides were developed to inform the discussions within the semi-structured interviews and focus groups. I used these flexibly to ensure that the main topics were covered, whilst also allowing for additional insights and the natural flow of discussion (Gill, Stewart, Treasure, & Chadwick, 2008). With the involvement of young people and practice advisors, they informed the development of two topic guides for young people, one for those aged 11-17 years and another for those aged 18-25 years. Through PPIE, the topic guide structure was

agreed upon, wherein the interviews would initially focus on exploration of known impacts of parental substance use based on the qualitative systematic review, before moving on to more in-depth topics of parental substance use. For instance, findings from the review highlighted that school and relationships could be impacted by parental substance use, therefore, to ease young people into the interview, the discussion initially focused on these areas. Both topic guides followed the same structure with age-appropriate questioning and to account for some retrospective accounts of those aged 18-25 years. Young people were facilitated to explore their experiences and impacts of parental substance use as well as the support they had received or needed in relation to these. The interviews ended on exploration of young people's ideas for what future support could look like and their hopes for the future. This was to ensure the interviews ended on a positive focus, wherein young people were reflecting about how their experiences could support others in a similar situation. To reflect developing themes, the topic guides were adapted throughout the data collection process. The topic guides used with practitioners were developed to align and be comparable with the young person's topic guide, with the focus on exploration of current practice, young people's experiences of parental substance use, and ideas for future support. The topic guide for practitioners was reviewed by a practice advisor. Including the views of practitioners was not to validate the voice of young people living with parental substance use, but to consider additional factors regarding support.

The topic guides for young people were designed pre-pandemic and therefore creative approaches were included to be used alongside the topic guide during the interview, as discussed with the young person PPIE group. These included, a self-portrait activity and relational map activity to explore different important relationships to young people, and a home-based activity to explore what their home was like at various times of the day (e.g., if a parent had used drugs versus when they had not) (Bagnoli, 2009). These art-based activities were going to be employed as some young people may struggle to express themselves due to the sensitive nature of the topic and activities would empower them to communicate and engage more comfortably (Bagnoli, 2009). The activities were mainly for the participants at the lower end of the age range, but anyone could have completed them. Similar creative approaches have been effectively used in research with young people whose parents use substances (L. Hill, 2015). Whilst young people were informed about these activities ahead of the remote interview, all participants chose to talk about their experiences and views instead of completing activities.

I had an active role in the interviews and focus groups, and through such interaction with participant(s) we generated data between us (Holstein & Gubrium, 1997; Yeo et al., 2014). However, I cannot assume that this study has captured the full understanding of the support needs of young people whose parents use substances, which in line with the critical realist orientation (Fletcher, 2017), I have used a methodological approach that aimed to generate the most in-depth understanding on this topic.

#### **4.4.3 Sampling strategy**

A purposive sampling strategy was undertaken for this study ensuring participants were selected based on different pre-determined characteristics relating to the research. Maximum variation was aimed for to facilitate diversity in the data. This contributed to a richer, more in-depth understanding of the support needs of young people whose parents use substances as the views and perspectives of participants could be contrasted and compared (Palinkas et al., 2015).

Young people were sampled according to, age; gender; self-reported parental substance use; level of socio-economic deprivation; living arrangements (e.g., living with parent who used substances or not); geographic location; and ethnicity. Socio-economic deprivation was gauged as a crude indicator of socio-economic status based on the young person's post code using the English Indices of Deprivation (2019). This index provides a measure of local area deprivation based on income, employment, education, health care, disability, crime, housing, and living environment with an index of multiple deprivation decile from 1 (most deprived) to 10 (least deprived) (McLennan et al., 2019). As studies included within the systematic review mainly recruited young people from more deprived areas, I wanted to aim for a variation in socio-economic positions, so that I could contrast experiences.

Practitioners were sampled based on their profession and geographic location. This study aimed to consult a cross-section of different providers working to support young people whose parents use substances. No further sampling criteria were applied (e.g., gender or age) as it was envisaged that recruitment may be difficult due to time pressures associated with care provision. To aid data analysis, practitioners did however provide data on additional contextual information including years spent in role/practice area, gender, age, and ethnicity.

Prior to data collection, estimates were anticipated for a sample range that would potentially generate adequate data for a rich, complex, and multi-faceted understanding of the support

needs of young people whose parents use substances. Twenty to twenty-five interviews with young people were initially envisaged to facilitate diversity in the data, whilst I aimed for between 3-5 focus groups with practitioners. Based on these estimates, as well as study confinements (e.g., time) and the point to which saturation was deemed to have been adequately achieved, recruitment and data collection were stopped (Braun & Clarke, 2021). Saturation was viewed as data saturation where no new data was perceived to be collected during data collection, as well as inductive thematic saturation, where no new themes were perceived to be identified during initial analysis, in relation to the research questions (Braun & Clarke, 2021; B. Saunders et al., 2018), termed as a hybrid approach to reach saturation which helps identify sample sizing. Keeping a reflexive journal and discussions with supervisors and public and practice members helped identify when potential saturation in the data collection and analysis process was met. For young people, recruitment continued until I felt that I had sufficiently met data saturation as well as maximum variation within the time limits and within the gatekeepers' limits. For instance, services that had capacity to aid recruitment did not support many young people, if any, from minority ethnicities and therefore such recruitment was difficult and hindered. For the practitioners, I conducted three focus groups of a large size, which were based on a convenience sample across the organisations. However, I then supplemented these with practitioner interviews to provide further detailed accounts of those not already recruited, for instance social workers or those from other organisations. Due to these factors, I recruited more practitioners than young people.

#### ***4.4.4 Ethical considerations for young people***

NHS ethics was deemed most appropriate due to the sensitive nature of the research, the age of the children and young people taking part, and that some of the voluntary and community sector organisations also required NHS ethical approval. Berry (2009) summarised some of the key ethical considerations for research focussed on children where there was family violence, including, informed consent, confidentiality and disclosure, questioning children around their experiences, as well as managing distress and danger, which has informed decisions within this study.

#### ***Informed consent***

It is acknowledged that according to the UK Medical Research Council (MRC) guidelines written consent is required alongside assent from young people under the age of 16 (Medical Research Council, 2004). However, requiring parental consent can lead to certain young



people not taking part because they do not want their parents to know about the specific details of the study (likely to become evident via consent processes), or their parents are unable to. Requiring parental consent also prevents young people from expressing their autonomy, impacting a young person's freedom to openly express their opinions, and restricting their responses, especially due to the nature of the study. This view is reflected in Article 12 ('respect for the views of the child') of the UN convention on The Rights of the Child (United Nations, 1989) and supported by guidance on interviewing young people issued by Save The Children (McCrum & Hughes, 2003). Therefore, requiring parental consent is likely to reduce the number of young people who are willing to take part and consequently reduces the validity of the research (Sanci, Sawyer, Weller, Bond, & Patton, 2004). This is especially an issue with young people who have experienced adversity, such as the population approached in this study, which can lead to underrepresentation (Sanci et al., 2004).

Whilst it is acknowledged that maturity is not defined by a chronological age, research has highlighted that young people from the age of 14 have decision-making capacity and therefore should be allowed to take part in minimal risk research without parental consent (Sanci et al., 2004; Santelli et al., 2003). This study was considered minimal risk research being purely exploratory and not involving any intervention (Weber, Miracle, & Skehan, 1994). Moreover, PPIE consultations with young people and practitioners around informed consent, identified that young people under the age of 16 accessed support from services without their parents' knowledge and would not take part in the study if they needed parental consent. The decision was therefore that parental consent would be sought for those aged 11-13 years but not for those aged 14 years and over. Due to the COVID-19 pandemic, wherein social distancing guidelines applied, young people were at home, and organisations were adapting to remote supportive roles, I was advised by practice partners to take the pragmatic decision to only recruit those who could consent for themselves, e.g., those aged 14-25 years. This decision was guided due to the concern over those aged 11-13 years needing parental consent for a study on parental substance use, where the interview would be conducted remotely. The young person might have been at home where a parent may be able to overhear the conversation, as well as them not routinely accessing support or school. Pre-pandemic all interviews were planned to be conducted outside of the young person's home so that the young person had privacy away from their parents (Duncan, Drew, Hodgson, & Sawyer, 2009).

To ensure those aged 14–15 years were competent in solely providing consent in this study, the medical principle of Gillick competency was also applied, to assess whether the young person had the maturity to make their own decisions and to understand the implications. As Hunter and Pierscionek (2007) stated, Gillick competency can be applied when the research is likely to generate greater societal benefit, pose minimal risks for the participants yet raise parental objection. Due to the nature of this study, exploring young people's experiences of parental substance use and support, and how findings could be applied to the development of an intervention, there may be parental objection to the study yet societal benefit for young people. Gillick competency was assessed by the gatekeepers who knew the young people, and not the lead researcher. This decision on the approach to consent was approved by the NHS ethics committee.

### ***Making initial contact - gatekeepers***

Contacting young people whose parents use substances in an ethical way was crucial for this project. Some researchers have warned that young people who have experienced adversity should be carefully chosen for research, as the interview may trigger memories and emotions in relation to past difficulties (Ward & Henderson, 2003). As young people had experience of parental substance use, I was aware of the potential for the interview to elicit such painful emotions and memories. Participation was therefore negotiated with practitioners or 'gatekeepers' who were working directly with young people. However, to ensure young people were given the right to make their own decisions about participation in the research, in line with other researchers (Kearns, 2014; Munford & Sanders, 2015), I asked if the gatekeepers could be as open as possible with the invitation to potential participants, e.g., asking them to not pick specific young people based on their 'resilience' but rather asking for general interest across those who they support. Through discussion with practice advisors, it was decided that there did need to be some parameters to open inclusion, which could involve further discussions with other gatekeepers (e.g., social worker or healthcare professionals) on the suitability of inclusion. These included, young people who had substantial safeguarding concerns, severe mental health difficulties, or cognitive impairment determined through the proxy measure of having a statement of special educational needs such as a learning difficulty.

### ***Interview process***

Within the interview with young people, it was important to protect them from harm, primarily the emotional distress that may arise from discussing sensitive topics. An 'ethic of

care' was adopted, which recognises that care is a process between people, and involved the recognition of need in young people with appropriate response (Meagher & Parton, 2004). To respond adequately I needed to develop trust throughout the interview and recognise and respond to their needs if appropriate. As interviews were remote, and lacked most non-verbal cues, I paid attention to pauses or sounds of discomfort, interpreting whether the pause was due to participants thinking about what to say or feeling uncomfortable (Whale, 2017). I explained that I would give them time to think and that there may be some silences and that was okay. If I felt the young person was uncomfortable to answer, I reassured them that they did not have to answer anything they did not want to, offered them breaks or reminded them they could end the interview at any point. There was also indication that the young people attempted to show care to myself, by asking if they were providing too much "gory detail", this emphasises the reciprocal nature of developing relationships during interviews. I treated these instances empathetically and acknowledged they could share with me how much they felt comfortable to. There was also concern over whether there would be disclosure of abuse, maltreatment, or self-harm that had not previously been reported. As requested by the ethics committee, I completed recommended online training entitled 'Level 2 Safeguarding Children' and I had access via telephone to a member of my supervisory team during each interview if a safeguarding disclosure arose so that we could discuss the protocol to be taken. I explained clearly at different points of contact with young people what confidentiality entailed. It was explained that there was confidentiality in their responses but if they disclosed that they or any other person was at a serious risk of harm then confidentiality would be breached. I also explained the anonymisation process and that they would not be identifiable in publications or reports. I also had contact details of the local services they were recruited from as well as national helplines that I could share with them after the interview if they needed further support.

Moreover, Holland, Williams, and Forrester (2014) explored ethical issues relating to researching parental substance use with families and stated the importance of keeping the researcher safe, both physically and emotionally. For this remote research, a member of my supervisory team was on call during and after each interview for safeguarding disclosures as well as to debrief and talk through any emotionally challenging elements of the interview. I also endeavoured to space out the interviews with young people to create time between each one and protect my own mental health. Developing the topic guide to focus on positive aspects towards the end of the interview was also a useful strategy to help manage the emotional burden of the experiences some young people recalled, both for myself and the

young person. We tended to leave the interview feeling uplifted and empowered. I received a lot of positive feedback about the interview process directly from the young people: *“I really enjoyed our chat, thanks for reaching out to me and wanting to hear about my experiences and how to support young people”* and from the gatekeepers on behalf of a young person: *“He has told us he has gotten so much out of chatting with you and is really happy to have been involved and listened to regarding what might help others.”*

#### **4.4.5 Approach to data analysis**

Braun and Clarke’s reflexive thematic analysis guided the approach taken for data analysis (Braun & Clarke, 2006, 2019). They proposed a six-phase iterative process that can be applied flexibly to generate, analyse, and interpret themes within the data. This approach is compatible with a range of philosophical orientations and has been applied within this thesis with a critical realist lens (Fletcher, 2017). Participants perspectives were explored to identify underlying patterns and mechanisms, linking experiences of parental substance use with the support needs of young people. I adopted a predominantly inductive approach to data analysis for this study, meaning I used open coding of the data and explored patterns within the data, rather than using a predetermined framework (Braun & Clarke, 2013). A degree of deductive analysis was also later employed where wider theoretical perspectives were identified to aid further interpretation. I took an active role in identifying and interpreting codes and themes within the data, using both semantic and latent coding to define surface level meaning of the data and my interpretations of the data. A subset of anonymised transcripts were provided to my supervisor (RM) and a young person advisory group (YPAG), aiming to achieve richer interpretations of meaning for the developing themes (Braun & Clarke, 2019). The value of involving PPIE partners in qualitative analysis has been recognised, as they can draw on their own experiences to make sense of the data, with involvement being recognised as a means of improving the quality and depth of the analysis (Staley, 2009). Appropriate training is usually provided beforehand to allow for public members to have the skills and knowledge to contribute meaningfully to analysis (H. McLaughlin, 2006). I provided training to the YPAG on thematic analysis ahead of their involvement within the analytical process.

Constant comparative analysis is a particular technique generally associated with grounded theory (Glaser, 1965), yet a similar process can be used within reflexive thematic analysis, wherein data is iteratively compared to one another, either within a code, across the same transcript or across transcripts to allow for a more in-depth analysis (Braun & Clarke, 2021). I re-examined the code each time data was added to it and looked for commonalities and

differences across the coded data. I also compared between young people and practitioners, as well as different categories relating to the participant demographics (e.g., age, gender, substance use, practitioner role). The data from young people and practitioners were analysed together and contrasted throughout, allowing for a holistic and deeper understanding of the research topic (Lindsay, 2019).

I kept notes and early writings of themes throughout the analysis process, as it enabled opportunity for comparison, review, negative case analysis, and further interpretation. This aided with deeper and rich interpretations of the data (Braun & Clarke, 2012). The final reporting and writing stage allowed for connecting themes in a meaningful manner and building a coherent narrative. This stage also allowed for reflection and further interpretive insights from the YPAG and supervisory team.

## **4.5 Data Collection Methods**

### **4.5.1 Ethical approval**

Ethical approval was received in February 2020 from Yorkshire & The Humber - Leeds West Research Ethics Committee (20/YH/0010) alongside Health Research Authority (HRA) and Health and Care Research Wales (HCRW) approval, authorising the involvement of participating NHS or similar care-providing organisations in supporting the recruitment process. I also gained Disclosure and Barring Service (DBS) approval. Due to the COVID-19 pandemic, a non-substantial non-CTIMP (Clinical Trials of Investigational Medicinal Products) amendment was submitted for the methods of data collection. This was approved in September 2020. The approval letters are provided in Appendix G, which cover both the interviews and focus groups, as well as later workshops (Section 5.4.1).

### **4.5.2 Eligibility criteria**

#### **Young people**

Young people aged between 14-25 years who had lived experience of parental substance use and lived in England, UK were eligible to participate in this study. Parental substance use was defined as the overall definition for this thesis as described in section 1.2.1, therefore, included any use that had the potential to cause harm to a child or young person. Young people who were impacted by other people's substance use were excluded e.g., siblings or friends.

## **Practitioners**

Health and social care practitioners working across statutory, voluntary, and community sector organisations from across England, UK, who supported children, young people or families with parental substance use were eligible to participate within this study.

### **4.5.3 Recruitment strategy and sampling**

#### **Young people**

Young people were recruited through a range of settings across England including drug and alcohol services, services especially for those affected by someone else's substance use, young carer's services, charities, schools, and supported housing services. A study title and mnemonic were developed through PPIE work with young people to help easily identify the study and was used in all documentation. Young people thought the study name needed to be positive and enticing, and a young person reflected that "*[Resilience is] like springing back and never giving up. Actually, that would be a good name for this [study], spring or something.*" The title was then created; 'SPRing: Study exploring Parental substance use and Resilience in young people.' Young people were recruited via three main pathways.

Pathway 1: Gatekeepers informed of the eligibility criteria approached young people to discuss the study with them and provide them with an information leaflet (Appendix H). The information leaflets were developed based on guidance from young people and practitioners during PPIE consultations. The young person provided their contact details and assent to be contacted, which were passed to myself by gatekeepers. I then directly contacted the young person. On two occasions, the gatekeeper facilitated the introduction on the request of the young person, by arranging a convenient time for the young person and I to meet remotely to discuss the study.

Pathway 2: Advertisements and study information were shared with organisations to pass on in 'digital bundles' of information and leaflets being provided to the young people they supported during the pandemic. Young people could contact me directly or approach the service first who could then share the young person's contact details and assent to be contacted.

Pathway 3: Recruited participants were supplied with study invitation letters and study information leaflets for dissemination to eligible young people within their networks. This

pathway was only used with a young person who joined the project's young person advisory group.

I utilised three different pathways to identify organisations that could support recruitment of young people. (1) I directly contacted organisations across England detailing the study information. To aim for maximum variation I approached organisations from a wide range of settings including community youth groups, alcohol and drug services, social care services, child and adolescent mental health services (CAMHS), local authorities, charities that support young people from a range of backgrounds, charities that support those affected by family substance use, young carers services, education settings, and supported housing services. (2) I developed advertisements for dissemination in electronic newsletters or social media platforms accessed by practitioners (e.g., Adfam, DrugWise Daily Newsletter and Equal England Network), which detailed the study information and my contact details (See Appendix I for example advert). (3) I attended local and national practitioner forums, hosted by Adfam. At these events I was able to present my recruitment materials and network with practitioners.

Brief demographic details of the young person were checked with the gatekeeper to determine purposive sampling of prospective participants (e.g., gender, age, parental substance use type). Interested individuals were contacted via their preferred means of communication to further explain the study and check eligibility criteria. Preferred contact details were taken, and the participant was either emailed or mailed the appropriate information sheet and consent form. Following the return of these materials, selected individuals were contacted to arrange for their participation in the study. All participants had a minimum of 24 hours to make an informed decision to take part in the study or not, allowing time for questions and discussion with others.

Data corresponding to these sampling criteria were recorded for each participant in a sampling grid, which was kept up to date across the course of the data collection period. This grid highlighted characteristics that remained underrepresented within the sample and directed further recruitment and participant selection. Within this study, individuals who identified as male, or had a minority ethnic status were initially difficult to engage. Such under-represented criteria were targeted with further recruitment efforts, by approaching organisations with this eligibility criteria for any new participants.

## **Practitioners**

Recruitment for practitioners ran parallel to recruitment for young people. Practitioners were identified using the same pathways for identifying organisations to recruit young people.

Invitation letters were circulated alongside a participant information leaflet (see Appendix J for information leaflet) via email within my professional network. Professions identified for sampling were social workers, support workers, drug and alcohol service workers, and mental health practitioners across a range of different statutory and voluntary health and social care organisations. Practitioners specified for consultation who proved difficult to engage within this study were those from within social care and mental health, they were targeted via invitation letters using the wider team's professional network links. Practitioners within education were also targeted but there was no uptake due to the constraints of COVID-19 on time and work priorities. An additional profession, those within commissioning of services for young people were also invited to take part via email invitation, due to themes arising in the data around issues with commissioning of services. Interested practitioners made initial contact using the details provided in recruitment materials. Those who got in touch were asked to specify their preference for an interview or focus group with colleagues. The participant was emailed the appropriate information sheet and consent form. Following the return of these materials, selected individuals were contacted to arrange for their participation in the study.

### ***4.5.4 Research process***

Interviews and focus groups were arranged at a time specified by the participant. Data collection took place remotely due to COVID-19 social distancing protocol, either over the telephone or video call software. Whilst the interviews with young people were conducted one-to-one, they could choose to have a trusted adult present during the interview as support if they wished. One young person chose this option, the trusted adult was the young person's support worker.

Before beginning each interview with young people, I explained the process of taking part, reiterated confidentiality, and safeguarding protocol, and highlighted the focus of discussion. A similar method was completed before the interviews and focus groups with practitioners, with additional emphasis on agreeing ground rules for participation in focus groups. Participants were given time to ask any further questions. During the written, informed consent process, all participants agreed to audio-recording. Each participant was made aware when the audio-recording had started. During data collection, I iteratively explored the topic



guide (see Appendix K for all topic guides) and probed around topics that were emerging, for instance exploitation. All interviews and focus groups were audio-recorded and transcribed verbatim, ensuring I was able to focus on interactions and data generation whilst retaining a detailed record of the discussion for analysis. Participants completed a demographic questionnaire, providing contextual information to advise data analysis. Written field notes were recorded to provide context to aid interpretation of the data. After interviews, young people were provided with a £10 voucher, posted to themselves, or a gatekeeper to pass on, as a thank you for their time and participation.

#### **4.6 Data Analysis**

Using the 6-phase reflexive thematic analysis process, I iteratively analysed the dataset. This process is detailed below as a linear pathway for ease of organisation, but there was iteration between the phases. I also detail below the public and practice involvement during analysis. Whilst the methodology of this study was informed by involving young people from a local service (i.e., PROPS) who support those with experience of someone else's drug or alcohol use, the analysis involved a new group of young people with lived experience. This was due to the COVID-19 pandemic, as PROPS Young Person's Project suspended group work with young people due to social distancing rules and they were prioritising the safety of their young people in a supportive role rather than involving them in research during this time. Therefore, I set up a remote group of young people with lived experience of parental substance use, through similar approaches to recruitment as used for the interviews. This YPAG consisted of four young people from across England, aged 17-24 years, who had experience of parental substance use and who were interested in being involved in research.

##### ***Phase one: familiarisation***

The first phase consisted of familiarisation with the data. For this, I developed comprehensive fieldnotes after each interview or focus group, allowing me to recount salient or interesting points and begin to note similarities or differences across participants. I shared these early reflections with supervisors, where we discussed developing 'themes' and discussion points for subsequent interviews. This process helped me to be reflexive and comparative at an early stage. I also transcribed two of the interviews with young people and one practitioner focus group allowing deep immersion into the early data. A professional transcription company transcribed all others. All verbatim transcripts were anonymised and cleaned, by listening to the audio I checked for accuracy and spelling. This process alongside repeated readings of

transcripts allowed familiarity of the data set and I added to my initial fieldwork notes with new observations or trends in the data.

### ***Phase 2: initial coding***

The second phase consisted of generating initial codes. On a subset of the transcripts, I performed initial inductive coding by hand, jotting down notes in the margins and highlighting key passages. A supervisor also reviewed these transcripts. We discussed developing codes and comparisons across the data. At this stage I also ran a 2-hour online training session on thematic analysis for the YPAG. I provided an overview of qualitative research, the research process I had taken, and the steps to thematic analysis. I showed an example of what coding could look like, and then we all practiced coding an example excerpt using PowerPoint (see example in Appendix L). We discussed as a group, and I added notes to the excerpt. Young people had the opportunity to ask questions, try coding independently, and then discuss each other's interpretations of the same text. At the end of this session, young people were provided with two transcripts, one that each of them had chosen to independently code, as well as being provided with one that everyone would code. I coded each of the transcripts as well. Young people coded these in their own time, and we scheduled another meeting for a week's time to discuss. During this time, young people could reach out to me via email or text and discuss concerns with coding. I also prepared young people that the transcripts may be upsetting to read, and they should schedule a fun activity to do afterwards, and that they should reach out to their support networks or practitioners if needed. At our next meeting, we first discussed the transcript that everybody had coded, going through examples of coding, and encouraging discussion and comparison. I took note of the discussions and codes on my transcripts, each line and page were numbered for ease of discussion. Next, each person took it in turns to talk through the other transcript they had coded. This is where I facilitated discussion on comparisons between the transcripts and interpretations were deepened. We started to develop a list of codes that I could apply to the other transcripts as well as beginning to build possible developing themes across the dataset (see Appendix M for example).

After this, I used NVivo 12 management software as an organisational tool to aid analysis, using 'nodes' or codes of data (QSR International Pty Ltd, 2018). The young people and practitioners' data were coded and analysed within two separate NVivo files but with the same initial codes as developed with the YPAG and during early familiarisation. I started coding with young people's data, then practitioner focus groups, and finally practitioner

interviews. This process allowed for comparisons between the datasets. I coded the transcripts inductively based on semantic and latent meanings.

### ***Phase 3: theme generation***

The third phase was the generation of themes. During coding, I started to refine and merge codes, keeping memos and notes on comparisons and meanings of each code. Once all young people and practitioners' transcripts had been initially coded in the separate NVivo files, I merged the two files to create a new file which contained all of the data. Having one file allowed me to merge and refine codes across the whole dataset. I kept detailed notes during this process, which helped develop my interpretation of meaning across the dataset. Through this exploration I generated four initial broad themes from the data: trauma, safety, resilience, and stigma. I mapped out the corresponding codes to these themes using sticky notes (see Appendix N). This process helped as a visual representation of the developing themes.

### ***Phase 4-5: theme review and naming the themes***

The next two phases consisted of reviewing the potential themes and naming the themes. I presented the initial broad themes to the YPAG, a practice advisor, and supervisory team to explore further interpretations and connections. Using these discussions and identification of suitable theories within the wider literature (section 2.3), I reconsulted the initial thematic map of sticky notes and started moving them and regrouping them. This process allowed me to explore the underlying processes to supporting young people whose parents use substances, linking young people's experiences to their support needs (see Appendix O). I wrote passages defining each theme and subsequent sub-themes, whilst also identifying and tabulating example quotations from the data. The YPAG helped in naming these themes (e.g., 'the role of surviving or thriving').

### ***Phase 6: producing the report***

The final phase consisted of formally writing up the themes for this thesis and selecting illustrative quotations. Analysis continued throughout this process, with continuous refinement, making sure themes were cohesive and relatively distinct, and establishing an order for presentation. One member of the YPAG team and a practice advisor reviewed the written report of themes, ensuring it captured the discussions throughout the analysis process. They also provided further comments. The quotations used to illustrate points throughout the findings section below are presented alongside short descriptive information of the corresponding participant. For practitioners, the codes FG, DI, or I are used to acknowledge

whether the practitioner was part of a focus group, dyadic interview, or individual interview, respectively. Young people have been given a pseudonym to identify them, alongside their age and parent's substance use, whereas practitioners have been provided with a unique code alongside their role and sector. This distinction was informed by the YPAG and practice advisors for communicating the results.

#### **4.7 Findings: Participant Demographics**

A total of 21 young people whose parents use(d) substances and 44 health and social care practitioners participated in this study. All young people participated in one-to-one interviews. Eleven practitioners participated in one-to-one interviews, 6 participated in one of three dyadic interviews, and 27 participated in one of three focus groups. The duration of recordings of interviews with young people ranged between 26-140 minutes in length (mean = 72 minutes). Interviews and focus groups with practitioners ranged between 44-112 minutes in length (mean = 66 minutes). Most young people took part in interviews over telephone, with four interviews taking place via video call software. Practitioners mainly took part in interviews or focus groups via video call software, with only one interview taking place over telephone.

##### **4.7.1 *Young people sample characteristics***

Demographic details for each young person are provided in Table 4.1. The age of participating young people ranged from 14-24 years (mean = 18 years). There were thirteen females and eight males, of which two identified as transgender. Participating young people were mostly White British (n=18). Two young people were mixed ethnicity, White/Indian and White/Japanese, with one young person who was Romanian. Most young people lived in urban areas, with only one from a rural environment. Participants came from a range of socio-economic positions, as indicated by their postcode. Seven young people were rated as coming from a high socio-economic area, and fourteen from a low socio-economic area. Young people were geographically spread, participating from across six regions in England. Fifteen young people were in education, three were employed, and three were not in education, employment, or training.

Young people participated from across 20 families, with one sibling pair interviewed separately. Living arrangements varied, with nine young people living with a parent who used

substances, eight living with other family members or friends, two living in supported accommodation, one in foster care, and one living alone.

Twelve young people experienced parental alcohol use only, two experienced parental drug use only, and seven experienced both parental alcohol and drug use. Most young people experienced maternal substance use (n=14), with three young people experiencing paternal substance use, and four experiencing both parents who used substances. Young people reported a range of drugs that were used by their parents, including heroin, cocaine, cannabis, and spice. Two young people also reported the parental misuse of prescription drugs including diazepam and morphine.

Most young people were recruited across ten health and social care organisations, with one who was recruited by another participant. Two young people who practitioners had identified were excluded from the study (after initial consent to contact) as they did not meet inclusion criteria of having experience of parental substance use, with one who experienced a sibling's substance use, where their sibling was not in a caregiving role, and the other young person experienced a friend's substance use. A further seven young people decided not to take part in the study after giving initial consent to contact for reasons including, disengaging from support, general disapproval of parents towards the study, or a change to family circumstances.

*Table 4.1. Demographic details of young people whose parents use substances*

<b>Pseudonym</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Parental substance use</b>	<b>Lives with parental use</b>	<b>Socio-economic status</b>
Ben	14	Male	White British	Mother's alcohol use	Yes	High
Jade	14	Female	White British	Father's alcohol and drug use	No	Low
Emma	15	Female	White British	Mother's alcohol use	Yes	Low
Alfie	16	Male	White British	Mother's alcohol use	Yes	Low

Daniel	16	Male	White-Japanese	Father's alcohol use	Yes	High
Amira	17	Female	White-Indian	Mother's alcohol use	No	High
Anna	17	Female	White British	Mother's alcohol and drug use	Yes	High
Josh	17	Male	White British	Mother and Father's alcohol and drug use	No	Low
Kate	17	Female	White British	Mother's alcohol use	Yes	Low
Luca	17	Male	Romanian	Mother and Father's alcohol use	Yes	Low
Mark	17	Male	White British	Mother's alcohol and drug use	No	Low
Zoe	17	Female	White British	Mother's drug use	No	Low
Daisy	18	Female	White British	Mother's alcohol use	No	High
Rebecca	18	Female	White British	Mother's alcohol and drug use	Yes	Low
Liam	19	Male (Trans)	White British	Mother's alcohol and drug use	No	High
Kelly	20	Female	White British	Mother's alcohol and drug use	No	Low
Sophie	20	Female	White British	Mother's alcohol use	Yes	Low

Tanya	20	Female	White British	Father's alcohol use	No	High
Sean	21	Male (Trans)	White British	Mother and Father's drug use	No	Low
Hannah	24	Female	White British	Mother and Father's alcohol use	No	Low
Naomi	24	Female	White British	Mother's alcohol use	No	Low

#### ***4.7.2 Health and social care practitioner sample characteristics***

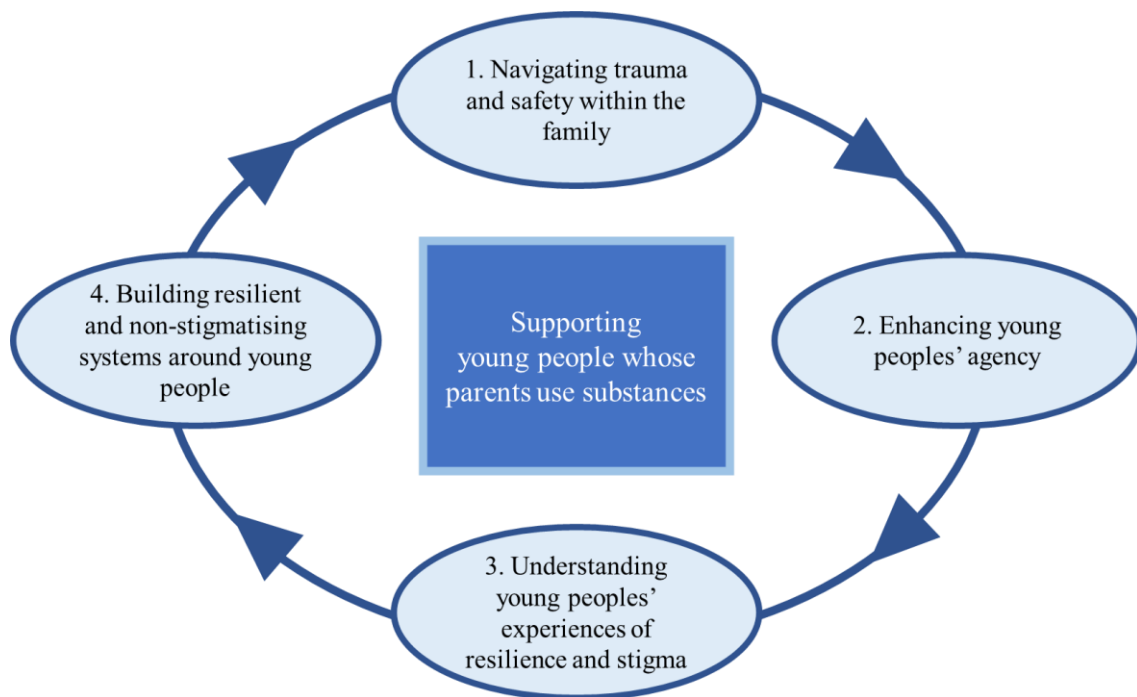
Participating practitioners mainly included frontline workers (n=32). These were support workers from voluntary and community sector organisations (VCSO) working with young people who experience parental substance use (n=14), support workers within adult drug and alcohol services (n=13), children's social workers (n=3), and mental health practitioners within CAMHS (n=2). Team leaders (n=6), managers (n=5), and a public health commissioner also participated. Practitioners had been working within the field of supporting young people and their families for between 2 and 36 years (mean = 16 years). Practitioners were geographically spread, participating from across eight regions in England, with most working within urban areas. Practitioners ranged in age between 25-64 years (mean = 42 years). Majority of the practitioners were female, with four males. Most were White British, except for one participant of Indian heritage.

Practitioners were mainly recruited via monthly national forums hosted by Adfam, which were free to attend and open to anyone with a professional interest in supporting families affected by substance use, as well as the Parental Alcohol and Drug Use knowledge hub hosted by the UK Health Security Agency, existing networks, and by other participating practitioners.

Two focus groups were made up of twenty-one members of a national peer-to-peer support group of practitioners working in 'hidden harm,' those working in the South of England (n=11) and those in the North of England (n=10). A further focus group was made up of six team members within a drug and alcohol service. Three dyadic interviews with team members were also conducted at the request of the participants.

#### 4.8 Overview of Themes: Supporting Young People Whose Parents Use Substances

Thematic analysis of 65 participants' accounts identified four main themes: (1) navigating trauma and safety within the family; (2) enhancing young peoples' agency; (3) understanding young peoples' experiences of resilience and stigma: the role of surviving or thriving; and (4) building resilient and non-stigmatising systems around young people. Within each theme, there is exploration of the underlying experiences of parental substance use as well as the support that could address such experiences. A depiction of the themes is presented in Figure 4.1 regarding supporting young people whose parents use substances.



*Figure 4.1 Depiction of the identified themes regarding supporting young people whose parents use substances*

#### 4.9 Theme 1. Navigating Trauma and Safety Within the Family

Participants reported that young people were under stress from living within an unpredictable and chaotic family, often experiencing a lack of safety within their relationships. Due to this insecurity, young people often perceived whole family support provided by services as 'unsafe' and unhelpful. They feared repercussions at home when discussing their parent's behaviour in the presence of their substance using parent or were not confident that they could talk openly with practitioners who also supported their parent(s), fearing that what they had said would be discussed with parents afterwards. Support that was young person specific and one-to-one with a practitioner was felt by many as being safer than processes involving the



family. Practitioners navigated support with young people to ensure they developed a gradual, trusting relationship wherein young people felt safe to disclose and be themselves.

#### ***4.9.1 Young people under stress: ‘a sprinkle of trauma’***

Both young people and practitioners recognised that children and young people can experience trauma related to parental substance use as well as wider interrelated factors. Some young people had experienced additional adversities within the family, including parental mental health problems, parental IPV, as well as parents who were in prison, or had died from complications with alcohol use. These experiences added to the stress young people were navigating due to their parents’ substance use. This was further reflected within the practitioners’ recounts of the experiences of young people they support, whereby these adversities were seen to both co-occur and compound one another. Young people’s home and family life were often characterised as being unpredictable and chaotic, as explored in-depth within section 3.7.1. This unpredictability could make living in such families feel unsafe for young people. Young people often reported feeling most unsafe within their home during the night, as this was a time when their parents tended to use higher levels of substances and conflict between family members was more prevalent. This was further compounded by fewer opportunities to access support during the night, whether that be informal (such as other family members and friends) or formal (such as services) support options.

The COVID-19 pandemic and multiple national lockdowns amplified young people’s experiences of stress and feeling unsafe within their families. Young people felt “*trapped*” in terms of not having safe places to go to, heightened by the worsening of their parents’ substance use as reflected in Emma’s account (*aged 15, Mother’s alcohol use*): “*I was a lot more closed off to the outside world with not as much help available because of the restrictions.*” Young people also reported worrying more about their parents’ substance use as they had “*more time on [their] hands to sit around and think*” (*Jade, aged 14, Father’s alcohol and drug use*). Practitioners stated that the young people they supported during the pandemic were struggling more with their mental health as they were “*stuck at home*” and “*there was more reliance on the children to be carers*” (*Manager, Drug and alcohol service, FG03*) for their parents. Practitioners also experienced a drop in referrals during the pandemic and worried about young people feeling alone during this time. Strategies young people employed to navigate the tension and worsening of conditions during the pandemic included spending more time in their room out of the way of their parents, utilising their daily walk (due to national restriction) as time just for themselves, or choosing to leave the family home

to live with extended family or friends. Likewise, practitioners reported that they had seen young people impacted by homelessness because of leaving the family home during the pandemic, due to heightened parental substance use. One young person recalled their reasons for moving out during the pandemic:

*Because [my mum] was like bound to go crazy with her drinking. Like abusing her partner and stuff. I just had to move out because I couldn't live there anymore (Amira, aged 17, Mother's alcohol use).*

Moreover, many practitioners reflected on emerging youth exploitation rising amongst young people where there was parental, or family substance use due to the vulnerabilities this can cause for children. Some young people recalled traumatic experiences of sexual exploitation and abuse due to adults that had exploited their family's vulnerable position. One young male (aged 14 years) also alluded to criminal exploitation with the selling of drugs due to knowing the wrong adults because of his parents. Whilst not all young people currently lived with their parents, they all reflected on times when this lack of safety within the home placed them under a lot stress within the family. Due to this, all young people stated that they were impacted emotionally, with some having diagnosed mental health problems (e.g., depression and anxiety) due to their parent's substance use and experienced trauma. Making sense of their experiences, young people tended to buffer from or downplay their experiences within formal support, recalling saying that they and their sibling had only experienced "*a sprinkle of trauma*" (Liam, aged 19, Mother's alcohol and drug use) due to their parent's substance use. Yet during the interviews, most young people spoke of harrowing accounts of physical and emotional abuse, as well as neglect within their families. This downplaying of experiences was usually when the young person's parent was also attending the same support service as the young person. Practitioners stated they often tried to navigate the emotional impact of parental substance use within support, providing helpful and age-appropriate resources for young people that deal with anger, sadness, or anxiety. Those in specialist roles working with parental substance use, often discussed supporting young people to access more targeted mental health support through referring them on to Child and Adolescent Mental Health Services. However, practitioners also acknowledged that current resources used for supporting emotional wellbeing of older young people (e.g., adolescents or young adults), were "*quite honestly awful*" and were not engaging or appealing for young people (Manager, VCSO, FG01). Young people also felt that the emotional support provided by practitioners when they were in their adolescence was often "*patronising*" as one young person recalled:

*So, she'd come in and sit there and count jellybeans out with me, and I didn't want to sit there and count jellybeans. She was a counsellor, I wanted to talk about my feelings, whereas she didn't do that (Kelly, aged 20, Mother's alcohol and drug use).*

Furthermore, emotional impacts of parental substance use were often seen as persisting even after a child had been removed from their parent's care or the parent had stopped using substances. Practitioners reflected that they supported young people with ongoing impacts from parental substance use despite reduced exposure. These young people were reported to often put their own needs last behind their families and their parent's problems.

*I guess for me, even young people who have been removed from the care of their family, who go into care and then go into foster care or whatever, the impact is still there for them even if they haven't lived with them for a few years. The impact is still ongoing (Team leader, VCSO, DI02).*

*What I have now is the impact of the parents' ongoing issues on the children. Also, the impact of the children's early experiences still impacts on them all these years down the line (Social worker; Children's Social Care, I03).*

It was also evident from young people's accounts that they experienced enduring impacts after exposure was gone, with some young people reflecting they had only felt able to access support with a practitioner, for themselves, after their parent was not using substances anymore and it was safe for them to do so. Young people felt their own needs and their development were not central but were often overshadowed by the immediate stress in the household, which was often echoed in the support that was provided to young people. The unpredictability and volatility of their experiences in the immediacy seemed linked to the delayed emotional aftermath. For instance, Naomi (aged 24) whose mum had passed away from complications with alcohol use reflected on the continued emotional impacts of parental substance use, where she “*struggled a lot with anger and conflict*” into young adulthood and still received support for her mental health. Additionally, it was only after Emma's mother had received support to reduce her drinking that Emma (aged 15) realised how much she had been impacted. She stated feeling “*overwhelmed*” because she had “*more time to reflect on how [she was] doing and think about [her]self*” after everything seemed safer at home. Zoe

(aged 17, Mother's drug use) also admitted that her experiences were *"going to haunt [her] for the rest of [her] life."*

Relationships with their parents tended to be described as unpredictable and often lacking in support, adding to the stress young people experienced as they felt they had no one to depend on. For some young people, they had come to the realisation that they could only rely on themselves as reflected in Zoe's account (aged 17, Mother's drug use): *"It sounds bad, but I don't really need her [mum] so I just became self-supportive."* Practitioners reflected on the lack of warmth and connection with a parent or protective adult that children and young people may experience. The insecurity many young people experienced within their parental relationships often impacted upon their ability to form positive relationships with others, including young people finding it difficult to trust practitioners. Moreover, young people also recalled confronting their parent about the substance use and their parent denying they had an issue with substances or said that their use was within normal limits like other families. In addition, if young people told someone about parental substance use, parents were reported to sometimes claim that the young person was lying about parental substance use for attention. Such experiences of 'gaslighting' reportedly made young people feel uncertain in themselves, their family, and their social connections, with long term impacts on relationships into young adulthood and a lack of trust in others.

*[My mum] just... I don't really know how to put it. She'd kind of not play the victim, that's not fair to say, but act as though there was a genuine reason to why I shouldn't feel intimidated or unsafe because of it. She would be trying to think of reasons to be like, "You shouldn't feel that way because it isn't really a problem." I kind of, for a little bit, thought it was all in my own head and it wasn't really that much of a problem (Emma, aged 15, Mother's alcohol use).*

*My mum then started just hiding it from me more and, like, fluffing out the truth, so I didn't know the truth anyway... When I was 12, she managed to convince my social worker at the time, and pastoral support, that I was a compulsive liar... The fact that nobody was believing me, and now I was being demonised, it was Year 7 and 8, when I got into secondary school, that my mum started creating this narrative of, like, [I'm] compulsive lying and stuff. I was like, "Oh, I am a compulsive liar." That's still something that I deal with to this day, where I'm like - Or one of my biggest triggers is*

*if someone accuses me of doing something that I just really haven't done. That still has an effect on me (Liam, aged 19, Mother's alcohol and drug use).*

Experiencing a lack of trust in others meant young people tended to “*bottle things up*” (Kelly, aged 20, Mother's alcohol and drug use) with regards to their emotions and experiences.

Therefore, most young people reflected they had only initially accessed and received support because they felt they were at a crisis point or “*at the peak of the bad bits*” (Daisy, aged 18, Mother's alcohol use) with their parent's substance use. Awareness of their parent's substance use was often cited as being early on in their life, with young people knowing that ‘something’ was happening within their home. However, this early awareness also contributed to a sense that it was ‘normal’:

*I did have some traumatising, horrible moments but because they were just moments and they weren't every day I didn't really understand that I should've been ringing [someone], or I should've been looking online or going out and reaching out myself (Rebecca, aged 18, Mother's alcohol and drug use).*

*It takes quite a long time before they realise their parents aren't quite like others. Unless they're picked up by other services for whatever reasons. Usually by the adult being drunk and picking up their kids and stopped by police, things like that. Really, [younger people] don't see there's a problem (Mental health practitioner, CAMHS, I07).*

This early normalisation was suggested to delay help-seeking in younger people and compounded the tendency to ‘keep it to themselves’. Yet young people wished they had known that support was available earlier through more proactive support measures, for instance within school, whereby the topic of parental substance use could have been approached, inviting disclosure in a safe way. Yet, when a young person had an awareness that they may require support, it was felt that it was unclear where to go to access services as nobody ever talked about it:

*I never really saw anyone like come on to school and talk to a vast majority of people, you know what I mean. So I never saw anyone come out and talk about drug and alcohol misuse but, like, within the home (Josh, aged 17, Mother and Father's alcohol and drug use).*

#### 4.9.2 *Needing space for themselves*

Young people often found support in which their parents were included as unsettling and unsafe. It was difficult for young people to feel like they could fully express themselves in the presence of their family members, despite their agreement to be there, as they had often felt silenced at home or not listened to. Young people tried navigating these sessions as best they could but whole family support felt “awkward”, and they worried “*how much [they] could say without it having an effect on later [at home]*” (Sophie, 20, *Mother’s alcohol use*). For some young people, being supported alongside their parents put the young person at risk of experiencing repercussions when they got home if they had shared an experience that their parent did not want them to.

*We’ve done family therapy, but it always turned into her blaming me. In turn, that really just affected me... At the end of the day I had to go back home to my mum. Then my mum would beat me that evening (Liam, 19, Mother’s alcohol and drug use).*

For other young people who attended the same service as their family but had different practitioners, a lack of safety was heightened by their view of a lack of confidentiality across the service. Young people worried about whether what they said could be truly confidential and impeded their willingness to share information or gain any benefit from support.

*Emma: Just me and mum had different people we’d talk to and I’d say something to mine and then that would get passed on to mum through someone else and words would get twisted and there’d be fall-outs because of someone else accidentally twisting my words that weren’t meant to get to anyone else in the first place because I was told it was confidential.*

*Interviewer: Yes. Can you give me an example of what you mean?*

*Emma: So, just like I’d be saying that I didn’t feel the safest or I didn’t feel the best or I was telling [my support worker], one time, about the most recent thing and it was still months and months before I started talking to her because mum’s drinking had died down a little bit before then. I was like, “The most recent time I found drink in the house, I just found a bottle of vodka behind the curtains.” That was well before the first lockdown. Then that got passed onto mum and it was like, “Oh yes, she found a bottle the other day.” And I did not say that and that caused conflicts between me and my mum, just because of twisted words which definitely weren’t the best (Emma, aged 15, Mother’s alcohol use).*

Practitioners may inadvertently put young people at risk within the home, when they share information with a parent about their therapeutic relationship with a young person. For young people this breach in confidentiality can then have a negative impact on the benefit of the service and quality of the support.

*I wasn't that happy because [the practitioner] told me that they weren't going to tell my mum [about what I told them]. But I got home and they had already told her, so I was quite annoyed and not prepared... I came in and got a complete ear battering (Alfie, aged 16, Mother's alcohol use).*

For practitioners, there was conflict between 'care and control' with the challenge of adequately addressing safeguarding concerns whilst also offering confidential support to a young person. This dichotomy created tension between a young person's need for safety and trust in support and the practitioner's duty to address safeguarding concerns. Within support, young people perceived that their needs would often be second to their parent's substance use. They also felt it was hard to trust practitioners who also had a relationship with their parent(s) as the practitioner may put their parent's needs first. One young person stopped attending support because her mum (who did not use substances) was also being supported by the practitioner and she felt it was "weird talking to someone that [she] knew that [her] mum had already spoken a lot to" and the practitioner "knew bits about [her] that [she] hadn't told" (Tanya, aged 20, Father's alcohol use). Likewise, young people often reported not "feeling safe to talk about stuff at home" (Amira, 17, Mother's alcohol use) with practitioners, for fear their parents were listening. Worrying about how much they could say in front of their parents further silenced young people in support, impacting their ability to engage with and benefit from support fully.

Some practitioners reflected on the positive outcomes of whole family support including increased positive communication and overall cohesion, whilst others noted that it was a delicate process navigating and combining the different care pathways for parents and children. Practitioners often stated the importance of having separate support for both children and parents that may become joined up once both are ready and happy to do so, yet funding cuts to services have impacted on how support is delivered.

*One thing that I have noticed is, since the hidden harm funding got cut, there is more and more family agencies being developed and children are supported within that.*

*However, I think, because of the presenting needs of the addicted parent, that it can be really difficult, and the child can get lost behind them. I think the child's needs get lost, which is why I'm an advocate for services which support children within their own right. It's a child service for these children and then parents or extended families could be seen in another section of the service. Just as the parent will have the space to talk about their experiences in treatment, I think the child needs the same thing to support them in their journey before they come together for family work a bit later (Social worker, Children's Social Care, I10).*

It was evident that young people wanted to have a safe space for themselves. Instead of including the family, young people tended to prefer separate support, wherein parents could receive support to reduce their substance use and young people received support for themselves. Additionally, young people felt it was important that they received support at the time when they needed it rather than as an add on to support received by their parents. One-to-one support with a practitioner allowed young people to have specific support that matched their needs and allowed them a safe environment to explore issues regarding their family.

*Sean: Family support is not helpful, not if they are possibly the issue. It could affect family at home as well. Like when my mum found out once I was offered counselling, she went mental because she knew it would be about her and she does not want to think she is a bad mum. You need to work with that child. You need one-on-one and you need the same person (Sean, aged 21, Mother and Father's drug use).*

Enabling young people “to create and be their own person” (Team leader, VCSO, FG02), wherein they could form an identity other than being the son or daughter of a substance using parent was important for practitioners when supporting young people. One of the ways practitioners achieved this was through promoting and developing young people's skills and abilities. A young person reported that a practitioner “helped [them] get a job” as they “would take [them] to interviews” (Kate, aged 17, Mother's alcohol use). Another young person reflected on the support he had received from a practitioner, who “helped with paperwork to go to college” (Luca, aged 17, Mother and Father's alcohol use). Within one-to-one support like this, young people felt safe to explore their own opportunities away from the family and the topic of substance use. Most practitioners recognised that support should initially focus on the emotional impact for a young person rather than starting with a focus on



the issue of substance use. Focusing on the needs of the young person first can help to make the young person feel safe and ensure the support is specially for them:

*Although the difficulty is all the experiences have been caused by substance use, the experiences are of an emotional impact, and I think it's really important to address it in terms of what those impacts might be and the kind of emotional lens on it. Many young people don't necessarily want to talk about the substance use, and that might be quite off-putting to seeking support, but that doesn't mean that they're not really affected and that there are not big impacts that they need support with. But they might want to do it in a different way (Mental health practitioner, CAMHS, I04).*

Young people and practitioners also talked about the need for services to acknowledge and increase young people's sense of safety within the home and family through supporting the development of strategies to mitigate physical risk, where appropriate. This included education around what to do if their parents had an overdose, learning basic first aid, and knowing how and when to contact emergency services. These strategies were usually in the context of a young person requesting this type of support and needed to be age and context appropriate. One young person reflected wanting this form of support after witnessing an overdose but stated that practitioners did not want to support him with this as they would not *"acknowledge the fact that [another overdose] could happen again"* (Liam, aged 19, *Mother's alcohol and drug use*). This young person felt unsafe and unprepared within his family, as well as feeling like his needs had not been acknowledged by the service. This experience further highlighted the tension between the need for practitioners to safeguard and support and the young person's need to feel safe and understood.

Many young people also tended to want to escape their experiences, for instance by leaving the home to visit friends or go for a walk. This space away from the home allowed them to calm down and distract themselves. Formal support that offered them an opportunity to have space and time away from the family was reported as useful and something that could be included in meaningful interventions for young people. Being able to have formal respite from the situation gave the young people space to explore their own interests and needs within a safe environment and to be a *"normal kid"* (Rebecca, aged 18, *Mother's alcohol and drug use*) for a few hours:

*Just being outside making stuff, like just completely being detached from the family sometimes really, really, helps. I'd just go into the house with a bit more of a positive attitude and that would help a lot (Emma, aged 15, Mother's alcohol use).*

*I did weekly respite groups. I didn't even realise it at the time, but, looking back on it, that was like my two hours where I just didn't have to give two S's. I just didn't. (Laughter) I could just do whatever I want (Liam, aged 19, Mother's alcohol and drug use).*

*I think young people having access to things like respite and other activities is important - so one of the things that we've built into our application is a couple of family intervention workers, but also fund for respite, so that would be things like residential day trips, gym passes, that kind of thing (Commissioner, Local Authority, I08).*

#### **4.9.3 Developing relationships and trust within support**

To establish a good therapeutic and supportive relationship, young people described building a gradual, trusting, and genuine relationship with their practitioner. Such a relationship was thought of as fundamental in feeling safe to express themselves with a practitioner. When young people felt like they were not listened to, believed, respected, or given choices, they felt like they could not trust the practitioner. This form of relationship can be indicative of their experiences at home, for example not being able to put their needs first, not having space or time for themselves, as well as not having a choice about how their home was or what happened in their unpredictable home life. The lack of safety experienced by young people within their home environments translated into feeling a lack of safety within support and difficulties with talking about their family experiences with practitioners. The ability of the practitioner supporting the young person to navigate the complexities of their experiences was seen as an important part of building the relationship. Practitioners who were viewed as being “very shocked” by young people’s disclosures or that talking to a practitioner was like “talking to a brick wall” (Rebecca, aged 18, Mother’s alcohol and drug use) tended to hinder the developing relationship. Whereas practitioners who could be friendly yet professionally curious and allowed young people to get to know them by doing activities that were not focused on the issue of parental substance use were seen as crucial factors in successful support with a practitioner. This type of relationship allowed young people to gradually open up to the practitioner. Therefore, beneficial supportive relationships were the opposite of the

unpredictable, unsafe interaction with the substance using parent; they were calm, predictable, and put the young person at the centre.

*It was really nice to talk to [my practitioner] about everything. Because I felt like – I don't know, she was just really nice, as a person. And she wouldn't always start with going into it and being, "How are things?" with my dad and that. She would start on lighter topics, just asking how I was, and making a lighter conversation (Tanya, 20, Father's alcohol use).*

*I find when it comes to agencies, it's not the organisation so much, that it is the person that you work with. I couldn't tell you if social services is good or bad, but I can tell you that I've had really good and really bad social workers. Social workers, two of them have been really great, really helpful with support. The most important thing is making themselves human. Humanise themselves. Because a lot of the time, especially when they're dealing with younger kids, like I was, all we see is a clipboard and a lanyard. It's harder to see them as a person. So, if they ask something like, "Hey. How was your day?" Or, "The weather is really bad." Just something mundane instead of, "How are you feeling? And how do you feel about that? How's your life at home?" Just something outside of that. Some of the best workers that I've had have made a point to say, "Do you want to go out for coffee this time?" Or, "Do you want to go on a walk?" Just something that takes me outside of the home and gives me a sense that this is a person that I can rely on to help me (Anna, aged 17, Mother's alcohol and drug use).*

Practitioners also reported that building an understanding of children and young people's lived experience, tailoring their responses and strategies to the individual young person, and aiming to establish trust-based and respectful relationships were seen as the most important and useful parts of their role. They often spoke of being passionate and caring deeply for children and young people's welfare, often going "*above and beyond*" their role to support young people. They endeavoured to be respectful of the young person's relationship with their parent by not using any stigmatising or judgemental language that could impact on the developing trust.

*We need to be the safe person to support them, to have as many feelings as they need to have in that moment and listen and just be there to support them, help them process*

*stuff. We can say things like, “That sounds like it must have been really difficult,” but we can’t pass any judgement because then that’s going to impact on the young person’s trust, they have of us. If they can’t trust us, if they can’t say things about their parents to us, who can they say it to (Social worker, Children’s Social Care, I10).*

#### **4.10 Theme 2. Enhancing Young Peoples’ Agency**

Young people spoke about utilising their learnt skills to try and control situations at home. Being able to act on and influence their circumstances empowered some young people. However, this could result in escalating situations or risks to young people. Having their agency acknowledged and built upon by practitioners led to reported increased confidence and self-esteem amongst young people. Young people wanted to negotiate safety and support alongside practitioners, be offered choices, and be supported to develop their agency. Allowing young people to tailor support to their needs, especially through using digital technologies was thought to be a useful approach to empower young people.

##### **4.10.1 The pursuit for agency**

Living with parental substance use and the uncertainty this could cause reportedly made young people feel like they did not have much choice over their home life. Yet, young people expressed their pursuit for agency from a young age to try to take back some control over their often-unpredictable home environments. All young peoples’ accounts of their experiences included ways in which they used what potential little resources they may have had as children, to adapt to and have influence over their home environment. Some practitioners also recognised young people’s attempts at expressing agency and described young people as being “resourceful” (*Mental health practitioner, CAMHS, I04*). Young people reported employing different strategies to help them to feel safe in the short term. Similar to the exploration in section 3.7.3, young people within this study were also hypervigilant to their environments, aware of escalating situations, and tuned into their parent’s changing emotions. This awareness reportedly allowed young people to adapt and mitigate risk within the home. Young people spoke of times that they had managed to have influence over their parent’s behaviours, which helped build their confidence, even if only momentarily. Young people would throw away or hide their parent’s substances, try to reduce conflict between family members, or confront their parents about their substance use. They reported succeeding at reducing their parents’ substance use, getting their parent’s help, or successfully intervening in an argument. They had found the strength within them to alter

their own experiences and being able to act and have positive influence over their circumstances was seen as an empowering experience for young people. Young people reported making choices as to whether they intervened in situations at home or not. When young people felt they could do something to calm the situation they ‘stepped in,’ otherwise they ‘ignored it’:

*I’ll have to step in because both of them [his parents] are going to act like big babies, some of the time; I might have to step in, and go, like, “Stop”, you know? Or sometimes I just ignore it depending if I can change it. So, like, “Screw it, not my problem” (Daniel, aged 16, Father’s alcohol use).*

In the quotation above, Daniel described his parents as ‘acting like big babies,’ potentially conveying that he thinks his parents were powerless whilst he was the one who had the power and influence to change the situation. Moreover, young people could show independence in terms of caring for others or looking after themselves. Whilst these situations were usually an option forced upon them through inattentive or neglectful behaviours of their parents rather than a decision of their own, young people who were the older sibling often felt “happy to take the control” (Sophie, 20, Mother’s alcohol use) over escalating situations with their parents as they wanted to protect their younger siblings and drew strength from being relied upon.

Another strategy employed by young people that highlighted their ability to act, was reaching out to informal networks or practitioners, who could help take the young people out of the situation or deescalate conflict or threatening situations. In such instances, young people tended to feel better that they had put themselves first and decided to seek help:

*A few months ago I called the police because she [her mum] was just going crazy. That’s like the first time when I realised I don’t have to protect her. I felt a lot better after I called them (Amira, aged 17, Mother’s alcohol use).*

Gradually taking control over their relationship with a parent who used substances was also a strategy the older young people employed to express their agency. They reported slowly setting boundaries with their parents, having control of when and under what circumstance they would see their parent (e.g., going out if they lived with their parents, or only visiting when they wanted to if they did not live with them), or they could end the relationship with a

parent. Such boundaries reportedly helped young people prioritise their own needs and could create healthier relationships with their parents.

*So, we're back on a civil relationship, I'm classing [my mum] as my social bubble [related to COVID-19 national restrictions] so I'm still able to go and see her every so often, but throughout my life I haven't let anything be on my terms. It's always been what mum wanted. So, I think to finally put it in my control and say, "I want to see you but it's only going to be every two weeks or something," it's working a lot better, and it's less arguments between us, and it's just a nice time when we spend time with each other (Kelly, aged 20, Mother's alcohol and drug use).*

However, these strategies did not always have the positive consequences as intended, as sometimes they placed young people at increased risk within the home:

*Sometimes if I was there and getting involved for them to don't fight or don't hit each other, yes. After I see that they start to argue with me, I was taking myself out (Luca, aged 17, Mother and Father's alcohol use).*

*In the home I would challenge her about her drug use and what it's doing, and she would hide things and become almost violent and throw things. It left me just challenging her (Josh, aged 17, Mother and Father's alcohol and drug use).*

As can be seen in both quotes above, by attempting to reduce conflict young people may inadvertently cause more distress for themselves. Despite the chance of heightened risk, young people expressed that they would try again and wanted to actively change their situations to create safety for themselves and others. They did not feel they were passive in their attempts but could adapt to their changing environments and would learn from failed attempts at control. Young people felt it was important that they had a sense of agency within their lives and that finding creative ways to adapt was a strength. However, they did acknowledge that they should not have had to experience the childhoods they had:

*I'm more experienced. I'd say, you know, maybe experienced is not quite a good thing in this kind of thing, but, yes, I know, kind of, how to deal with things a bit better because of my experiences (Daniel, aged 16, Father's alcohol use).*

#### **4.10.2 Negotiating support together and building agency**

As explored in the first theme, building genuine and caring relationships with young people was seen as paramount to effective support with a practitioner, something that could help or hinder the young person's experience of support. To further build trust with a practitioner, young people valued the opportunity to negotiate their support alongside practitioners. When young people felt powerless in their relationships with other adults, support that allowed young people to take ownership and develop their agency was thought to be important by both young people and practitioners. Acknowledgment and consideration that young people have shown agency and strength within their experiences was also reported to be useful. Young people wanted their voice to be heard, listened to, and respected by practitioners. Practitioners were required to continually navigate consent, providing genuine opportunities for young people to exercise choice and control, and for those choices to be affirmed and validated.

*So actually, you're just giving them clear opportunities to be themselves and supporting them in their own likes and dislikes. And giving them lots of free choices I think is really important because it starts to give them that message that they are important, that they matter and that they deserve to think about them and what they need and what they feel, and to get support for that. Very often, those things need to be done not just verbally, like when you sit with a group of children and tell them, "Oh, you're important. What do you feel?" They won't take that in. You show them that through the way that you structure the support you're offering, the choices that they have, the responses that you give them, the way you encourage them and, really, you are interested in them as individuals and care for them. Then, that will speak really powerfully (Mental health practitioner, CAMHS, I04).*

*I guess one of the issues we do find, is that the young person's needs, or the young person's voice hasn't been asked before the referral has been put in place. That's one thing that I've made sure has been put on our referral process, "Have you discussed this with the young person?" A lot of the time they identify a need that Mum or Dad is using, and they just say, "Okay, well this young person needs to speak to (service name)." No one is actually asking the person how they feel about it, and I've had a couple of young people in the past who have been, "Actually, I don't want to speak to you." So, for me, again, it's going back to the referral, or going back to the parents and saying, "Look, I've listened to your son. I've listened to their voice and their*

*opinion, and at the moment they don't want any support. I have to respect that." If I just force that support on them and meet them every week, they're not going to get anything from it, because they're not really engaging (Support worker, VCSO, I02).*

Accessibility and flexibility were common factors throughout discussions around fostering agency. Resources and services were needed that provided young people the opportunity to access interventions or support when they wanted and how they wanted. Young people often spoke of ways in which support had increased their self-esteem through giving them *"the resources so that [they] can look at things [them]selves,"* and through being provided with options young people could *"have the information for [them]selves and be able to pick"* (Anna, aged 17, Mother's alcohol and drug use). Practitioners being flexible to young people's needs in this way was seen as advantageous and helped build trust as well as engaging support. Young people regarded the opportunity for space and time to make their own decisions as important. One approach that was identified that would allow young people to express their agency was by using interactive and digital platforms (e.g., an application or website). Such technologies were thought to easily allow young people to make choices about what content they wanted or needed to access, as well as what time and how often they wanted to access it. Yet, as service delivery had moved to online support, due to the social restrictions in place throughout the pandemic, young people and practitioners identified a lack of digital resources targeted for young people whose parent's use substances. Young people had tried different digital applications for mental health, including those with mindfulness-based exercises, but felt they were not useful as they were not specific to their experiences or needs. Both young people and practitioners felt that digital technologies could be developed to be used by both practitioners in support with young people and for young people to use on their own. Support in this way was required to be age-dependent but digital approaches were thought to ensure that those of adolescent age, who were reportedly usually missed in support, would have increased opportunity to access it.

*As children get older, a resource with the internet would be good, they would want somewhere where they can go and learn themselves and decide (Social worker, Children's Social Care, I10).*

Likewise, the open-endedness of a service so that young people could choose how many sessions they wanted to attend or that they could return to support if needed was described as a *"safety net"* (Hannah, aged 24, Mother's alcohol use) that helped young people practice



agency. Support that had a low or fixed number of sessions was seen as restrictive for young people, wherein they did not have time to build relationships and their voice. Most practitioners reported that they were flexible within the structure of their service delivery to allow them to meet the needs of young people. However, some young people had not always experienced or been given choices within their support. These young people reflected that they wished they had been given more opportunities to express agency and work together with their practitioners:

*It would have maybe been nice to know that [my social worker] was coming or I was getting a visit, so I could prepare what I wanted to talk about. Like, let's make this a two-way stream, rather than a one-way stream, of just people asking us questions. I like to be engaged with my own support (Daisy, aged 18, Mother's alcohol use).*

When young people felt that they were not listened to or that they were not provided with choices, they tended to disengage from support. Some young people reported feeling like practitioners saw them as incapable of making choices as they were viewed as vulnerable and needing protecting rather than being capable of engaging in their own support. Such a lack of flexibility and not allowing young people to make decisions can have a negative impact on their developing agency:

*I've, kind of, just taken whatever support I can get because it was really, a few times, just bare minimum support and I thought that was the best I could get. It was just, kind of, accepting whatever help I could get and not having choices (Emma, aged 15, Mother's alcohol use).*

Young people and practitioners also discussed other strategies that had helped build and promote their agency. For some young people, becoming a peer mentor or role model allowed them to move from a place of being supported to offering support to other young people coming through the same service. This experience enhanced their esteem and built on their strengths by utilising their life experiences and turning them into a positive impact for other children in similar situations. In addition, some young people also trained practitioners in the lived experience of parental substance use from a young person's perspective. These were empowering experiences for young people, as they could draw on their strengths from their experiences and not only focus on the adversity or trauma. They were able to reframe their

experiences more positively that helped them to develop resilience, whilst also co-creating safety and support alongside services.

*I live in this environment, I'm the professional of my environment. I know my mum a lot better than any professional who just walks in my house. A lot of the problems that we face as carers, is that nobody really listens to us. We're very pushed aside. I've been in the service such a long time, I'm quite useful and I know what I'm doing, so they do like to invite me out to a lot of things still and still get me involved in, so that I can help younger kids as well and guide them through the service and make it easier for them (Rebecca, aged 18, Mother's alcohol and drug use).*

*I just took an activism stance and just started public speaking. That started off as, like, doing workshops and stuff for professionals, sort of using the bad experiences, and, using them, like, yes, doing workshops to tell professionals: "Look, this is my experience. You could do better." That started off just workshops, and then it has just evolved into, like, presentations, like just standing up and talking about how professionals can best support young carers and myself, especially around substance misuse, because, I don't know, I was just getting frustrated that I found, in my personal life, professionals don't understand it (Liam, aged 19, Mother's alcohol and drug use).*

*One of the tools that we use, I had a young lady who is now at university. She would come back quite regularly to come and help with the groups. She's helped me run groups. She herself had gone through substance misuse herself, following her mum's mental health and substance use difficulties. She'd had some quite nasty experiences. She comes and talks to young people, tells her story, and says the difficulties she's had, the choices she's had to make and the choices that she's made to be who she is today (Mental health practitioner, CAMHS, I07).*

Practitioners also wanted to learn from young people within their services to adapt the support they offered by making it more acceptable and accessible to young people. One practitioner shared that they are in the process of setting up a group of young people who will help them tailor their support services to young people's needs.

*We are currently pulling together what we have called the Hidden Harm Youth Experts Group. So, a group of young people, across all services, looking at pulling that together, and then having their views about what support they need, where they want support to go, what they feel has been beneficial to them, and kind of helping us develop as an organisation based on what young people need, not what we think they need (Support worker, Drug and alcohol service, FG02).*

#### **4.11 Theme 3. Understanding Young Peoples' Experiences of Resilience and Stigma: The Role of Surviving or Thriving**

Experiences of stigma and being bullied reportedly impacted on young people's help-seeking behaviours and subsequently their resilience. Young people often described feeling that they had 'survived' within their experiences of parental substance use, rather than 'thrived'. Their strategies for survival could be viewed by others as 'positive' wherein they internalised their emotions and were seen to be doing well at school or in society, or 'negative' wherein they externalised their emotions and became excluded from school or society. Such survival techniques played an important role in the immediacy but also placed young people at risk within their social environment and both ultimately led them to feeling lonely and isolated from others. To ensure young people were not only '*surviving*' but were '*thriving*', they needed to have recognition of parental substance use and to feel like they were connected to others.

##### ***4.11.1 Surviving is a lonely experience***

Isolation and loneliness were common experiences reported by most young people, linked to underlying feelings of stigma and shame due to their parents' substance use. Young people reported experiencing stigmatising comments or having been bullied by others within school or the community due to their association with a parent who used substances. This experience of associated stigma and shame was strong, and even existed when young people had never known or had a relationship with their parent who used substances. They believed that their parents substance use reflected badly on them to other people. Such experiences of stigma and being treated differently increased their feelings of loneliness. Feelings of stigma and shame delayed help-seeking behaviours and support, impacting young people's ability to develop and build social resilience, and to '*thrive*'. Sean's account below reveals his lonely position due to the internalised shame from being bullied about his parents' substance use which also stopped him from reaching out for support:

*Sean: I was the kid with the mum that was the weed dealer and the dad that was the drug smuggler. Everyone used to call me a druggie in school before I took drugs.*

*Interviewer: How did that make you feel?*

*Sean: Bloody shit, but eventually I was like, "Do you know what? If that is what you think of me, that is what I am." Everyone assumed that was the route I was going down, so I had low self-esteem. I fell, I guess, in the trap... I was also the class clown, so I turned it into a joke. So, when people started mentioning it, yes, I got emotional, but then I was like – I turned into a clown. You laugh about it, or you cry about it. So, I used to always make fun of the fact that I was a council estate kid. Or, "Yes, my dad's in prison. Shit, he is probably getting bummed" and it was a funny joke. But someone would have said that to me anyway, in an offensive way. Do you know what I mean? But if I said it and it was a joke, people did not offend me then. It became something less emotionally hurting. I cannot put words to describe it. That is the way I blocked it out, I guess. I just laughed about it, and I still do. "Ha, ha, my mum's a crackhead." Laugh it off, otherwise it is shit. But the truth is, that it is shit... I didn't ever approach anyone in secondary school, primary school and said, "I need help because my dad is in prison and my mum is a drug dealer and drug using and all this." I never asked. I never asked for help. It was too hard. (Sean, aged 21, Mother and Father's drug use).*

Intersectionality, wherein existing experiences of discrimination (e.g., race), where a young person reflected, they were "*the only brown kid in a school full of white kids*" were compounded by the associated stigma experienced because of parental substance use resulting in a young person experiencing higher levels of stigma and using it as 'proof' as to why they were called "*weird*" at school (*Amira, aged 17, Mother's alcohol use*). They felt unable to fit in with their peers and felt 'outcasted.' Likewise, feelings of isolation due to experiences of bullying because of parental substance use were also amplified by experiences of social deprivation, parental neglect, and gender identity, wherein young people felt rejected by peers or their family:

*Yes, I got bullied but it probably wasn't, well it wasn't all because of the alcohol but more of like, "You're nitty Nora", or, "Have you ever had a wash." The neglect side of the alcoholism was what I was picked on for (Naomi, aged 24, Mother's alcohol use).*

*I came out trans. She [my mum] disowned me. Like she did not want to know. I guess it was a shock to my family. The whole family were a bit- It has taken them six years to accept it (Sean, aged 21, Mother and Father's drug use).*

Young people who had been stigmatised and bullied, often found acceptance and comfort in those whom they felt were more like themselves. In such groups, young people identified and drew social support from their peers, buffering them from negative consequences such as isolation, which helped them to feel safe.

*I was in quite a middle-class – My school was in a very middle-class place. My house was in a very middle-class place. So pretty much everyone around me was always very stereotypical, like tame and not very exposed [to substances], and had good parents, who had money to have good parents and a good upbringing. But then you'd find I'd seem to connect and go towards the people that are like the one or two people in my year that just had the dysfunction. I tended to drift towards them, probably... I found to connect with them quite a bit where their parents were also like... We never explicitly were like, "My mum is on drugs." "Oh, my mum is, as well," but looking back on it, their parents were also on drugs. We all just had that connection (Liam, aged 19, Mother's alcohol and drug use).*

However, practitioners discussed that young people may find support in those young people who are using substances or that families where there is social deprivation can be a target for criminals. In such instances, young people are targeted to sell and distribute drugs.

Practitioners felt that some young people in either of these situations were trying to find connection with others and figuring out "where they belong" in the world (*Support worker, Drug and alcohol service, DI03*). If young people had found this connection, some practitioners reflected they had a difficult time engaging them in one-to-one support as they had already found what they were looking for, regardless of the consequences to the young person.

Nevertheless, some young people felt they had built up some social resilience through "having the diversity of a network" (*Alfie, aged 16, Mother's alcohol use*) or the unconditional support and trust of a friend or caregiver. This social resilience allowed young

people to overcome the initial feeling of stigma or fear about reaching out for support, which facilitated their help-seeking behaviours of formal support.

*Home life was pretty harsh for me and the way my mum acted with drugs was noticeable for my girlfriend. The way the house was etc. etc. She noticed a lot which I knew how wrong it was and I was quite embarrassed. I had been in a relationship with her for about six months at that time and I was pretty comfortable with her so I could share things with her. And then she was the first person I opened up to about my family's addiction. Ever since I became really open, she pushed me to say something to my teachers at school and that's what got the ball rolling (Josh, aged 17, Mother and Father's alcohol and drug use).*

Opening up about their experiences of parental substance use was difficult for young people. Most young people chose to disclose to selected individuals or formal support for the first time, but for two young people they chose to publicly talk about their experiences, which impacted their experiences of stigma and resilience in different ways. For Liam, he realised through speaking out about his mum's substance use that there were lots of people who were dealing with something traumatic and managed to reduce the stigma he was feeling, which increased his social resilience, he no longer felt alone:

*I started speaking out about my problems and issues when I was about 13, like on a very public stage quite often. I'd then meet other young carers, and the other young carers were normally in pretty much every friendship group in the school. Then, because of that, everyone just knew that we all face demons. like we all have problems and stuff like that, so I wasn't really bullied for it (Liam, aged 19, Mother's alcohol and drug use).*

Whereas Rebecca spoke out in a school assembly about her parent's substance use and became a target for bullying, increasing the stigma she felt and reducing her social resilience. She felt very alone, isolated, and punished by her peers for her honesty at school. After this Rebecca spoke about mostly making friends through online gaming as it was easier for her to connect with people this way due to the anonymity online gaming offered her and people not knowing about her parent's substance use.

*I did an assembly when I was in year seven speaking about the fact that I was a Young Carer when I came into the school. It was when I was in year seven and I didn't really understand, I didn't have a lot of friends, I didn't really get that I could be bullied. When I did that assembly I just realised as soon as I was talking about it and I was looking at people's faces, I was like, "Oh, God. What have I done?" Then I went back to my class and it was just like, "Oh, oh, you're a benefits scrounger. Oh, your mum's an alkie. I'll go have a drink with her", and stuff like that. It was like, "Oh God, why did I do that to myself?" I was just treated as an outcast or like- I don't know how to explain it, just a target really because it was like, "Oh, she has a problem at home" (Rebecca, aged 18, Mother's alcohol and drug use).*

With growing awareness that their experiences were not 'normal,' young people felt that they may be perceived in a certain way by others, therefore they felt like they had to wear a "mask" to overcome stigma and prejudice. They discussed times they had to portray themselves as being "fine" or "normal" or act like the "good child" so that others would not suspect what was happening at home. They felt like they might be viewed and labelled as a "problem child" (Amira, aged 17, Mother's alcohol use) due to their parent's substance use and tried different strategies to counteract that image. Young people acted differently or were afraid to express themselves authentically for fear of how they would be perceived by others. Young people suppressed their true feelings and emotions to make other people more comfortable in their presence or to come across as 'normal.' This strategy left them feeling unnoticed and alone.

*I was super angry. And I didn't want to be, especially not around the police because I don't want them to think I'm just like a problem child. But I was really angry (Amira, aged 19, Mother's alcohol use).*

Additionally, young people did not want to be singled out or bullied for their parents' substance use. The fear of what would happen if someone found out about their parent's substance use prevented them from acting like they needed help. They feared social isolation and discrimination, as well as being removed from the family home and the stigma of being placed in care. Hiding their identity provided a social benefit for the young person but limited their opportunities for support. The appearance of 'thriving' or being resilient, may have been the young person trying to hide their experiences and 'survive' in their social environment. For instance, a young person may be seen as resilient at school when they are doing well,

handing in their homework, and getting good grades. For some young people, this survival strategy may be a way to better themselves for their future, helping them to contribute positively to society, as well as receive praise and encouragement from others, allowing them to subsequently thrive. They were hiding their experiences but receiving positive external approval. For other young people, this strategy left them feeling unnoticed and uncared for.

*I used to go into school at 7:00 in the morning...And I used to stay there until about 5:00, because I just didn't want to go home... Teachers didn't notice because I used to do work in the mornings and stuff (Zoe, aged 17, Mother's drug use).*

*None of my teachers had any idea what was going on at home because I didn't express or show any sign or repeated characteristic of what my mum was like, So, they thought I was fine, like a normal child. (Daisy, aged 18, Mother's alcohol use).*

Doing well at school to survive the stresses at home signalled to the outside world or to their teachers that they were not a need for concern. However, these young people, whilst succeeding to go unnoticed, were then not receiving any support. The young people reflected that they desperately wanted to be noticed and given support but were just too scared of the consequences of having to make a disclosure, especially when teachers did not talk about the impact of parental substance use. Moreover, some young people reflected that their teachers knew of their home life, but because they were doing well at school, they were perceived to be doing fine and received no further support.

*Teachers were making sure that I wasn't falling behind in my schoolwork, or any obvious signs of emotional distress or anything. But I was quite a quiet child. The thing with any sort of distress is you can't see it physically. Being mature for my age and having an old soul, are things that all my teachers say. But it was just a performance (Anna, aged 17, Mothers alcohol and drug use).*

*I always had it in my head that I was an A\* student, I was an achiever. School did not have any red flags about me, because they just saw me as an achiever and just left me as that. I had a lot of stuff going on and they did not acknowledge that, to be honest. I was giving them [teachers] what they wanted. But I started smoking weed. I used to do that off my mum, because it was all over the place, like bags and bags...I was on my*



*own. No teacher cared, because I was an achiever (Sean, aged 21, Mother and Father's drug use).*

As can be seen by Sean's account above, going unnoticed at school because they present as an "achiever" can have risks for young people, whereby they go unsupported, feel alone, and later may start exhibiting externalised behaviours, for instance using substances, to cope with the pain they were feeling inside as well as the loneliness. Young people and practitioners reflected on the narrow focus currently seen within schools as well as other services of what it is like to be resilient for a young person whose parents use substances. Academic ability did not always equate to resilience or 'thriving'. It was deemed problematic as it missed young people who were trying to mask their identity to evade social stigma and did not account for the many ways young people may have been struggling in other areas of their lives.

Moreover, what may appear as "*problematic behaviours*" for the practitioners or adults in the young person's life, was often the way that young people had found to cope. Behaviours such as drinking or using drugs provided some release or benefit in the immediacy but mostly had risks to young people. Young people reported that practitioners, especially teachers, saw their externalised behaviours (e.g., drinking or skipping school) as a fault with the young person that needed addressing, changing, or punished rather than being seen as a way that they were trying to cope. Some young people reported behaving in these ways so that they would become noticed by practitioners, thinking they would receive the support for their parent's substance use that they felt too stigmatised or afraid to ask for help for directly. At times they were not equipped to recognise the additional difficulties these actions of 'surviving' may cause. Some young people experienced problems with their own substance use that impacted the way school viewed them and were subsequently excluded from school. One young person spoke of having been at a "*point of despair*" because they had "*been left without support*" and with "*no more options*" (Ben, aged 14, Mother's alcohol use) after being excluded from school. He felt that his teachers had not listened or understood his reasons for using substances and his "*desperate call for support.*" Additionally, some young people experienced judgemental and discriminatory interactions with practitioners, leading to increased feelings of stigma and isolation and feeling misunderstood.

*Every service, I have literally left or got angry with them. Because a lot of mental health services would judge me as soon as I mention that I am a drug user. They*

*would immediately assume that my mental health was to do with drugs (Sean, aged 21, Mother and Father's drug use).*

Young people in situations like those above did not know who they could trust or where to go to for support. These experiences led to further stigmatisation of their ways of coping and added to their feelings of loneliness, impacting their opportunities to develop resilience. Practitioners also felt that young people could be judged and abandoned by others in their lives for the choices they make. They further acknowledged that practitioners can also “*stigmatise people all the time because even as professionals [parental substance use] is not discussed and made part of [their] learning*” (Team leader, VCSO, DI02).

*One that I feel is quite difficult is the anger thing, where they're constantly being told they've got an anger issue or they need anger management, when in actual fact they're reacting in a perfectly normal way to a really, really horrible situation. Yet they're made to feel it's them that's got the issue. They have to work on their behaviour... I struggle with that quite a lot in that if they're living in a horrific, awful situation, why shouldn't they be cross? Why shouldn't they? You need to be helping them and trying to work with their parents around what's going on, rather than telling them, "Something needs to change" (Support worker, VCSO, I02).*

Both situations, where a young person may be viewed as ‘positively surviving’ (e.g., looking for positive external approval or hiding their problems) or ‘negatively surviving’ (e.g., externalised, or destructive behaviours) created a situation wherein the young person was alone with their problems, isolated from their peers and supportive networks, and in need of support.

#### **4.11.2 Supporting young people to thrive emotionally and socially**

Young people wanted to be able to ‘thrive’ across many domains and aspects of their life, especially their emotional and social wellbeing. This ability to thrive pertained to both enhancing internal resilience and overcoming the feelings of stigma. All young people reflected that they wished someone had recognised in them the need to connect and be seen. To overcome the feeling of stigma and promote social resilience, both young people and practitioners thought that developing support that allowed young people to attend or be a part of a group with other young people with similar experiences was a beneficial technique. When services offered group support, young people were often apprehensive to attend

because of the internalised stigma they felt but reflected that once they had attended, it was a safe space to be authentically themselves.

*It was the most amazing thing the first time that I realised that I wasn't the only one that was like this. No one in the media says it. It's not talked about. It can feel really isolating when you don't know that there's anyone else out there. Meeting up with other people, face to face, and having them say, "Oh yes, my life is kind of like that too," and it actually be relatable. When your school friends say that their mum sometimes shouts at them, it can feel really isolating to know that they're relating to something that they don't know. they don't know the half of it. And you can't tell them because it's actually kind of scary. But have other people know that experience, know it's scary and be able to say, "Hey. My mum's an alcoholic too." It helps so unbelievably much (Anna, aged 17, Mother's alcohol and drug use).*

Internalised shame and stigma experienced by young people were often overcome through raising the awareness that there were other young people in similar situations to theirs. Participants reported that providing young people opportunities to identify with other young people helped them realise that they were not alone. Knowing that there were peers that recognised what it was like to be a child whose parents used substances and for them to understand how it felt without the young person having to talk about it was reported as a powerfully supportive experience. It helped young people to enhance their internal resilience and to 'thrive.'

*Honestly, I do not think that I would have any confidence, any ability to speak about it or actually just be able to help others with my story if it wasn't for [the service I attended]. That was the only support that I got which really worked. Obviously, when you're surrounded with young kids who have- even though every experience isn't similar, you can always pick up on those little traits that an alcoholic would have which you can be like, "Oh, my mum does that and your mum does that." It's something to talk about and it's nice because you're not talking to a scary professional about it, you're talking to someone on your level and your age. So yes, that was honestly the best supporting thing that I could've done I'd say (Rebecca, aged 18, Mother's alcohol and drug use).*

Practitioners also discussed the positives of facilitating groups of young people. They emphasised that young people often felt safe to talk freely with other young people and groups helped develop resilience which decreased young people's internalised stigma and shame.

*Really, it's bringing the kids together, and allowing them to understand that there are other people in the world, it's not just them. And to try and break down that secrecy barrier a bit (Mental health practitioner, CAMHS, I07).*

*One of the most helpful things, I think, is in the very first session, the very first 5 or 10 minutes, when we all come together into circle time, and we ask the children if anyone would like to say why we're all here. Most of the time nobody wants to say so then myself or another adult might say, "Okay, so you're all here because your mums or dads currently do, or used to use, drugs and alcohol." That's the only thing we say together like that, really. You just see the children, phew, suddenly they just relax. Suddenly, in that moment, they're not different anymore. They don't have to hide a secret anymore. They're not going to be judged. They're just the same as everybody else (Social worker, Children's Social Care, I11).*

However, practitioners also mentioned the complexity they faced when organising groups of young people, where some of the barriers included the capacity of the service to offer group support, logistical issues around organising venues and transport, as well as having suitable risk assessments in place. Practitioners therefore felt they had to be flexible in how they engaged young people and tailored their strategies to young people's specific preferences. Approaches needed to consider a full range of options including remote or impersonal approaches at first (such as online) through to more intensive relationship building practices. Practitioners acknowledged the needs of the young people they supported and facilitated young people's ability to connect with peers. One practitioner raised the concern of young people who may feel exposed if forced to meet people who are in the same school as them:

*It's been quite a difficult one, to be honest. We've had conversations with young people around doing it [online group support] but the young people didn't really want to be identified by other young people who, potentially were in their school, who might be in their group also (Support worker, VCSO, I02).*

For a few young people, attending group support within a specialised service had helped them feel less alone in those moments, but they still felt alone when they returned to other settings such as at school. Stigma and secrecy around parental substance use within their school environment was often found to be harder to overcome as currently there was very little support provided within schools, with few opportunities to have open dialogue about parental substance use.

*So, there were other young carers or there were other people whose parents were using drugs or alcohol. We'd meet and talk about experiences we'd had or drop in that week and that really helped to be around other people in the same situation. We would both have the more serious side of talking about the alcohol or the impact on our parents and the on the other side just mess around and play on the Wii and have a good time together. It'd feel like a very safe space. Whereas at school people knew... It was a bit more of a taboo, not a taboo, a bit more of a bigger thing. Let's not talk about it. Whereas when you had a group of people or a space you could just go and sit and chat and let it out and not worry about the repercussions (Naomi, aged 24, Mother's alcohol use).*

All young people and practitioners spoke of the need for more effective support within the school environment for young people whose parents use substances. School was the main environment identified where it can be both a place of safety and normality as well as a place of risk and vulnerability. School could therefore help and hinder help-seeking for young people. Developing support within schools was mentioned as having the potential to create a lasting impact for young people, as schools “*have to see kids every day*” and if young people “*are too scared, they won't go to an organisation, but they have to be in school*” (Zoe, aged 17, Mother's drug use). Young people and practitioners reported feeling that parental substance use was a taboo subject within schools, whereby young people had never heard anyone mention it and therefore found it difficult to bring up themselves. Young people felt that currently education focuses on the risks of young people's own substance use without focusing on the impact of other people's substance use. It was identified that education needed to be developed in both primary and secondary school to allow a forum where substance use could be openly discussed. Most participants discussed the need for schools to plan lessons or hold assemblies around the impacts of someone else's substance use. Recognition of parental substance use within a school environment was thought to help young people to feel less alone at school. It could also provide opportunity for young people to be

open with teachers or other practitioners within a school setting that could help to reduce the internal stigma and shame young people experience, supporting their ability to thrive and not waiting until crisis point for a disclosure. Additionally, having an open approach within the school environment was thought of as a starting point to breaking down the public stigma.

*I don't think we actually had anything like that in school. So, maybe having that in school would make a difference, so it is, kind of, spoken about, and it's not just a subject that no-one speaks about, if that makes sense, because we had nothing like that at school. There was hardly even any talk about drugs or alcohol with any age, never mind parents' or families' use or anything like that. So, maybe even just that awareness for everybody (Kelly, aged 20, Mother's alcohol and drug use).*

Whilst a few young people thought that small group work sessions within school or targeted lessons for select individuals could be useful, most thought that it would be stigmatising to be pulled out of main lessons or grouped with “other problem children.” In such circumstances, young people recalled their friends or teachers would “keep asking questions” as to why they had left, and they would feel embarrassed. Participants explored how peer support could be made more easily accessible within schools and how it could be managed, and whilst this was generally thought to be a potentially helpful intervention, possible approaches suggested by participants were typically considered difficult to implement with potential unintended outcomes. One suggestion was to identify individuals who could act as peer mentors, although logistically it was hard to see how this could be managed. Another alternative was to establish a peer support network via established services who could facilitate group meetings within schools. However, young people also worried about the issues of confidentiality and privacy within such a setting. Moreover, targeted groups may also not engage or be accessible for the group of young people who go unnoticed within school. Likewise, practitioners reflected on the need for schools to avoid re-stigmatising young people by labelling them for a targeted lesson and thought more universal lessons or whole class approaches were more appropriate.

*If you've got the needs of one child with lots of issues of bullying going on, or relationship difficulties, they'll make it a whole-class issue in order to avoid singling out the child, but do it as a whole-class intervention, which is less stigmatising. All children benefit from this education in these areas anyway about relationships or alcohol. Also, for so many children, there may be a lot of stuff going on that it's just*

*totally invisible to everybody. Just because they're not presenting with the problems doesn't mean the problems aren't there, so that's why anything that's universal, I think, is beneficial (Social worker, Children's Social Care, I03).*

Most participants wanted parental substance use to be spoken about as early as possible, including within primary school to have enduring positive impacts on young people:

*It could have a bigger impact to a kid outside of just that classroom or that lesson or that school time because somebody might be in that assembly and they'll hear it, and they'll think it resonates but they don't want to do anything about it [at the time] but then it might just stick [five years later] (Naomi, aged 24, Mother's alcohol use).*

Participants felt that age-appropriate education at primary school would help raise awareness and offer young people experiencing parental substance use an opportunity to reach out and access support. One suggestion was to develop storybooks that depicted young people's experiences and impacts of parental substance use. Stories were a tool that teachers already used to communicate with children, and they could facilitate conversations in a child-friendly way across a class. Stories could also help young people to relate to the characters within a safe context and help make sense of their own experiences.

*In my therapy work, we use stories all the time. With children, that's the only way you can really communicate things like this. It's a really effective way. Actually, more of these would be very useful, because those kinds of resources can be promoted to schools, so schools can have them...I think having resources like that that give the adults around the child, so people in schools, a bit more awareness of some of the things that I've been saying around the emotional impacts and what's going to be helpful, what some of the experiences might be and what's going to be helpful in supporting the child. So, I think those kinds of things to support the adults in a child's life with how to support the child, but also things like stories for young children that help them to understand them and how to change that narrative (Mental health worker, CAMHS, I04).*

Another way to support young people to feel like they were more connected was developing online technologies including digital applications, websites, online forums, podcasts, or social media groups for children of parents who used substances. The benefits discussed of such

online resources included, helping young people to connect with other young people in similar situations especially where there was a barrier within a school setting, helping them connect with practitioners, helping them connect to and read stories or case examples about other young people, and helping them to not feel alone. Some young people thought that developing online support would help young people to overcome the fear of seeking support, especially through having anonymous text or chat support lines. This could be a useful first step before seeking additional support, which could help to raise their internal resilience and shame and overcome fear of stigma. Talking to someone they did not know was beneficial for young people who felt scared to talk about their experiences with someone they knew for fear of being judged.

*I think if someone got comfortable enough to be able to speak to someone, because I think that would have helped me, instead of just going straight into, “Right, this is your counsellor. Here you are, sit in a room for an hour, talk about your feelings.” It didn’t work for me. So, maybe having that first initial step of being able to reach out and learn online and then moving onto it (Kelly, aged 20, Mother’s alcohol and drug use).*

*I think it’s best to start online because then people don’t feel as intimidated because you don’t have to see the person to talk to them and maybe if they’re comfortable with it, then move to face to face after (Alfie, aged 16, Mother’s alcohol use).*

#### **4.12 Theme 4. Building Resilient and Non-stigmatising Systems around Young People**

Whilst support was needed for young people as individuals it was expressed that there was also a need to build resilient and non-stigmatising environments for young people. Young people and practitioners both spoke about the need for changes across multiple different environments, including services becoming poverty informed, increasing Government investment, as well as specialised training for practitioners. Focusing on changing and building the systems surrounding young people could have a benefit for young people, including feeling acknowledged by adults and practitioners in their lives.

##### ***4.12.1 The need for poverty informed services***

Social conditions often amplified young people’s experiences, where poverty tracked together with parental substance use resulting in worse outcomes for young people. Young people



recounted times that they did not have enough food to eat due to poverty as well as their parents spending on substances, *“I used to open the fridge and see nothing. I used to have to go downstairs for a bowl of cereal at night just to fill my stomach”* (Sean, aged 21, Mother and Father’s drug use) or they worried about being *“malnourished”* (Naomi, aged 24, Mother’s alcohol use). They also discussed times their families could not afford hot water or electricity that paired with their parent’s neglectful practices due to intoxication and left some young people going to school unwashed or in dirty clothes, leading to bullying. In few instances, they would not attend school. Other young people reflected on their parents not being able to keep up with paying for rent and subsequently they *“got kicked out”* of their house and *“lived in eleven different houses”* (Zoe, aged 17, Mother’s drug use) during childhood and adolescence. In these situations, young people found it hard to concentrate in school, or they ‘acted out’ in class. It was evident in participants accounts that more was needed to help children and young people who were living with both parental substance use and poverty to feel less stigmatised at school. They did not want to stand out due to receiving free school meals or not having the right uniform. Young people felt that schools and services needed to have a better awareness and understanding of how a young person who lives with these two forms of adversity may behave or feel in certain situations and consider the impact of poverty and parental substance use in that situation in a sensitive way. Yet, young people discussed that schools and services had largely only provided financial support rather than understanding in such circumstances of social deprivation. Young people reported being provided with *“free period items”* or that they had gotten *“school trips for cheaper”* (Rebecca, aged 18, Mother’s alcohol and drug use). Whilst this was seen as a supportive act, it also increased stigma for the young person when the school was not discrete about it and their peers found out. Older young people expressed gratitude at being provided with additional funding by services to help become more independent and buy housing essentials.

*They give you £100 on a home fund, so I bought a laundry basket, towels, so that when I move out, I’m all set up. Which is something that my parents would never bloody do, so it’s quite nice. I’m not used to it at all* (Sean, aged 21, Mother and Father’s drug use).

Likewise, some practitioners discussed how support services needed to link young people to free activities or clubs or help young people access grants or funds so that young people can have access to hobbies or *“something they really want to do, like a holiday, or swimming lessons or whatever that might be”* (Team leader, VCSO, D01).

#### ***4.12.2 Training and investment can help young people feel acknowledged***

The impact of austerity measures on the closing of services for children and young people was raised across most of the interviews and focus groups with practitioners. Practitioners shared their frustration at not having Government investment into developing specialised support for children and young people whose parent's used substances. Young people also recognised there was a lack of funding into services and acknowledged this as a barrier to accessing support:

*There are a million things that could be helpful, but the problem is developing funding and awareness (Anna, aged 17, Mother's alcohol and drug use).*

The lack of funding within this area was felt across all services, with many practitioners experiencing job insecurity or a heavy caseload. The insecurity within the services from funding cuts meant practitioners, especially those in management positions, found it hard to forecast and plan. They also reflected it was difficult to ensure other services in the local area knew about their service when there were constant changes in investment. Practitioners felt like they were not always able to best respond to the needs of young people due to the funding cuts, reduced services, and reallocation of resources into adult support. Many practitioners reported that services for young people whose parent's used substances were often add-ons to adult services, and therefore the service was *"more around managing the parents, than the needs of the young people"* (Manager, Drug and alcohol service, FG03). There was a need for more recognition of independent services for children. Some practitioners reported that their services *"were not commissioned to cover the affected other stuff"* but *"they recognised the massive, massive issues and deficit in services for young people who are affected others"* (Team leader, VCSO, DI01). Practitioners within these roles had taken it upon themselves to deliver support for young people whose parents used substances or had sought external funding to cover the costs of their *"important work"*. In these instances, practitioners reported a dilemma in terms of what took precedence, service outcomes or relationship building and support for young people. The instability of funding directly impacted on young people's support, with some services only being able to offer a limited number of sessions despite the acknowledgement that more sessions were often needed for enduring impacts from parental substance use. Due, in part, to reduced services and funding cuts, practitioners felt that young people were usually at crisis point by the time that they supported them and required extensive specialised support. Developing resilient support services, with stable funding and Government investment and prioritisation were reported as essential to ensure practitioners

could support young people with ongoing and long-lasting impacts from parental substance use and so that young people felt their needs were acknowledged.

*There needs to be a government strategy that put's pressure on commissioners that puts pressure on services to deliver an appropriate and effective and to a safe standard programme (Manager, VCSO, FG01)*

Early identification of children whose parents use substances and prevention work were reportedly missing in this field, and were areas identified as being important to further develop. As young people may be hidden and therefore not seeking support, some practitioners reported that commissioners in their local area did not see the need to fund specialist services (e.g., there was no demand). Moreover, there were issues raised with commissioning of services across the country, with practitioners reporting that “*in some places, there have been excellent things going on. In other places, there just isn't really anything. It's really patchy*” (mental health worker, CAMHS, I04) due to limited acknowledgement by the Government that children and young people need support services in their own right. Practitioners felt that earlier identification of young people would support the case of needing specialised services commissioned across the country. However, it was described as a ‘catch-22’ situation, wherein increases to earlier identification of children and young people whose parents use substances, without increases in funding to deliver specialised support would mean there would not be adequate support in place for young people. Young people also wanted “*Government investment earlier*” for younger children to “*prevent issues*” and the enduring impacts of parental substance use into adolescence and adulthood (Naomi, aged 24, Mother's alcohol use).

Participants shared the view that there was a need to improve pathways between adult's and children's services, as well as statutory and non-statutory services. There was a gap between the adult treatment services linking up with children's services to help identify children who may be exposed to parental substance use. To help bridge the gap between services, practitioners identified improved communication, co-working spaces, and taking a partnership approach could help.

*We are working within a system where services are underfunded and under resourced, completely, which sets us against each other sometimes. So, working in partnership is*

*extremely important, which, again, can be quite a challenge and quite difficult to do in some circumstances (Manager, VCSO, FG02).*

Practitioners wanted more linking up of services across the country to learn from each other, understand what works, and offer each other support. Connection with other practitioners and services was therefore seen as important to ensure practitioners are supporting the needs of young people. Moreover, they wanted a resource that maps out the different services across the country to understand where there is need and where resources are missing.

*I'm still at the stage where I want other young people's services, especially affected by services, just to meet up, share good practice. I think a group of services getting together who work on the frontline and developing an idea that we can both go away and play with and see if it works, that would be a great starting point (Team leader, VCSO, I05).*

Young people reflected on some practitioner's lack of ability to identify "*the signs of how addiction can be in the family*" (Josh, aged 17, Mother and Father's alcohol and drug use) and to understand what it is like to be a young person growing up in such families.

Practitioners acknowledged that training was needed to help build specialised knowledge and capacity when working with young people whose parent's used substances. Such training was identified for any practitioner who may encounter a young person such as doctors, paramedics, police, school staff, or social workers.

*There's other things that we used to do when police used to attend in an overdose or drug related death; they always used to give out little signposting cards, to the family member. Things like that, we don't necessarily do anymore. So, the thought about training for not only drug and alcohol staff, not only schools and universal services, but I guess responders, so thinking about training around ambulance service, around police response, accident and emergency, on them picking up key signs and realising that actually, the person is here, we're treating the person. But, what about the person sitting in the chair, or that young person who has come along with them? What do we do with them? (Commissioner, Local Authority, I08).*

Specialised training could help develop understanding of being a young person with parental substance use, and the different impacts they may experience. It centralises the child's needs

alongside treating the parents for substance use. Likewise, training would help practitioners become aware of the different services that exist in their local area as well as online resources for young people that they can signpost to. Practitioners also reflected that the hidden nature of adolescents across services and the “*difficulty with identifying neglect in adolescents*” (Team leader, VCSO, DI02) caused a barrier for identifying young people who are being exploited. There was a reported need for practitioner training around the signs of exploitation amongst children in families where there is family substance use as well as social deprivation or adversity. Practitioners also discussed the reluctance of professionals having conversations with adults around their alcohol or drug use. Supporting practitioners to become more comfortable asking questions around substance use in a non-stigmatising way was considered important to include in training. This could contribute to identifying young people whose parent’s used substances. Raising awareness, through training and education of practitioners, around the impacts of parental substance use would help with earlier identification of young people who are exposed to parental substance use. Different forms of training included, developing a co-produced toolkit with guiding principles for supporting young people, delivering training days for school staff and first responders, and including specific sessions and content within social care or medical degrees or training programmes.

*There does need to be some resource put in there to improve for instance the social work training, to include it to improve GP training, to include it at schools training, all those professionals that come into contact with young people to be aware of what might be going on (Manager, VCSO, DI02).*

#### **4.13 Chapter Summary**

This chapter first presented the methodological consideration as well as the specific methods used for the qualitative fieldwork and analysis. Data were generated through semi-structured interviews and focus groups with young people and practitioners allowing for an in-depth exploration on the topic. Next, the findings of the qualitative fieldwork were presented exploring the support needs of young people whose parents use substances through the perspectives of both young people with lived experience and the practitioners who support them. Twenty-one young people whose parents use substances and forty-four practitioners participated. The developed conceptualisation of supporting young people whose parents use substances was discussed across four main themes: (1) navigating trauma and safety within the family; (2) enhancing young peoples’ agency; (3) understanding young peoples’

experiences of resilience and stigma: the role of surviving or thriving; and (4) building resilient and non-stigmatising systems around young people.

Young people reported experiencing stress in their everyday lives due to parental substance use, often resulting in feeling unsafe within their families. Due to this insecurity, young people perceived whole family support provided by services as unsafe and unhelpful. Support needed to be young person specific, focused on their needs, and facilitated by a trustworthy practitioner. Young people often felt their agency was compromised due to the unpredictability of their parental substance use, so tried to mitigate risks within their everyday lives. Support that acknowledged young people's strengths and empowered them through providing choices or flexible access allowed for increased engagement. Moreover, young people often described feeling that they had 'survived' within their experiences of parental substance use, rather than 'thrived' due to received stigma and feelings of shame which led to isolation and loneliness. Young people reported wanting to feel connected to others in similar situations. Finally, there was a need to build resilient and non-stigmatising environments for young people, in which training for practitioners could help young people to feel acknowledged and recognised. The next chapter will detail the co-production approach to prioritisation of intervention ideas, proposed by young people and practitioners within this chapter, to support young people whose parents use substances.

## **Chapter 5. Co-production Approach to Prioritisation**

### **5.1 Chapter Overview**

This chapter presents the methods and findings for the co-production approach to the prioritisation of intervention ideas to help best support young people whose parents use substances. The rationale and specific methods involved in the prioritisation process will be outlined, including details for the content and activities used. After, the findings from the consultations and workshops with young people and practitioners will be outlined. The top priority intervention ideas will be presented, followed by the intervention principles, and proposed logic models.

### **5.2 Aims and Objectives**

The aim of this co-production approach was to identify, prioritise, and select, intervention ideas for young people whose parents use substances based on insights from young people who experience parental substance use and the practitioners who support them. In addition, this study aimed to develop guiding principles and underlying mechanisms underpinning an acceptable intervention to support young people whose parents use substances, based on discussions during the prioritisation process. These findings then informed the development of high-level logic models for the top prioritised intervention ideas.

### **5.3 Methodological Approach to Workshops**

#### ***5.3.1 Rationale for prioritisation of interventions***

There has been an increased interest in acknowledging and learning from different perspectives, including patients, practitioners, and members of the public into decision making and prioritisation across health and social care settings (Cowan et al., 2021; Forbes et al., 2022). This increase has been, in part, due to the finding that there was a ‘mismatch’ between the priorities of different stakeholder groups regarding their support needs and what was being researched and developed (Crowe, Fenton, Hall, Cowan, & Chalmers, 2015; Tallon, Chard, & Dieppe, 2000). This discrepancy highlighted the need for contributions from people with ‘lived’ or ‘professional’ expertise of a particular issue or service to support the development of priorities. Different stakeholders can therefore bring specialised knowledge to the prioritisation process that may be missed if decisions were informed by researchers only. Such inclusive involvement is thought to improve the quality of decisions and interventions

developed as well as improve service accessibility and engagement (Buchecker, Meier, & Hunziker, 2010).

The UK Medical Research Council produced a four-phase framework for developing and evaluating complex interventions (Craig et al., 2008). However, this guidance was criticised for lacking sufficient detail and specificity to inform intervention development. O'Cathain et al. (2019) conducted a consensus exercise based upon a systematic review and qualitative interviews, producing key principles and actions to be considered when developing complex interventions. Within the guidance, a key action was to involve stakeholders throughout the development process to help identify priorities and solutions that can make a difference to the later implementation in the 'real world'. A variety of approaches to stakeholder involvement exist with differing levels of involvement from consultation, which may consist of a one-off meeting to discuss discrete decisions or contextual information, to co-production wherein stakeholders share at least equal decision-making powers with members of the research team (O'Cathain et al., 2019).

Most interventions in this area focus on the parent who uses substances to reduce the risk to the young person (Barrett et al., 2023; McGovern et al., 2020). A systematic review examining interventions which directly intervened with the children of parents who use substances found mixed and low-quality evidence of effect for dependent age children and no effectiveness for young adult children (McGovern, Smart, et al., 2021), resulting in a paucity of evidence-based interventions that are young-person focused. There was also limited evidence-based interventions that have been co-produced with multiple stakeholders, especially involving young people with lived experience (Barrett et al., 2023). Therefore, to ensure that newly developed intervention(s) supporting young people whose parents use substances are relevant and acceptable to young people, and to those who support them, it is important that their voices are included in the decision-making and priority-setting process, as well as later stages of designing and refining interventions.

### ***5.3.2 Rationale for approach to prioritisation***

There are a variety of approaches that can be used when determining priorities, which are usually group consensus-based approaches, metrics-based approaches, or a combination. Group consensus-based approaches involve group decision making on priorities that can improve acceptability, whilst metrics-based approaches involve pooling of individual rankings that can prevent dominance of a few individuals (Viergever, Olifson, Ghaffar, &



Terry, 2010). Metrics-based methods can include surveys, and online crowd-voting. Consensus-based methods can include focus groups or workshops. A combination of both approaches is common, wherein an iterative process is taken, with individual prioritisation and group discussions. Structured examples of which are the nominal group approach or the Delphi method. The nominal group approach is a structured group interactive activity, wherein there is silent, individual generation of priorities, followed by discussion amongst the group with additional idea generation, followed by clarification and then voting (ranking or rating) (Van de Ven & Delbecq, 1972). The Delphi technique is also a structured group interaction but with the use of questionnaires rather than face-to-face interaction, preserving anonymity (Linstone & Turoff, 1975). Stakeholders rate statements on a Likert scale with the option to write in a free-text comment box to explain their ratings. These responses are collated and used to generate an additional questionnaire, wherein stakeholders can see the original ratings and comments and can re-rate the statements again. Both approaches allow for individual ranking and then group-consensus building. This thesis has used both individual and group consensus techniques.

Different approaches (e.g., focus groups, Delphi Survey, and online crowd-voting), for involving the public in prioritisation activities have been compared (Lavalley et al., 2020). The authors found that there were similarities in priorities across the different approaches, but the experience of involvement was different. Therefore, there was scope to use different approaches depending on stakeholder preferences or study constraints that allowed for replicable results. This thesis has used a range of approaches depending on the stakeholder group, including workshops with young people and online crowd-voting with practitioners.

Approaches for prioritisation have mainly focused on prioritising research agendas or research questions, with very few studies that focus on the intervention prioritisation phase. Therefore, there is a lack of accepted guidance for how this should be achieved. Morton et al. (2017) developed a three-stage framework for engaging stakeholders, including young people, in a public health intervention prioritisation process. The stages included developing a list of potential intervention strategies through formative stages of the research (stage 1), preparing the documents to be sent to stakeholders (stage 2), and conducting individual and group prioritisation, similar to the Delphi technique, with selection of the interventions to take forward (stage 3). Likewise, Fellenor et al. (2021) developed a three-stage, multi-method prioritisation process for co-producing a research agenda with multiple stakeholders. The first stage was generation of preliminary research questions, then consultation and ranking with

stakeholders (stage 2), and finally consensus building and prioritisation at a workshop event (stage 3).

Co-production has emerged as an innovative and popular approach in intervention prioritisation and development involving young people (Reed et al., 2021). When involving young people, Kendal, Milnes, Welsby, and Pryjmachuk (2017) and Taylor et al. (2021) used co-production and participatory research approaches to prioritise young people's mental health support needs. They reflected that using creative workshops or groups with young people allowed them to generate trustworthy and credible findings on key priorities and were useful approaches for engaging young people in priority-setting studies. Kendal et al. (2017) developed a consensus-based method that involved an adapted nominal group technique. They used vignettes of hypothetical young people, and their support needs to facilitate discussion amongst young people and included individual and group consensus-based activities. Taylor et al. (2021) used a three-stage approach, including a priority-setting workshop with young people; priority-setting workshop and online consultation with other stakeholders; and a workshop to identify final priorities. Elements from the above approaches were adapted for this thesis to produce a three-stage approach to intervention prioritisation with young people and practitioners.

### ***5.3.3 Rationale for prioritisation criteria***

There are different methods to assess priorities, including single or multi-criteria approaches. Approaches that consider multiple criteria, such as the multi-criteria decision analysis tool, over single criteria methods, such as cost-effectiveness or equity analysis, have been encouraged in priority setting as they consider all relevant information for developing interventions (Baltussen & Niessen, 2006). Morton et al. (2017) used six criteria for assessing priority including: reach (e.g., which intervention will reach most individuals); equality (e.g., which intervention will generate disparity); acceptability (e.g., which intervention will be most acceptable to stakeholders); feasibility (e.g., which intervention will be most feasible to implement); effectiveness (e.g., which intervention will be most likely to improve desired results); and cost effectiveness (e.g., which intervention is the best value for money). This approach is similar to the APEASE model which offers a multi-criterion tool for designing and evaluating interventions (Michie, Atkins, & West, 2014), which has since also been trialled in intervention priority setting (Borek et al., 2019; Forbes et al., 2022). The APEASE model includes six criteria, affordability; practicability; effectiveness and cost-effectiveness; acceptability; safety; and equity.

From these two approaches, the priority criterion considered for this thesis were:

- *acceptability* – whether the intervention was likely to be acceptable to relevant stakeholders
- *practicability* – whether it was feasible and practical to deliver the intervention as intended
- *equity* – the extent that the intervention would reduce the disparities between different groups of society and provide equal access to the intervention across the social spectrum
- *safety* – the possible unwanted or unintended consequences of an intervention.

These criteria were picked to guide discussions as they were the most relevant to the expertise and experience of stakeholders involved and would inform decisions on readiness for intervention development.

#### ***5.3.4 Approach to developing prioritisation content and activities***

##### ***Intervention ideas***

Like Morton et al. (2017) the intervention ideas identified and used throughout the prioritisation process were informed by the findings of the earlier phase of the research: interviews with young people; and interviews and focus groups with practitioners. The interviews and focus groups involved discussions regarding what an intervention supporting young people whose parents use substances ‘could look like.’ Within similar intervention development studies, the use of qualitative interviews to explore practical considerations of intervention content have also been used ahead of workshops (Alderson et al., 2019). The identified intervention ideas were tabulated and shared with two practice advisors who had professional expertise regarding supporting young people whose parents use substances, they provided comment and further clarification.

##### ***Personas***

Similar to the Kendal et al. (2017) approach, the personas were developed from the findings of the previous stages of the research. Personas are fictitious characters used as a design tool to represent typical end users of an intervention, providing tangible and engaging images to refer to throughout prioritisation (Pruitt & Adlin, 2006). They are created from a synthesis of data from real people gathered through different methods, including interviews (Tomitsch, Wrigley, Borthwick, & Ahmadpour, 2018). The personas developed within this doctoral study

of young people whose parents use substances, and their different support needs were based on narratives from the semi-structured qualitative interviews with young people and findings from the qualitative systematic review (e.g., the stigma and shame young people faced when deciding to seek support). The purpose of using personas were three-fold: to provide an overview of the main findings of the formative stages of the research; to introduce a range of support needs that an intervention may need to target; as well as remove the focus on stakeholders own personal experiences to facilitate discussion.

### ***Workshops***

Workshops were delivered separately for young people and practitioners, with the young people's workshop informing the practitioner's workshop. This was to help stakeholders feel comfortable and able to contribute to discussions. This strategy was similar to that used by Taylor et al. (2021) and was informed by the research advisory groups (both young people and practitioners) suggesting a separate approach would enable young people's voices to be important and central to the decision-making process. To ensure there was connection between the groups, two lived experience experts presented at the practitioner event on the intervention ideas that young people had collectively prioritised.

#### ***5.3.5 Prioritisation outputs***

The workshop findings resulted in the top three prioritised intervention ideas that young people and practitioners felt should be selected for further co-production and development. In addition, the workshop findings informed intervention principles that provide insights into the ways in which stakeholders perceived the prioritised interventions may bring about positive change. Finally, the workshop findings taken with the qualitative systematic review findings, and qualitative interview and focus group findings resulted in the development of three high-level logic models. High-level logic models depict broad causal pathways, but do not show causal relationships between specific factors or intervention strategies, providing a conceptual aid to intervention development (Sonderegger et al., 2021). The developed high-level logic models summarised the main prioritised intervention ideas and provided an illustration of the relationship between the proposed assumptions, resources, activities, outputs, and desired outcomes of each, linking experiences of young people to potential supportive solutions. A logic model can aid as a planning tool and can be continuously refined throughout the intervention development process (W.K. Kellogg Foundation, 2004). This approach can also help identify where the proposed intervention may potentially lead to unintended outcomes

and can further inform the refinement of the intervention to reduce the risk of harmful effects (Bonell, Jamal, Melendez-Torres, & Cummins, 2015).

## **5.4 Methods**

### ***5.4.1 Ethics and governance***

The ethical approval in section 4.5.1 covered both interviews and workshops. As part of the one-to-one consultations, young people aged 14 years and above provided informed consent and those who were under 14 years provided assent and parental consent. Young people were also asked if they would be happy to be involved in a workshop. The workshops were then based on a co-design methodology where all stakeholders (research team, young people, and practitioners) held shared ‘power’ in the prioritisation of the intervention (O'Brien et al., 2016). No personal data were collected at this point, the formal consent process to participate in the workshops was not required.

### ***5.4.2 Eligibility criteria***

#### ***Young people***

Young people aged between 11-25 years who had lived experience of parental substance use (alcohol and/or drugs) and lived in England, UK were eligible to be involved in this study.

#### ***Practitioners***

Health and social care practitioners working across statutory and voluntary organisations from across England, UK, who supported children, young people or families with parental substance use were eligible to be involved in this study. Additionally, the workshop was open to practitioners within educational settings, public health researchers and academics, as well as commissioners and practitioners in Local Authority and other organisations who plan, commission, scrutinise or provide local health and wellbeing initiatives with children, young people, young adults, and families in mind.

### ***5.4.3 Recruitment strategy***

#### ***Young people***

Young people were recruited through the same approaches as outlined in section 4.5.3 for the qualitative interview recruitment. Additional recruitment strategies were also employed, wherein young people involved in the qualitative interviews had the option within their consent form to express an interest in being contacted for future workshops. It was made clear

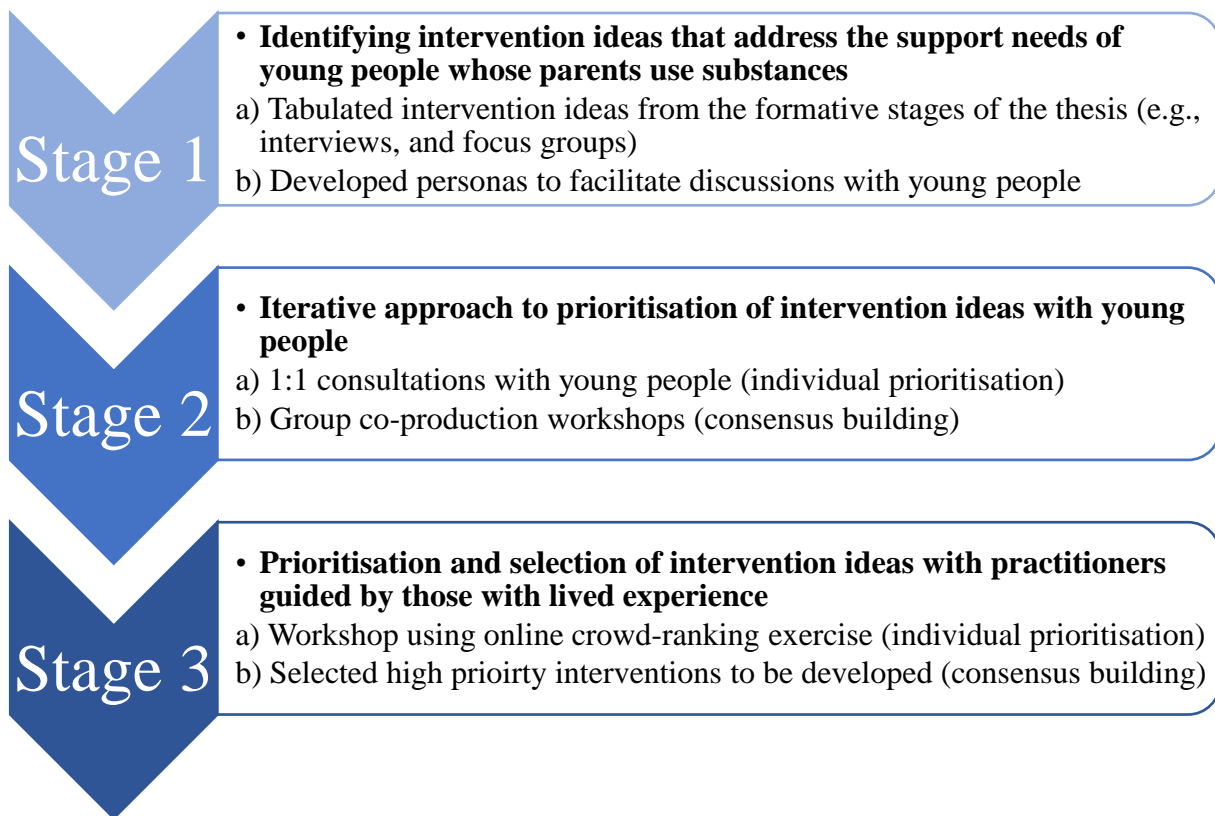
that this was not obligatory and did not impact their participation in the interviews. If they were interested, they were provided with a consent to contact form in which they provided their preferred contact details. Young people could be involved in the consultations, workshops, or both, which were arranged at a time and place most convenient to them.

### ***Practitioners***

Practitioners involved in the qualitative interviews and focus groups who had provided consent to be contacted about the next stage of research were invited, via email communication, to be involved in an online dissemination and workshop event. They were provided with a weblink, where they could sign up to the event via Adfam's Eventbrite page. Additionally, the information and weblink to the online dissemination and workshop event were also circulated across local and national social media platforms and newsletters (e.g., Adfam, NIHR School for Public Health Research, Fuse – the centre for translation research in public health, and NIHR Applied Research Collaboration North East and North Cumbria) inviting practitioners to sign up and attend (see Appendix P for event details and Appendix Q for the event programme).

#### ***5.4.4 Prioritisation process***

As can be seen in Figure 5.1 there were three stages to the prioritisation process as outlined below. These approaches were all conducted online due to the COVID-19 restrictions in place and to capture a geographical spread of stakeholders. Young people received compensation for their time in line with national guidance (NIHR, 2022).



*Figure 5.1 Three-stage approach to the intervention prioritisation process with multiple stakeholder groups*

***Stage 1: Identifying intervention ideas that address the support needs of young people whose parents use substances***

The first stage comprised of identifying intervention ideas and developing personas to facilitate discussions with young people.

***Intervention ideas***

Twenty intervention ideas focusing on how to support young people were identified and collated from the qualitative data within this thesis. I tabulated different intervention ideas that were discussed within each interview or focus group and then looked across the entire set to identify commonalities, resulting in twenty different ideas. The document containing intervention ideas from each interview or focus group as well as the twenty identified ideas were then shared with and reviewed by two practice advisors. No further ideas were added by the practice advisors, only clarity of description and discussion of ideas, for instance there was discussion on whether primary and secondary school resources should be separate or combined, these were left separate as they could be prioritised differently. These intervention ideas are presented in Table 5.1.

Most of the items were young person-focused interventions, consisting of resources to be used in educational settings (such as storybooks, interactive games, lessons, or assemblies within primary or secondary school), digital interventions (such as applications or websites, forums facilitated by practitioners, social media peer-to-peer support groups or a podcast), support lines (such as text messaging or phonelines), in person support (one-to-one with a practitioner, peer mentor guidance, groups of young people in similar situations, or whole family support), and activity based interventions (residential weekends, respite activities, or access to grants or resources for activities/hobbies). Four further items (items 17-20 in Table 5.1) were proposed as having potential indirect beneficial impacts on young people (such as substance use support targeted towards the parent, brief information for adults regarding the impact of substance use on children, a national campaign to reduce public stigma, or specialised training for practitioners). There are also several common change processes underlying the identified interventions. Some ideas aim to achieve change for young people by increasing social support and social learning through the sharing of experiences (e.g., social media peer-to-peer support groups, peer mentor, podcasts, residential weekends, and respite etc.) or increasing emotional support and management of symptoms (e.g., text support lines, one to one support, groups of young people, or school wellbeing resources). There are also ideas that aim to empower young people, for instance developing a digital application or website and improving access to grants or resources. Additionally, there are ideas that aim to raise awareness amongst others regarding the impacts of parental substance use, including stigma (e.g., training of practitioners or national campaigns) as well as raising awareness amongst young people of available support (e.g., school resources or podcast). Finally, some ideas may also achieve change for young people by providing psychoeducation to the adults in their lives (e.g., brief information for adults or parental support), as well as providing psychoeducation to young people themselves regarding learning about substance use and addiction, as well as mental health tips (e.g., digital interventions, interactive games, school resources). Most of the intervention ideas were proposed by young people during the qualitative interviews, whilst four of the proposed items were only reported by practitioners, including the podcast, interactive games, training for practitioners, and brief informational support for adults. Each intervention idea would need further co-design and development after prioritisation.



*Table 5.1 Twenty intervention ideas regarding how to support young people, proposed by young people and practitioners within the earlier stages of this thesis*

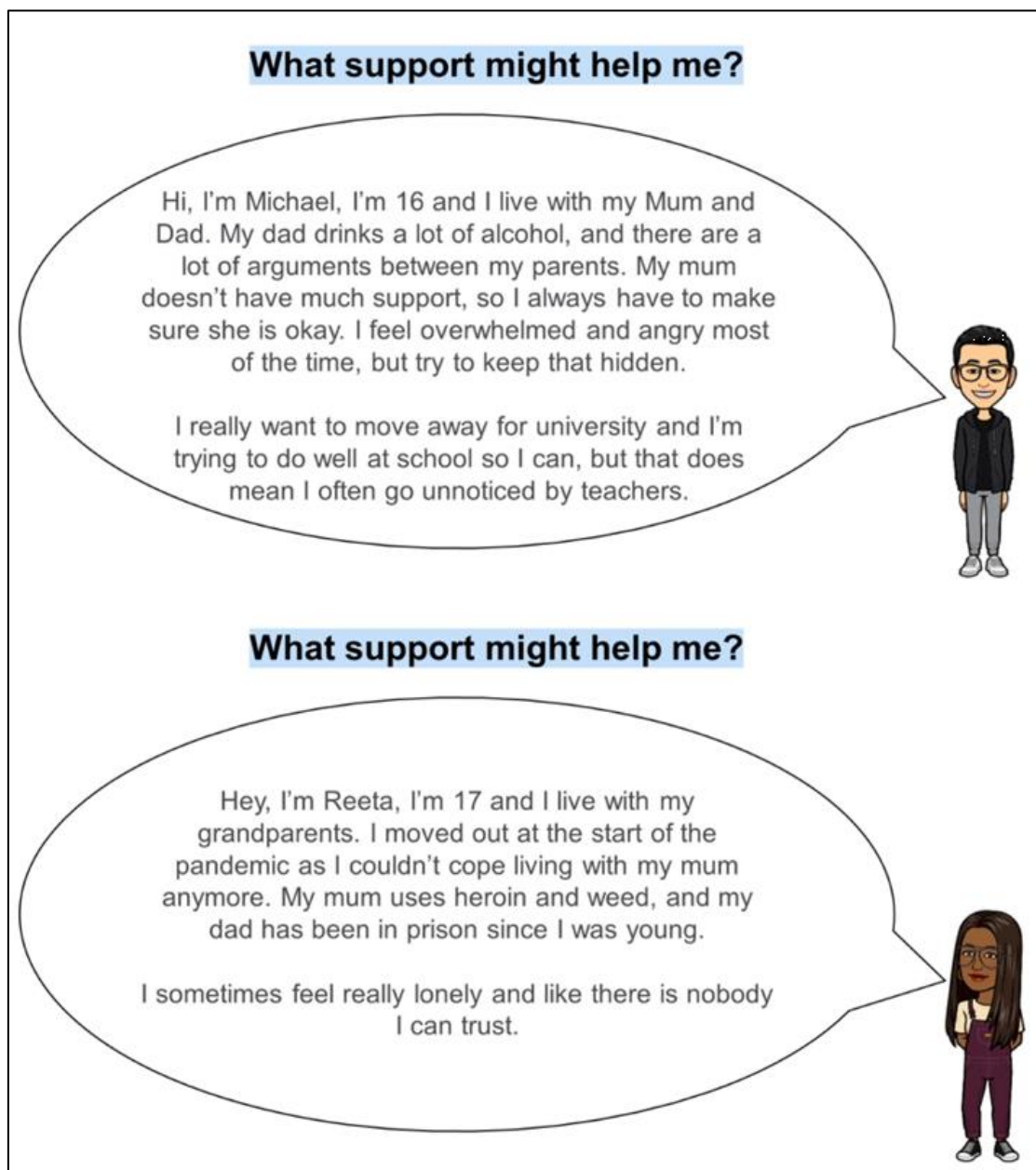
<b>Item No.</b>	<b>Intervention idea as proposed by young people and practitioners</b>	<b>Description</b>
<b>1</b>	A digital application or website	An online platform that young people can access focusing on issues relating to parental substance use for young people. It could be tailored to young peoples' needs including content around information on parental alcohol/drug use and addiction, how to access support, other young people's stories, understanding different relationships, mental health advice, safety procedures and risk management etc.
<b>2</b>	Social media peer-to-peer support group	A group/account (via Instagram or Facebook) that young people can join or access to learn from and provide peer-to-peer support with other young people whose parents use substances. Young people can ask questions, reply to each other, or share helpful tips and advice through a social media account.
<b>3</b>	Online forum facilitated and monitored by professionals/practitioners	A group that young people can join or access that is separate from their social media accounts and focuses on issues relating to parental substance use. They can join anonymously. Young people can ask questions to professionals or other young people, reply to each other, or share helpful tips and advice. A professional would monitor, moderate, and facilitate discussion.
<b>4</b>	Podcast for young people	An online platform that shares audio content around the issues of parental substance use for young people, including segments where young people could share their own experiences and learn from others.
<b>5</b>	Stories or books	Different stories or books that young people can read or be read to from the perspective of young people whose parents use substances, including their

		perceived impacts, tips on how to cope, and how to seek support.
<b>6</b>	Interactive games	Interactive games across different platforms e.g., video games or card games, around parental substance use from the young person's perspective. Young people can either play by themselves or in a group format. The games could cover different impacts of parental substance use, strategies to cope, understanding emotions, helpful advice, or how to seek support.
<b>7</b>	Text support line	A free, anonymous text support line that young people can access at all hours. They will be able to text and chat to a trained professional/practitioner.
<b>8</b>	Call support line	A free, anonymous call support line that young people can access at all hours. They will be able to call and chat to a trained professional/practitioner.
<b>9</b>	Access to grants, money, or resources	Young people who may also have financial difficulties (as well as parental substance use/other adversities) are supported to access money or resources within existing services to use on activities or hobbies of interest.
<b>10</b>	One to one support with a professional/practitioner	Young people are provided with one-to-one support with a trained practitioner where they can discuss issues relevant to them including parental substance use, mental health etc.
<b>11</b>	Groups of young people who have similar experiences	Young people can access and receive support from groups of young people who have similar experiences to themselves. They can discuss issues relevant to them including, parental substance use, mental health etc.
<b>12</b>	Primary school lessons	Lessons or assemblies within primary school around how other people's substance use can impact young people, as well as tips on how to ask for support, and shared resources.
<b>13</b>	Secondary school lessons	Lessons or assemblies within secondary school around how other people's substance use can impact young

		people, as well as tips on how to ask for support, and shared resources.
<b>14</b>	Youth/peer mentor	Within existing services or schools, young people can receive guidance and support from a youth/peer mentor (somebody who has had similar experiences).
<b>15</b>	Residential weekends or respite activities	Young people can access and attend residential weekends or respite activities away from the home and family with other young people in similar situations. The focus is more on 'fun activities' rather than parental substance use.
<b>16</b>	Whole family support	Young people can attend whole family support alongside their parents and/or siblings with a trained professional/practitioner, to openly discuss parental substance use and facilitate family communication and cohesion.
<b>17</b>	National campaign	A campaign targeted to a population (rather than young people) that highlights the impact of parental substance use from a young person's perspective to help reduce public stigma as well as shame around talking about parental substance use.
<b>18</b>	Parental support	Parents are provided with support by a trained professional/practitioner to help them reduce their substance use and/or improve their parenting skills.
<b>19</b>	Training for professionals/practitioners	Specialised training for all types of professionals/practitioners who may encounter young people (e.g., teachers, police, paramedics, social workers etc.) around parental alcohol/drug use, including the impacts on young people from their perspective, signs to look out for, and how to support young people.
<b>20</b>	Brief information for adults	Adults accessing alcohol/drug treatment services or where there are high-risk patterns of use identified (e.g., within GP appointments) are provided with brief information around the impact of alcohol/drug use on young people.

## ***Personas***

Next, five different personas were developed in two stages. Firstly, I developed the personas, reflecting the different experiences of the young people who participated in the research. Common experiences depicted within the personas included the experience of stigma and shame, the lack of confidentiality and safety in support, feeling unnoticed within school, feeling lonely and isolated, as well as their own use of substances. Secondly, these personas were then reviewed by the YPAG who considered them appropriate for use. There were three female and two male personas aged 11-24 years with varied living arrangements. An example of two of the personas can be found below (Figure 5.2) and all other personas can be found in Appendix R.



*Figure 5.2 Two of the developed personas used in the consultations and workshops with young people to facilitate prioritisation of intervention ideas*

## ***Stage 2: Iterative approach to prioritisation of intervention ideas with young people***

The second stage comprised of an iterative approach to intervention prioritisation with young people, including individual consultations to rank intervention ideas and two group consensus-building co-production workshops.

### ***Young person consultations***

Individual consultations allowed young people to reflect on their own priorities before discussing as a group. All young people involved in the consultations were provided with a consent form (assent form and parental consent for those under 14 years) via email and the opportunity to ask any questions before commencing. The personas and intervention ideas were sent to young people for consideration ahead of time and they were asked to rank them in order of priority based on which would be most acceptable for young people. One being most acceptable to twenty being least acceptable. They returned their answers prior to the consultation taking place. When the one-to-one consultation occurred, a brief overview of the main findings from earlier stages of the research were shared and then the young person was asked to describe why they had ranked the interventions as they had. Young people elaborated on their rationale for each intervention and were asked to reflect on the other prioritisation criteria including equity and safety. I prepared detailed notes to capture key insights about intervention prioritisation. Consultations lasted between 30 and 60 minutes (mean = 42 minutes). Once all consultations had taken place, the intervention ideas were ranked in order of highest priority (lowest overall score) to lowest priority (highest overall score) by combining all young people's scores on each intervention idea. This order was then discussed at two workshops with young people, and they came to a consensus on overall key priority intervention ideas.

### ***Young person workshops***

Two iterative workshops were conducted examining prioritisation with young people. The discussion allowed for young people to consider others' points of view before reaching a consensus. The first workshop consisted of young people from the consultations and the second workshop involved young people from a service who support young people whose parents use substances. Of those young people from the consultations who wanted to and were available to join, a time and date was organised to accommodate most young people. A Zoom link to join the online workshop was sent to the young people. Once all young people had joined the workshop, we all introduced ourselves and did an ice breaker activity to help the young people get to know each other and the researcher. Everyone was asked to say what

they were looking forward to at the weekend. We then co-produced the workshop ‘ground rules,’ which were:

- Equal – We all bring expertise to this group
- Confidential ‘room’ – We do not discuss personal details outside of the group
- Safe space to disagree and discuss – all responses are valid
- Respect the opinions of others
- Listen and allow others to contribute
- Only share relevant information and experiences if you feel comfortable and safe
- Stay focused on topic
- Try to resolve any questions

Using Microsoft PowerPoint and Google Jamboard we briefly discussed the five personas and overall initial ratings for the intervention ideas. Young people used the personas as well as their own experiences to discuss and prioritise the intervention ideas as a group. As suggested by Morton et al. (2017), the prioritisation criteria centred around acceptability, equity, and safety. Young people also briefly talked about content of the different intervention ideas. Discussions were captured on ‘sticky notes’ on Googles’ Jamboard. The workshop lasted two hours. A similar approach was taken for the second workshop, wherein they discussed the order from the first workshop and provided any further perspective on prioritisation.

### ***Stage 3: Prioritisation and selection of intervention ideas with practitioners guided by those with lived experience***

The final stage comprised of a workshop with practitioners to prioritise and select the top ranked interventions, using online crowd-voting technology.

#### ***Practitioner workshop***

Practitioners, who had registered to attend the online dissemination and prioritisation event were emailed the intervention ideas and programme information ahead of the event. They were advised to familiarise themselves with the intervention ideas and think about which ones they felt would be the most and least beneficial for supporting young people whose parents drink alcohol and/or use drugs, as well as the acceptability and feasibility of these interventions.

During the first half of the 2-hour event, I presented the study findings alongside two lived experience experts. They shared their lived experiences as young people whose parents use substances as well as what young people had prioritised as the key intervention ideas at the young person workshop. There were additional presentations around the practice and policy implications of support for young people whose parents use substances, as well as a research presentation on effective interventions for parents who use substances. The second half of the event was the workshop. I used OMBEA, a web-enabled response option, which was integrated with Microsoft PowerPoint that allowed the audience to easily submit responses to questions around the prioritisation of intervention ideas. Such a crowd-voting technique was used to allow for prioritisation within the constraints of a widely attended event and had been found to produce similar results to other approaches (Lavalley et al., 2020). Practitioners' discussions and reasons for prioritisation were captured in the chat function on Zoom as well as questions throughout the online voting. Practitioners could interact with each other in the chat function as well as see live data collected from their peers on key priority areas. Moreover, a structured discussion towards the end of the event allowed practitioners to 'unmute' and share their thoughts or ask questions.

For the OMBEA voting activity, there was a unique session ID that linked to the questions being asked during the presentation. Practitioners were guided to join the session by going to the weblink and entering the passcode. Once entered, practitioners could answer the questions live. The twenty intervention ideas were grouped into two groups of ten for prioritisation due to the constraints of the voting platform that allowed only 10 voting options. Practitioners were guided to individually vote four times. For the first group of ten intervention ideas, practitioners were asked to vote for what they thought were the two most beneficial intervention ideas for supporting young people. They repeated this action again for the next ten intervention ideas. They were then asked to vote for what they thought were the two least beneficial intervention ideas for supporting young people. They repeated this action again for the next ten intervention ideas. This produced four live graphs with the frequency score on the highest and lowest priority areas. Based on the top scores, practitioners were guided to type into the OMBEA response app one pre-determined word that described which intervention they thought should be prioritised and selected to be developed (e.g., 'training' for developing specialised training for professionals/practitioners). Practitioners were provided with live feedback in the form of a word cloud on the selected intervention ideas. During these votes, practitioners were also guided to consider and discuss in the chat function their reasons for their prioritisation based on the criteria of feasibility, acceptability, equity, and safety. After

the workshop, the young people who attended had opportunity to reflect on the practitioner's prioritised intervention ideas through a private discussion and agreed on the selected intervention ideas for further co-production and development.

## **5.5 Data Analysis**

Stakeholders were involved in data analysis throughout the workshops as they were building consensus of the key priority intervention ideas (Kendal et al., 2017; Taylor et al., 2021). In addition, a pragmatic approach that resembled thematic analysis was applied to the workshop findings (O'Brien et al., 2016; Taylor et al., 2021). Notes generated on discussions were collated and then tabulated for each intervention idea. This approach allowed for the identification of recurring ideas regarding intervention prioritisation, which became the 'intervention principles.'

## **5.6 Findings: Demographics**

### **5.6.1 *Young people***

Thirteen young people aged between 12-24 years, with lived experience of family substance use were involved in this phase of the project. There were a mix of females, males, and transgender young people. Young people were from White-British and minority ethnicities. Ten young people were involved in the consultations, of which four young people engaged in the first workshop and a further three young people were involved in the second workshop.

### **5.6.2 *Practitioners***

Ninety-four practitioners were involved in the workshop. The majority were health and social care practitioners working across statutory and voluntary organisations from across England, UK, who supported children, young people, or families with parental substance use. Additionally, there were practitioners from local authority and commissioning services, education and research, as well as lived experience experts.

## **5.7 Findings: Prioritised Intervention Ideas**

The following results will focus primarily on the top prioritised intervention ideas from young people and then practitioners.



### 5.7.1 Young people

The prioritised order for the intervention ideas by young people can be found in Table 5.2. Firstly, young people ranked the intervention ideas within individual consultations from 1 (most acceptable) to 20 (least acceptable) and the overall scores across stakeholders were used to rank them in order of highest priority to lowest priority (which can be found in column three in Table 5.2). The prioritised order was discussed at workshops with young people to build consensus on the prioritisation of the intervention ideas. Young people placed the intervention ideas into three self-selected groupings to facilitate the prioritisation process and aid discussion, ‘absolutely essential’, being the highest-ranking intervention ideas and colour coded as green in Table 5.2; ‘nice if they existed but not essential’ colour coded as yellow; and ‘low priority and not essential’ colour coded as red.

The top five prioritised intervention ideas as ranked by young people after the consensus building workshops are as follows:

1. Age-appropriate educational resources - primary and secondary school educational resources as well as stories for primary school aged children were combined
2. Training for professionals/practitioners
3. Text support line
4. A digital application or website
5. Groups of young people

*Table 5.2 The intervention ideas in order of highest priority to lowest priority based on the young person group consensus workshop. Initial rankings and scores based upon the individual consultations are also shown in column three.*

Workshop		Consultation
Priority order	Intervention idea	priority order (score)
1	Age-appropriate educational resources	Secondary school education 2 (57)
1		Primary school education 7 (78)
1		Stories or books 11 (101)
2	Training for professionals/practitioners	1 (54)
3	Text support line	3 (64)
4	A digital application or website	4 (65)
5	Groups of young people	5 (67)

6	Youth/peer mentor	6 (69)
7	National campaign	9 (92)
8	Podcast for young people	13 (108)
9	Interactive games	15 (133)
10	Residential weekends or respite activities	16 (147)
11	Access to grants, money, or resources	17 (149)
12	One to one support with a professional/practitioner	14 (120)
13	Social media peer-to-peer support group	8 (79)
14	Online forum facilitated by professionals/practitioners	12 (107)
15	Call support line	10 (95)
16	Whole family support	18 (166)
17	Parental support	19 (168)
18	Brief information for adults	20 (181)

The workshop top priority ideas were similar to the individual consultation rankings except young people within the workshop decided it was equally a priority to develop primary school educational resources alongside secondary school educational resources. The main way they thought this could be achieved within primary school was by developing storybooks about children whose parents use substances that could be read out loud by the teacher in class. These intervention ideas were therefore combined and moved to joint first position. Training for all practitioners was therefore changed to second place and was thought to complement the educational resources for young people. Rankings 3-6 retained their positions in group consensus. Figure 5.3 shows the interactive Jamboard slides for the ‘absolutely essential’ grouping and young people’s top prioritised intervention ideas that should be considered for development. See Appendix S for the Jamboard slides of the mid-priority grouping and Appendix T for the Jamboard slides of the low priority grouping.

As can be seen in Table 5.2 the lowest priority intervention ideas from the consultations with young people were brief information for adults about the impact of substance use on children; parental support; whole family support; residential weekends or respite activities; and access to grants, money, or resources. Within the workshops, young people rated similarly with whole family support; parental support; and brief information for adults as the lowest priority areas. However, they decided to include the social media support group, online forum monitored by a practitioner and call support line in the low priority ideas as they felt other options, including the text support line and digital application would be more acceptable and

safer for young people to access. Residential weekends and respite activities as well as access to grants and resources for activities outside of the home were ranked higher. Young people felt these options would be accessed and needed less frequently but were important for services or an intervention to include as they could provide young people with a break from their homelife. Young people had prioritised one-to-one support with a practitioner as low priority. During discussions, that decision was made due to one-to-one support being more widely available and usually the only option of support for young people whose parents use substances. They agreed that one-to-one support was acceptable and needed, but the other intervention ideas were prioritised as they were harder to currently access or did not exist (e.g., it was harder for young people to currently access groups of young people in similar situations).



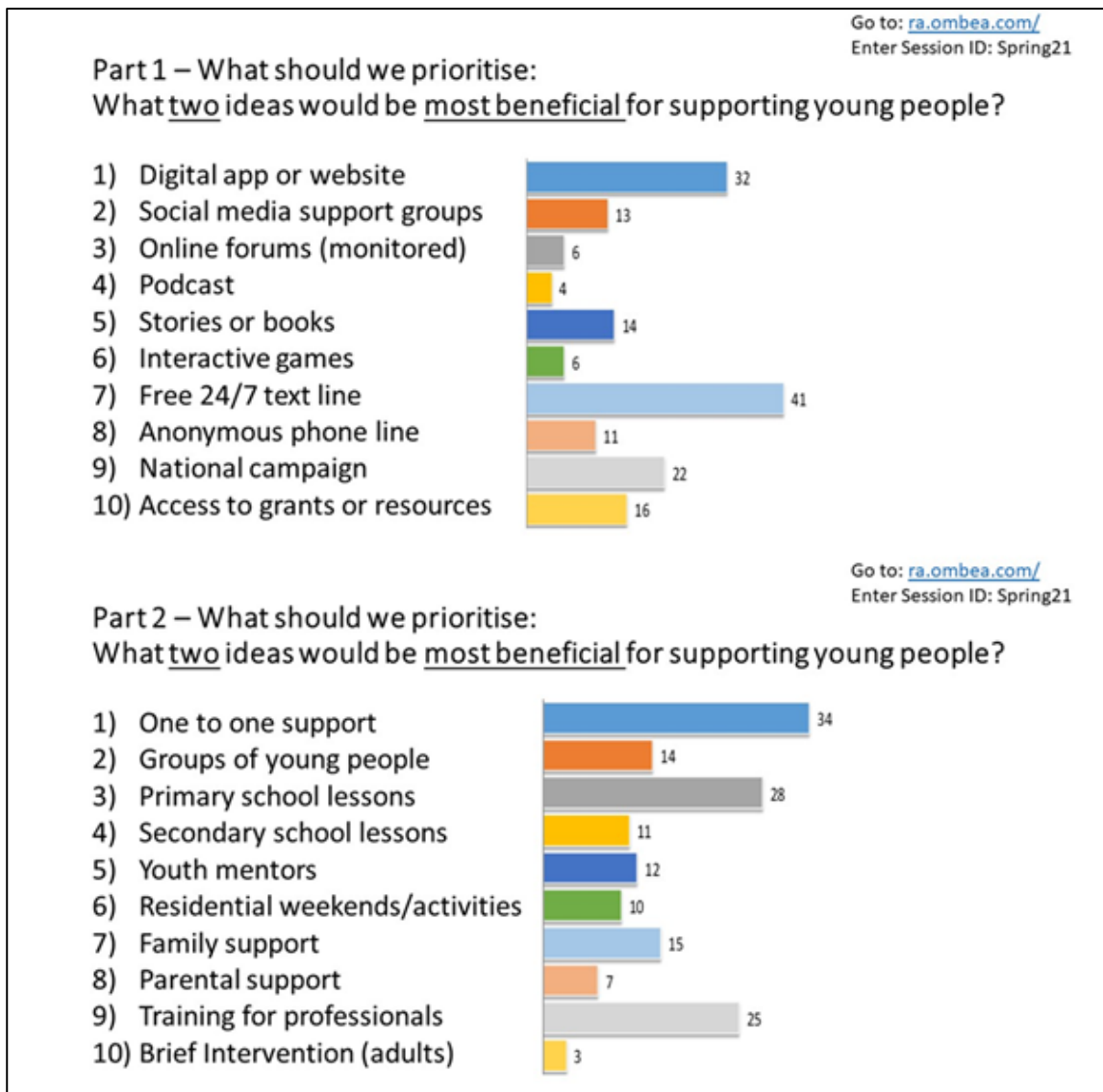
Figure 5.3 Jamboard slides from the workshop with young people regarding their 'absolutely essential' and top prioritised intervention ideas.

### 5.7.2 Practitioners

Young people's prioritised intervention ideas were presented to the practitioners, who also prioritised the twenty ideas. Scores were based on the frequency of the intervention idea being chosen as a top priority area. See Figure 5.4 for the OMBEA response live graphs that were

produced and shared during the workshop for high priority intervention ideas. The top five key priority intervention ideas as voted by practitioners were:

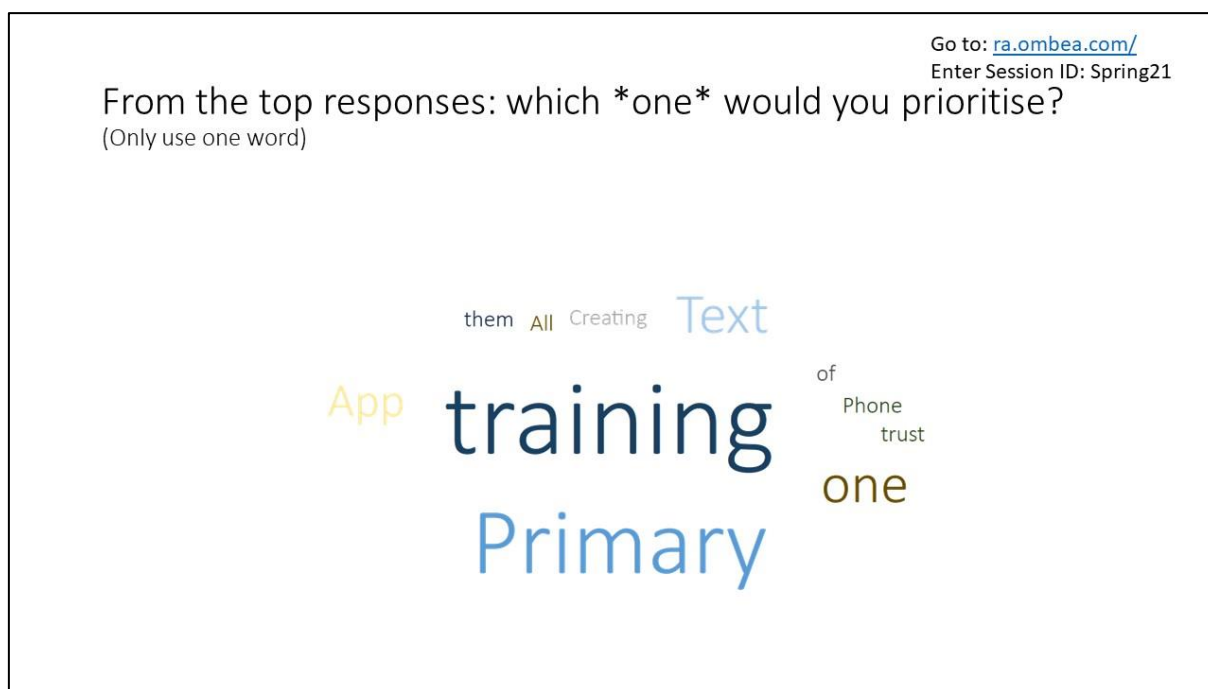
1. Text support line
2. One-to-one support
3. A digital application or website
4. Primary school education
5. Training for professionals/practitioners



*Figure 5.4 The OMBEA response live graphs produced during the practitioner workshop for prioritised intervention ideas.*

Despite a different order, the practitioners top five intervention ideas were similar to those prioritised by young people. The main difference being that young people had prioritised groups of young people above one-to-one support with a practitioner for reasons as mentioned

above. From the five top prioritised ideas, practitioners then built consensus and chose which intervention ideas should be selected. Practitioners selected training for practitioners (29%) and primary school education (25%) as the highest priority areas (see Figure 5.5).



*Figure 5.5 The OMBEA response word cloud produced during the practitioner workshop for the top priority intervention ideas*

For practitioners, the lowest priority areas were the online forum; residential weekends; interactive games; a podcast for young people; and brief information for adults. See Appendix U for OMBEA response graphs and Appendix V for OMBEA response word cloud for the low priority areas. Practitioners and young people agreed on the lowest priority area as the brief information for adults. Practitioners thought that podcasts, as well as forums, and interactive games were options that young people may not interact with or would not find engaging, with limited reach or accessibility. Young people thought that these options could be useful as they would offer a range of possibilities for access but were not a main priority as they would not reach a wide range of young people. Young people also ranked whole family support as lower than practitioners, as they thought it would have more opportunity for unintended outcomes and risks for young people. Young people acknowledged the difficulty of discussing parental substance use in whole family support as they ‘still have to live in their families’ after support. Practitioners felt whole family support was feasible when done appropriately. Young people thought that supporting the parent to stop using drugs was useful as ‘without the support for parents there is a high chance parents will not stop using drugs or

alcohol.’ However, it was felt that support that prioritised their own wellbeing was more important as there can be ongoing and long-lasting impacts even when their parents have stopped using substances. Young people also felt that their parents receiving support should not be a pre-requisite for their own support.

### **5.7.3 *Selection of intervention ideas***

Based on the consensus building workshops with young people (stage 2) and practitioners (stage 3) the three highest priority areas across both stakeholder groups that were selected to be co-produced and developed in the future were:

1. Emotional and social wellbeing resources to be used within primary schools (including developing a storybook)
2. Emotional and social wellbeing resources to be used within secondary schools
3. Training for professionals and practitioners

Two further highly prioritised intervention ideas by both groups were to develop a text support line and a digital application/website, particularly a combination of the two.

## **5.8 Findings: Intervention Principles**

During the consultations and workshops, reasons for prioritisation were explored and developed into intervention principles that represent the underlying mechanisms for supporting young people whose parents use substances. These principles provide insights into the ways in which stakeholders perceived the prioritised interventions may bring about positive change and are organised under three themes: creating connections amongst young people; raising practitioner and public understanding and awareness; and allowing for flexibility, personalisation, and agency. Within each principle a high-level logic model was developed for the main prioritised intervention idea with the proposed distal outcome of improving children and young people’s social and emotional wellbeing.

### **5.8.1 *Creating connections amongst young people***

Approaches which aim to address isolation and feelings of loneliness were important, especially through the creation of connections. When discussing the acceptability of the intervention ideas, stakeholders rated highly those that allowed young people to know there were others who have shared their experience. Being able to meet, hear about or read about other young people who have experienced parental substance use allowed young people to



feel connected and like they were not alone or ‘different’ to others. There was a need for support that allowed young people to create these connections at the young person’s own pace, whether that is joining a group of young people with shared experiences, reading stories about a young person’s journey with parental substance use, having a peer mentor to talk to, listening to a podcast from a young person’s perspective, or accessing an app on their phone to interact with others.

One of the main ways to address isolation and loneliness was by introducing the topic of parental substance use at an early age, especially within primary school education and continuing this conversation into secondary school (see Figure 5.6 for the logic model). It was acknowledged by some practitioners that this idea could be the ‘hardest to get delivered at the scale required’ due to constraints on teachers and within the curriculum. Yet, practitioners within educational settings encouraged the development of resources that could be ‘easily embedded into the relationships, sex, and health curriculum as part of a more holistic approach.’ This approach could facilitate the acceptability and feasibility of such resources. Looking at parental substance use from both a ‘physical and mental health angle’ for young people and considering the topic from the child’s perspective rather than the parents or adult perspective was thought to be important to reduce isolation and to normalise young people’s experiences or responses. Rather than formal talks/assemblies or lessons within school provided by an external service, it was felt that providing teachers with age-appropriate tools to engage with and identify vulnerable young people was preferred. Children’s storybooks were felt by young people to be an acceptable way to approach the subject of parental substance use within primary school and short animated videos within secondary schools. Both would depict the common emotional and social experiences of children or adolescents who experience parental substance use, which was discussed as an original approach to this topic that could help to create connections and reduce feelings of isolation and loneliness. These tools were felt to be easily embedded into a classroom situation, where the teacher could facilitate age-appropriate discussion about how they think the child is feeling and what might help them to feel better. Having teachers communicate about parental substance use from the young person’s perspective, through the sharing of young people’s stories, can also help to reduce the risk of personal disclosure for the young person and could initiate the reduction in shame, stigma, and fear felt by many young people.



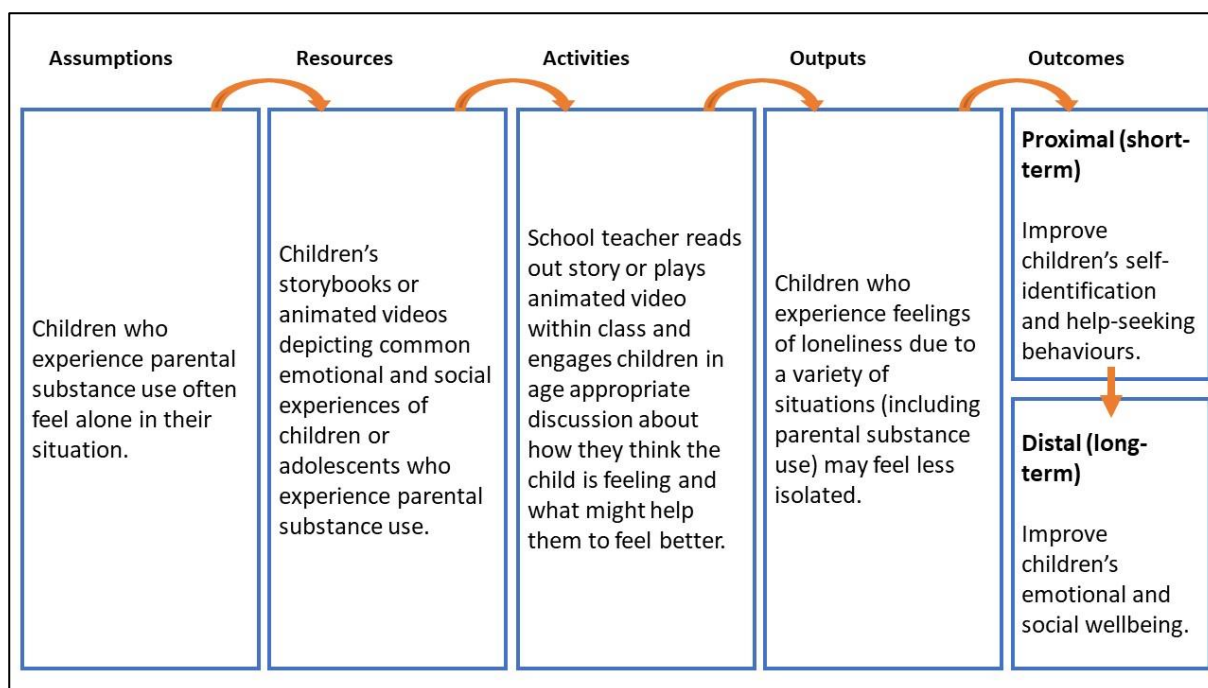


Figure 5.6 High-level logic model for children's educational resources

### 5.8.2 Raising practitioner and public understanding and awareness

Approaches which aim to address feelings of being misunderstood and ensuing stigma or discrimination, were a priority, primarily through raising practitioners understanding of parental substance use from the young person's perspective, as well as raising the public's awareness too. Stakeholders felt that frontline practitioners encountering young people should receive specialised training to know what to look out for, how to respond, and where to refer to with regards to parental substance use. In terms of what to look out for, stakeholders felt it was important for the awareness of externalised behaviours as a way to express need and hiding or masking emotions as a response to social stigma and fear. Practitioners reflected that 'children are fearful to speak up but desperate for someone to notice therefore training for professionals is a key priority.' Young people wanted practitioners to demonstrate understanding towards young people experiencing parental substance use, through acceptance, compassion, and non-stigmatising approaches.

Specialised training developed for practitioners with the input of young people would enable training to be focused on the young person's perspective. Co-producing specific training for teachers and school staff was a high priority focus identified within the overall 'training for practitioners' (see Figure 5.7 for the logic model). It was discussed that school staff could attend short training sessions on the above areas as well as an introduction to using the age-appropriate tools mentioned in the previous principle. Training for school staff could be

delivered by local services who provide support for young people whose parents use substances. Such training could allow teachers and school staff to feel more comfortable and confident to have supportive and non-stigmatising conversations with children whose parents use substances, as well as increased awareness of parental substance use throughout the school. Children may then feel more understood and less discriminated against, which could improve their help-seeking behaviours and disclosure.

Practitioners also reflected that a toolkit compiling effective resources and guiding principles about how to support young people would be useful for practitioners in supportive or therapeutic roles with young people. They wanted training to include how to build trusting, compassionate and non-stigmatising relationships so that young people could feel safe to talk about parental substance use. Moreover, raising the public awareness through national campaigns would also allow young people to feel like the topic of parental substance use was not taboo and could be spoken about, with potentially more understanding from the person they are sharing with. Interventions that aim to raise the awareness and understanding of a young person’s experience allow young people to feel like they are seen, heard, and understood by those around them, making it easier for them to seek support.

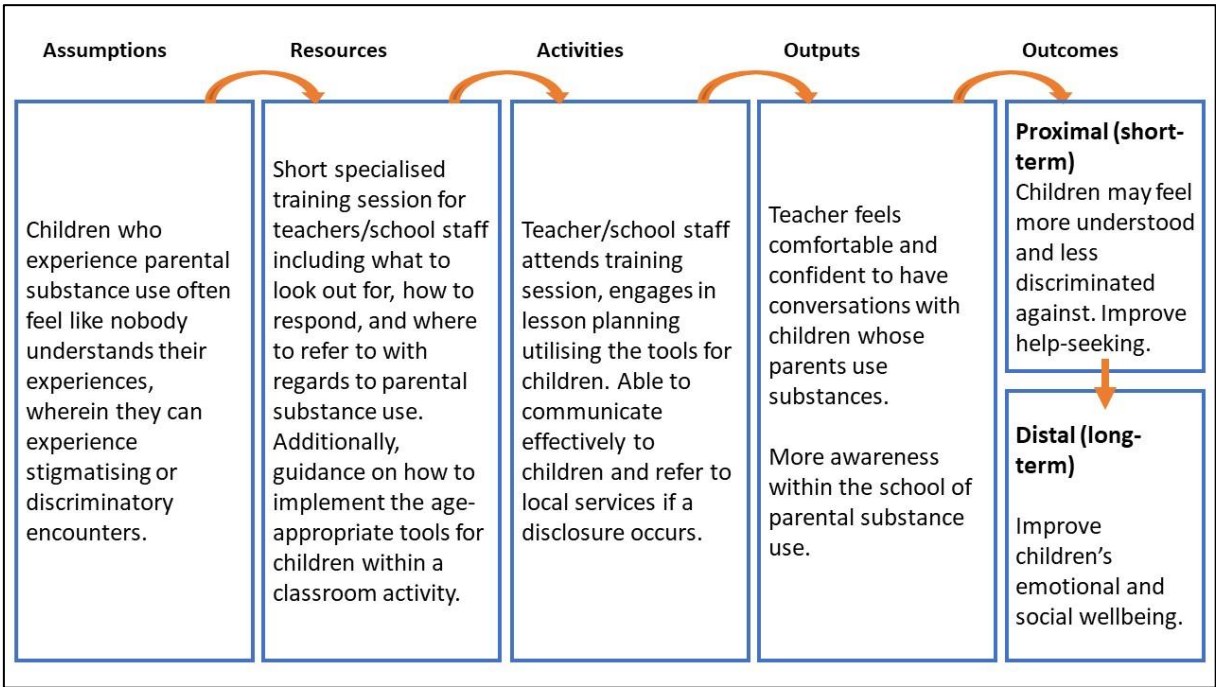


Figure 5.7 High-level logic model for specialised training for teachers/school staff

### ***5.8.3 Allowing for flexibility, personalisation, and agency***

Approaches which aim to address the unpredictability and insecurity of family and home life whilst acknowledging young people's agency were important. To address the unpredictability and insecurity, young people wanted stability in their relationships with practitioners but flexibility in intervention content, approach, and accessibility. They wanted to be provided with choices and for support to be tailored to their needs, allowing for agency. It was noted that it was difficult to prioritise some of the ideas over others as there was 'not a one solution fit for all' and a combination of methods would be useful. Yet digital interventions were discussed as providing the greatest opportunity for personalised content and flexibility in access (see Figure 5.8 for the logic model). Digital support was thought to provide opportunity to reach a wide range of young people, especially from adolescence onwards. It was also acknowledged as an acceptable approach that would help reach young people who may feel too afraid or stigmatised to speak to someone they already know. A stepped approach to support was discussed, wherein young people could first reach out for support anonymously, via a digital application, or text messaging service, before being stepped up to a more personal approach that may be face-to-face.

Stakeholders felt that a digital application or website and text support line could be combined into one intervention allowing young people to access support when they wanted or needed. Regarding the text support line, it was acknowledged that 24/7 would be ideal, but stakeholders recognised that this would be unlikely to be feasible. This led to discussions around available text support lines via existing services, young people believed that a line available until 10.30-11pm would create a good compromise. It was recognised that for many young people it was the hours between finishing school or college and bedtime which were the most unpredictable, and when they were exposed to parental intoxication and/or substance induced conflict within the home. However, it was not until later in the evening, when they had retreated to the privacy of their own room or their parent's had left the home/fell asleep that they would consider accessing a support line, and text/web chat was preferred over phone call.

However, young people and practitioners recognised the equity issues of these forms of support, wherein they could widen disparities between groups of young people due to 'digital poverty.' The option of accessing online platforms was discussed as being much harder for those without access to smartphones, computers, or the internet as well as younger people of primary school age who may have limited access to phones and internet without parental

guidance, which may increase the risk of reprisals. Likewise, the safety aspects of using online or text platforms were identified as needing to be taken into consideration and any attempt to access support should not be traceable. It may be helpful for interventions and support for young people whose parents use substances to consider offering personalisation to the individual's circumstances and preferences, providing a flexible intervention with tailored support that allows for increased agency and improved engagement with support.

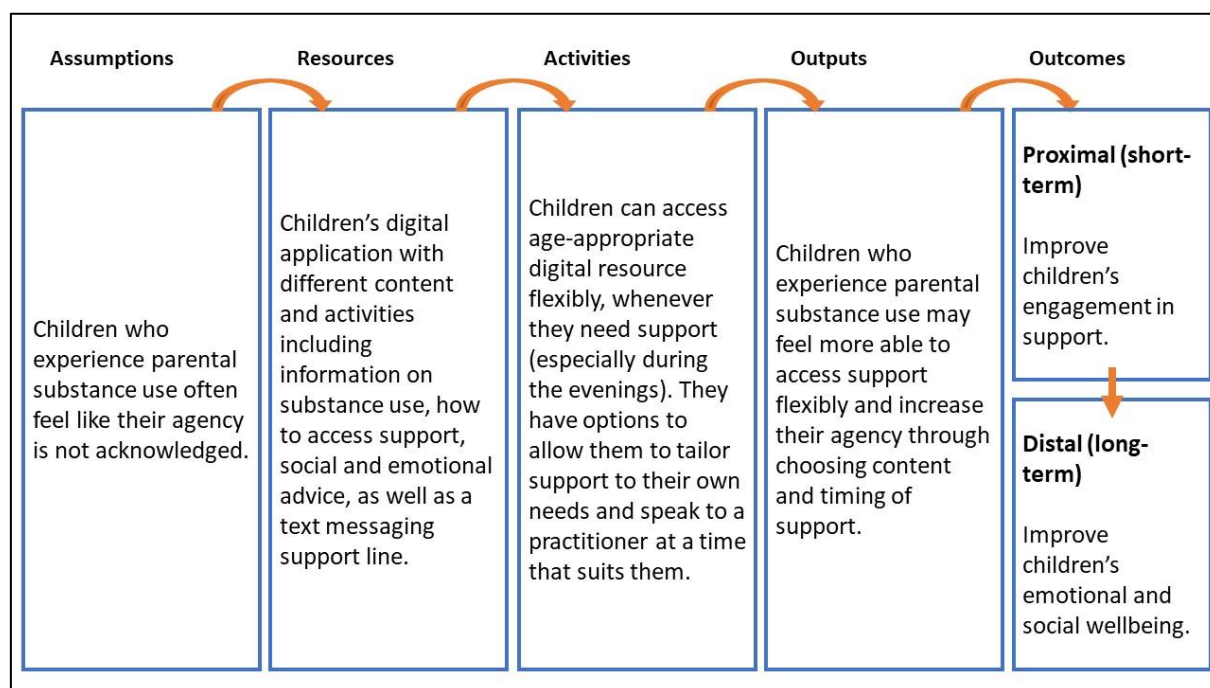


Figure 5.8 High-level logic model for a digital application

## 5.9 Chapter Summary

This chapter has detailed the methodological considerations and methods employed for the prioritisation of intervention ideas that support young people whose parents use substances. Specifically, this involved the use of a three-stage, online, co-production approach with multiple stakeholders to 1) identify, 2) prioritise, and 3) select, intervention ideas for further development. This was an iterative approach, with individual consultations and co-production workshops. Next, the findings were presented focusing on young people's and practitioner's top priorities. The selected intervention ideas were to develop age-appropriate emotional and social wellbeing resources to be used within educational settings, including storybooks of young people whose parents use substances, and specialised training for professionals or practitioners who encounter young people. The guiding principles underpinning an acceptable intervention to support young people whose parents use substances, based on discussions

during the prioritisation process were then explored. The next chapter is the discussion, wherein the findings from the qualitative systematic review, qualitative fieldwork, and prioritisation approach will be combined and critiqued in relation to the wider literature. Strengths and limitations, future research directions, and policy and practice implications will also be presented.

## **Chapter 6. Discussion**

### **6.1 Overview**

This final chapter presents the summary and interpretation of key findings from across this thesis regarding supporting children and young people whose parents use substances, highlighting practice and policy implications and recommendations throughout. The key strengths and limitations are detailed regarding the overall approach taken, methods used, and data presented. Following this, the directions and considerations for further research will be presented, ending on the conclusions of this doctoral research.

### **6.2 Summary and Interpretation of Key Findings**

The overarching aim of this research was to explore and develop a child- and young person-centred understanding of their experiences with parental substance use as well as views on supporting young people whose parents use substances, to inform the development of future intervention(s). To achieve this, three key research objectives with associated approaches were utilised. First, a qualitative systematic review examined the literature focused on the experiences, perceived impacts, and coping strategies of children and young people living with parental substance use. Second, a qualitative study explored the experiences and support needs of young people whose parents use substances from the perspectives of young people with lived experience and the practitioners who support them. Third, a prioritisation and co-production study identified the most acceptable intervention ideas for supporting young people whose parents use substances that had been proposed by both young people and practitioners during the fieldwork. The findings from across these three main approaches (Chapters 3-5) build upon one another and provide suggestions and practical implications for developing support for young people whose parents use substances that meet their needs, address their experiences and perceived impacts, and that are acceptable to both young people and the practitioners who support them. The following sections summarise the main prioritised intervention ideas from Chapter 5, combining the central experiences and impacts that led to those findings from across the thesis, as well as exploration and interpretation across the wider literature and main practice and policy recommendations.

#### ***6.2.1 A school-based approach to supporting children and young people***

A key finding from this doctoral research is the importance young people and practitioners placed on the role of schools in supporting children and young people whose parents use

substances. In the prioritisation of intervention ideas, the highest rated ideas were developing resources to be used within both primary and secondary schools as well as training for practitioners, especially for teachers and education practitioners. This finding demonstrates that taking a school-based approach to address the impacts of parental substance use on young people could be highly acceptable to both young people and practitioners within the context of the UK, and therefore a potentially effective intervention approach. This doctoral research contributes important findings as to how to possibly provide support within the school setting, which addresses the current gap in support offered directly to young people. Recent research highlights the limited evidence-based interventions that directly promote the wellbeing of young people whose parents use substances, and particularly a lack of those within the school context (Barrett et al., 2023; McGovern, Smart, et al., 2021; Templeton et al., 2010), especially within the UK (Bröning et al., 2012).

The lived experiences of young people and the practitioner insights from across this thesis suggest a number of possible strategies that could be combined to develop a complex intervention within schools, affecting change across multiple different systems of the ecological model (Bronfenbrenner, 1979). For instance, the far-reaching effects of stigma due to children and young people being associated with parental substance use, mean that young people want direct promotion of their social and emotional wellbeing (microsystem); education linking how other people's substance use impacts on young people rather than only focusing on the impacts of young people's own substance use (mesosystem); building the skills of teachers and education practitioners to confidently identify and communicate with young people whose parents use substances (exosystem); and taking a poverty-informed approach across the whole school (macrosystem). Therefore, improvements across these multi-layered systems within a school setting, can potentially promote children and young people's resilience to the impacts of parental substance use (Liu et al., 2020).

### ***The social impacts of parental substance use are important***

Policies within the UK currently suggest that support for young people affected by parental substance use targets preventing or reducing the young person's own substance use (Home Office, 2022). Whilst this form of support is necessary, it does not consider young people's need for support addressing other impacts of parental substance use, including their social and emotional wellbeing (NICE, 2022). Whilst there were some participants who were currently engaging in their own risky levels of substance use and some who were not, neither spoke of the need for preventative approaches specifically targeting substance use amongst adolescents

or young adults. Rather, the young people in this study spoke of the need for early social and emotional support, which could subsequently prevent initiation or reduce use as well as also addressing feelings of loneliness and stigma (Horigian, Schmidt, & Feaster, 2021).

Despite their different ages and thus developmental periods (Arnett, 2010), young people across the qualitative research recounted similar experiences of parental substance use and support needs. The findings demonstrated the importance placed on the social impacts of parental substance use on children and young people, with them often reporting feeling alone in their experiences and going unnoticed. There were limited people within the family and external to the family that young people could trust and depend on, as well as them not knowing who they could turn to for support. Additionally, young peoples' feelings of loneliness could also become social isolation, wherein they were actively excluded and bullied by peers or received punishment for their externalised ways of coping, for instance being excluded from school for their own substance use. These findings are corroborated by two smaller qualitative reviews of the literature, one exploring the impacts of parental alcohol use only (Adamson & Templeton, 2012), and another which only looked at a small selection of UK based studies (Kroll, 2004). This finding therefore adds to the literature, showing that social impacts are pertinent to those whose parents use both alcohol and drugs, as well as cross-culturally as studies from across twenty countries were included in the systematic review within this thesis. Moreover, recent longitudinal research within a similar field found that feelings of loneliness and isolation during childhood and adolescence mediated the role between experiencing parental intimate partner violence and abuse, and young people's social and relationship problems in young adulthood (Barnes et al., 2022). Therefore, support that addresses these issues during childhood and adolescence may protect young people from longer term impacts.

Feelings of loneliness and subsequent social isolation were often reported to be exacerbated and driven by perceptions of stigma, shame, and discrimination due to children and young people being associated with parental substance use and a belief that they were not 'normal'. Such a belief that their families were not 'normal', and by association they were not 'normal', has been found amongst other young person populations who experience parental mental health problems (Haug Fjone, Ytterhus, & Almvik, 2009), and parental intimate partner violence and abuse (Arai et al., 2021). However, the concept of what is 'normal' has been criticised because it glosses over differences amongst individuals that have been structured and reproduced through histories of societal power and privilege, grounded in colonialism,



patriarchy, and ableism to name a few, making those who use substances and associated others to feel inferior and suppressed because of who they are as well as what they do (Tyler, 2018). Associative stigma and feelings of difference are nonetheless pertinent and prominent for young people who experience parental substance use, impacting their social wellbeing and resilience (Haverfield & Theiss, 2016). In a qualitative study, young people who experience parental intimate partner violence and abuse also reported to experience associative stigma with negative labelling and othering, leading to feelings of loneliness and isolation (Barnes et al., 2022). Needing to address such feelings of loneliness and isolation, as well as feelings of stigma and being misunderstood amongst children and young people whose parents use substances was a key finding from the qualitative fieldwork and prioritisation of intervention ideas. This finding is consistent with current UK policy to address loneliness amongst young people (HM Government, 2018), wherein the Department of Education set out compulsory guidance for primary and secondary schools to teach ‘relationships education’ which embedded loneliness in the curriculum (Department for Education, 2019). Whilst these are important national advances, there is limited evidence as to how to address loneliness within schools for young people who may be at increased risk of loneliness due to associated stigma (HM Government, 2018), for instance parental substance use.

### ***Addressing loneliness and isolation***

To address feelings of loneliness and isolation, young people and practitioners within the qualitative fieldwork reported that there was a need for resources within school that demonstrated that there were other children and young people who have experienced parental substance use, to ‘create connections’ amongst young people. Whilst addressing loneliness in the wider young person population is often effectively achieved through a group-based peer support format (DDCMS, 2023; Osborn, Weatherburn, & French, 2021), the qualitative fieldwork identified that this approach within a school environment could cause further risks for young people whose parents use substances as they may feel singled out from their peers, increasing stigma amongst these young people rather than decreasing it. Therefore, targeted group approaches within a school-setting with selected individuals deemed at-risk may not be the most effective approach within the context of parental substance use to create connections. This may also indicate why other school-based interventions in this population have not been successful, as they have utilised targeted group approaches (Bröning et al., 2012; Dore et al., 1999). Young people did however report the usefulness of forming and attending peer support groups within a community setting, implying that the setting and context of such an intervention may be important for effectiveness.

The qualitative fieldwork and prioritisation workshops from this doctoral work provide a possible strategy as to how to overcome this stigma whilst also increasing connection. The use of storybooks in primary school or animated videos in secondary school, depicting the experiences and social and emotional impacts of other children or young people whose parents use substances were highly prioritised. Whilst the young people who participated were not of primary school age, they reflected back on their desire for earlier approaches to address the hidden nature of parental substance use and to initiate conversations from an early age. Practitioners also shared this view. Storytelling has been found to be an effective way of delivering messages to children in an engaging manner that can encourage the sharing of problems and ideas (Bouchard, Gervais, Gagnier, & Loranger, 2013). Additionally, storybooks can demonstrate positive responses for dealing with a complex problem, by signalling to children what to do if they feel similar to the main character (Bouchard et al., 2013). Storybooks could therefore facilitate conversations between a child and a trusted adult within the school, as well as whole class discussions around bullying and talking to a safe adult, which could lead to enhanced social resilience (Tillott, Weatherby-Fell, Pearson, & Neumann, 2022).

An evaluation of a storybook resource for children experiencing parental alcohol use found that it improved teachers confidence to initiate and manage difficult conversations within the classroom and helped children feel less confused and guilty about their parents alcohol use (Morrison & Stinson, 2012), therefore providing improved support to vulnerable children within a school setting. The focus of this storybook was around the main character not blaming themselves for their parents' alcohol use. However, this resource is only available for schools within Scotland. Therefore, there is scope to develop additional storybooks that focus on other impacts of parental substance use, for instance loneliness, as well as encompassing parental drug use that may also prove effective within a primary school setting and fill a gap in support for young people in non-Scottish/English schools. Furthermore, a systematic review found that the use of cartoons, comic books, or pictures were also highly promising components of school-based interventions for adolescents who have experienced relationship violence, which like parental substance use can be stigmatising and fearful to disclose (Rizzo et al., 2022). Such resources, both within primary and secondary school, provide a fictional character to engage with at a safe distance. This could therefore be a less personal way to evoke conversations within a classroom setting without having self or peer disclosures and without being targeted as different. The discussions could focus on raising awareness of the impact of someone else's substance use, that there are other people in similar situations, and

signposting who to talk to within the school and other local services or resources. They would be universal across the class, rather than targeted to selected individuals. Moreover, they would provide opportunity for young people to openly talk about an often-taboo topic within the school, either without having to expose themselves or if they feel comfortable and safe to do so, they could self-disclose to a trusted adult. This would encourage positive coping and help-seeking behaviours and begin to reduce the stigma, loneliness, and hidden nature of living with parental substance use (Haverfield & Theiss, 2016).

For these strategies to work in the long-term, school engagement and commitment was deemed important, therefore they should be delivered by teachers at a class level rather than by an external agency (Pearson et al., 2015). Findings from a realist review on implementing health promotion programmes in schools found that concordance of the intervention with current practice and policy as well as consultations with key stakeholders during development helps to embed delivery into routine practice, builds on the staff-pupil relationships, and ensures responsibility is rooted within the school (Pearson et al., 2015). It has also been found that teachers want resources to support young people's mental health that could be easily adapted and used within the school environment (Shelemy, Harvey, & Waite, 2019). Implementing the storybook or animated video in ways that align with the national curriculum on relationships education and possibly linking targets for loneliness across multiple areas of the curriculum for both primary and secondary schools, including across 'mental wellbeing' and 'drugs, alcohol, and tobacco' (Department for Education, 2019) could therefore facilitate the acceptability and feasibility of delivering such resources.

### ***Training of teachers***

Alongside resources for young people within schools, training of practitioners, especially teachers, was also prioritised by both young people and practitioners. Many practitioners identified that across different child and adult services as well as education, practitioners are ill-equipped to respond to the needs of children and young people whose parents use substances. Yet, teachers are often cited as an important source of early help and validation for children and young people when disclosing cases of abuse or family problems (Schols, de Ruiter, & Öry, 2013; S. Walsh, 2006). In the qualitative findings, young people often sought help from teachers at times of crisis rather than early help-seeking. Building trust from as early as possible was an important factor throughout the qualitative findings in establishing safe people who young people could confide in. Research demonstrates that identifying and developing safe and trusted relationships with adults can help overcome the impacts of

parental substance use on young people and is linked to resilience (Merrick et al., 2017; Park & Schepp, 2015; Wlodarczyk et al., 2017). However, such a delay in reaching out for support was often due to feelings of distrust in education practitioners, based on fear that young people may be discriminated against, worry there may be children's social care involvement, a lack of open communication within the school about issues of parental substance use, and feeling like teachers do not understand their experiences. A lack of trust in practitioners and teachers is a common feeling amongst other similar young person populations who experience family adversities (Arai et al., 2021; Barnes et al., 2022; Yamamoto & Keogh, 2018). Whilst the resources identified previously, including developing a storybook and animated video, can create an open dialogue between young people and education practitioners, specialised training, developed with the voice of the young person at the centre, is also important to promote practitioners' confidence in identifying and supporting young people whose parents use substances. Relational practice principles could be a useful concept, which is about building an understanding of children and young people's lived experience; establishing trust-based and respectful relationships; as well supporting young people to be at the centre of decision-making processes, which is increasingly seen in social care work (Ferguson et al., 2022; Munford, 2022), but could be adapted to be utilised in training for teachers and education practitioners within this context. Similar relationship-building practices can also be seen within trauma-informed care, whereby any professional presumes all those they encounter have experienced trauma in some way and at some point, enabling supportive, nurturing, and non-stigmatising relationships from the onset (Goddard, 2021). Key principles include developing safety and trust, and allowing choice, collaboration, and empowerment (SAMHSA, 2014), similar to themes found across this thesis. Such relationship-building practices and trauma-informed responses could therefore be implemented within training for teachers when providing early support to children and young people whose parents use substances. Young people felt it was important that practitioners and especially teachers knew what it was like for young people living with parental substance use, which could make encounters with practitioners or teachers feel safer and less stigmatising, as well as helping to build trust.

Within the literature, using substances, offending, or self-harming tend to demonstrate that a young person is not resilient (Velleman & Templeton, 2016). Yet, the qualitative findings demonstrated that young people may exhibit externalising behaviours when trying to cope with parental substance use. Not all young people have equal choice or resources to access support and therefore their agency and ways of coping can be impeded by external factors

such as their social position (Tyler, 2020; Tyler & Slater, 2018). Substance use or other similar behaviours could therefore indicate attempts of young people to find ways to navigate an unequal society, yet their behaviours were often misunderstood by teachers and practitioners who saw them as disruptive and needing to be excluded or punished. To further add to this, young people can move from a position where they receive associative stigma or family stigma (Mehta & Farina, 1988; Park & Park, 2014) due to closeness with their parent's substance use when younger to being directly stigmatised for their own survival strategies and behaviours when older, especially from those who were in a position to help, and without recognition of their lived experience and trauma. Similar findings have been reported in children of incarcerated parents (Kotova, 2020). Those young people who are seen in practice and policy as "risky" (Bancroft & Wilson, 2007), due to their own substance use or offending may be trying to cope with the impacts of parental substance use and adapt to their environments, but because their form of coping is also stigmatised, they are likely to experience discriminatory interactions and further negative outcomes. Relatedly, for children and young people who have experience of parental intimate partner violence and abuse, practitioners and teachers may view their externalising behaviours as problematic and an issue with the young person rather than as a contextualised response to their experiences that need support (Callaghan, Fellin, Alexander, Mavrou, & Papathanasiou, 2017). In recent years across the UK, there has been an increase in the number of young people excluded from secondary schools (Department for Education, 2018a) possibly reflecting difficulties schools have with managing behavioural problems that have underlying and often ignored causes (Shelemy et al., 2019). Young people's underlying emotional and social support needs may be overlooked in favour of only addressing their behaviours, leaving young people feeling further isolated. Specialised training for teachers and practitioners could help raise awareness of the role externalised behaviours may have for some young people and highlight how discriminatory behaviours within their own practice towards young people who externalise their behaviours can stigmatise and isolate young people further.

Moreover, doing well at school and academic achievement is often viewed as a protective and resilient factor for young people who experience parental substance use (Velleman & Templeton, 2016), however this may not always be the case. Experiences and perceptions of stigma, especially from peers and practitioners within the school environment, led to some young people trying to change and adapt their behaviours to fit in, resist being labelled as a 'problem child', and avoid being discriminated against. Whilst this had social benefits in the short term, young people often felt more alone and unsupported in the long term, with some

experiencing their own substance use problems or mental health difficulties later on. This is an important finding within this thesis and adds to the existing knowledge base, as it demonstrates that there can be support needs within a group of young people who are typically viewed as resilient and achieving well at school. These behaviours reflect an understanding by young people of what society thinks and condemns of those who use substances and consequently those who are associated with them (Muir, McGovern, et al., 2022). Within the United Kingdom, the construction and labelling of some families and young people as ‘troubled’ due, in part, to substance use has been driven by government policies, national programmes, and media depictions, many of which have propagated stigma towards families and young people (Cameron, 2011; Goldson & Muncie, 2015). If young people act like a ‘good’ child, then they may not become noticed for the parts of their identity they think would be perceived as shameful, but this can make it harder for practitioners or teachers to identify them as needing support (Barnes et al., 2022). Specialised training for teachers and practitioners could therefore help raise awareness of these forms of coping amongst young people and help teachers to understand that there are young people who may need additional support who seem to be doing fine. Similar recommendations for training were reported for teachers where young people may mask mental health problems (Shelemy et al., 2019). However, it is important to note that there are still issues around actually identifying those who would then need additional support. Therefore, this finding also provides further support for a more universal approach to intervening within the school environment, rather than targeted, to ensure a wider range of ‘hidden’ and isolated young people are supported.

### ***Poverty-informed schools***

Children and young people who grow up experiencing poverty and deprivation are more likely to be exposed to a number of other adverse childhood experiences, such as parental substance use, compared with their more socially and economically advantaged peers (Marmot, Allen, Boyce, Goldblatt, & Morrison, 2020). A social gradient has been found in the experience of parental substance use, as well as other adverse childhood experiences related to deprivation (M. Allen & Donkin, 2015). Findings from both the qualitative systematic review and qualitative fieldwork identified that the social and emotional impacts of parental substance use were often compounded for those from socio-economic disadvantaged areas. They tended to experience heightened feelings of loneliness, shame, stigma, and discrimination, which has also been found in similar young person populations including parental domestic violence and abuse (Holt, Buckley, & Whelan, 2008) and parental mental

health (Reupert et al., 2021). Young people experienced discrimination by both peers and teachers for not having the right uniform, equipment, or fees for school trips as well as for receiving free school meals, which could impact on externalised behaviours as well as low attendance. Whilst interventions to address poverty, including income supplementation, are important and discussed in section 6.2.3, schools could also benefit from incorporating a poverty-informed approach to their policies.

To be ‘poverty-informed’ means viewing practices within the school through the lens of poverty (Mazzoli-Smith & Todd, 2016), and with this doctoral work, how poverty and parental substance use can compound one another and make it more difficult for some young people to show up and learn within school. This approach could address the social impacts of poverty and linked parental substance use across the school day, whereby similar approaches have aimed to reduce the stigma and shame experienced by families and young people where they have compounding adversities (Atkins, Cappella, Shernoff, Mehta, & Gustafson, 2017; Cappella, Frazier, Atkins, Schoenwald, & Glisson, 2008). Whole school approaches and teachers showing understanding and being sensitive to how these forms of adversity may impact on the school day, including across attendance, attainment, and young people’s behaviour, can help children and young people feel understood and less alone or stigmatised, removing the barriers to learning and feeling safe at school. An evaluation of a whole-school based approach to tackling poverty within the North East of England, termed ‘poverty proofing the school day’ found significant impacts to school culture and ethos and evidence of direct positive impacts on young people’s attendance and attainment (Mazzoli-Smith & Todd, 2016).

Taking a school-based approach to supporting young people whose parents use substances, by addressing feelings of loneliness, isolation, and stigma, could therefore incorporate poverty-informed policies and practices within the school, awareness of impacts into teacher training, alongside direct resources to be used in classrooms to promote social and emotional wellbeing amongst children and young people.

### ***6.2.2 A direct approach to supporting young people***

#### ***Problems with current support***

Findings from across this doctoral research demonstrate that young people whose parents use substances want direct support in their own right, yet research has highlighted that young people are often provided with indirect support, focusing on reducing risk to young people via

promoting changes in parental substance use (McGovern, Newham, et al., 2021) or affecting change at a family level (Calhoun et al., 2015; Templeton et al., 2010). Enduring impacts of parental substance use have been found in a recent meta-analysis of longitudinal studies exploring outcomes for children aged up to 18 years (Kuppens, Moore, Gross, Lowthian, & Siddaway, 2020). The qualitative findings also demonstrated that the emotional and social impacts of parental substance use can endure for children and young people even after a reduction in risk, and that young people were not always supported with these impacts at a time that was beneficial for them. Moreover, the unpredictability in parental substance use and young people's familial relationships had emotional and social impacts on children and young people in the absence of abuse or wider safeguarding concerns, demonstrating that direct support for children and young people was also needed earlier, outside of the context of children's social care and child protection. Findings from the priority-setting study identified that whilst parental support to reduce substance use was welcomed, it should not be done without also supporting the young person's own wellbeing and it should not be provided as a pre-requisite for supporting the young person.

Furthermore, the findings from the qualitative fieldwork demonstrated that whole family support can at times feel unsafe and unhelpful for young people. Some young people both feared potential and had experienced actual repercussions from their parent after talking to a practitioner about their parent's substance use. Fear of subsequent punishment may constrain young people from fully engaging in the support, resulting in their needs not being met and their voices being silenced. Whole family approaches are often encouraged within practice where there is parental substance use, due to the interrelated nature of a family's needs, and have been found to effectively address parental substance use and the impacts on children, (Early Intervention Foundation, 2022; Woodman, Simon, Hauari, & Gilbert, 2020). However, it is important that practitioners ensure that the young person feels safe within whole family support foremost by listening to their voices, separately from the family. A systematic review on family-based interventions identified that to effectively address parental substance use, as well as parental mental health and domestic violence and abuse, family focused interventions need to be redesigned to recognise and work with the whole family appropriately and effectively (Allen et al., 2022). A recent qualitative study with young people who had received family support, called for a shift in family services towards "protection with participation to incorporate the voices of children as an everyday practice" as young people had experienced their needs not being listened to, met, or valued (Stafford, Harkin, Rolfe, Burton, & Morley, 2021, p. 13). Not only could this approach keep young people safe by



involving young people in the decisions about whole family support and when it is appropriate, but it could also promote benefits to young people's wellbeing including enhancing their agency (Erwin et al., 2016; van Bijleveld, Bunders-Aelen, & Dedding, 2020). Some young people also felt confidentiality was broken in practitioners' communication between children and parents who accessed the same service but had separate sessions. In such instances, misunderstandings ensued, conflict between family members increased, which impacted negatively on the outcomes for the young people, who may then disengage from support. Similarly, findings from the priority-setting study identified that whole family support was one of the least prioritised and least acceptable intervention ideas for young people, mainly due to safety. In support, a recent evaluation of a service targeted towards families where there was identified parental alcohol use found that an area of concern for some young people was the practitioners management of confidentiality within a whole family approach (Alderson, Mayrhofer, Smart, Muir, & McGovern, 2021). Where confidentiality was not met, this impacted families' feelings of safety and subsequently engagement within the service. Recent evidence for the involvement of family members in support has also reported that it is not cost effective or acceptable for children whose parents use substances (NICE, 2017). There is an increased need to put the young person's voice at the centre of support to determine whether whole family support would be safe and helpful. Only focusing on interventions that remove risk or support the whole family, neglects how the child or young person is feeling and their need for safety, ignores their already developed strengths, and may lead to worsening of emotional and social outcomes if not directly supported in their own right.

### ***Recognising agency***

Most of the included studies within the qualitative systematic review positioned and described young people as vulnerable or passively coping with parental substance use, with notable exceptions (Bancroft et al., 2004; Hagström & Forinder, 2019). This consistent positioning within the literature does not recognise young people's agency and attempts to change, control, and resist their experiences or impacts (Callaghan, Fellin, Alexander, et al., 2017). This means that when supporting young people, practitioners could be failing to make use of, and account for existing adaptive coping strategies that young people adopt. A key finding from this doctoral research is that children and young people whose parents use substances expressed agency and resistance in dealing with and managing their experiences of parental substance use from a young age (as young as four within the included review studies) and continued to do so throughout adolescence and young adulthood, regardless of resilient

outcomes. Whilst their strategies could sometimes pose risks to young people or be constrained by wider influences, these strategies tended to provide young people with a sense of empowerment and a way to navigate their family lives that helped them to in part ‘control the uncontrollable’. They were negotiating the boundary between safety and risk, with context-specific expertise, therefore demonstrating young people’s resistance as acts of edgework (Lyng, 1990).

Within a similar field, Arai et al. (2021) conducted a qualitative systematic review of children’s experiences of intimate partner violence and abuse and found comparable themes on children’s agency and coping, whereby children found creative and meaningful ways to change their situations to protect themselves and others, irrespective of resilient outcomes. Researchers within the field of intimate partner violence and abuse have argued that interventions should focus on supporting young people by enhancing the strengths they have developed due to living with violence and abuse and to recognise their need for agency (Fellin et al., 2019). Therefore, agency enhancing interventions may be a useful direct approach to supporting young people whose parents use substances. Young people within this thesis described engaging in and benefiting from support that offered them choices and allowed them to define what safety meant for them, creating a sense of empowerment. The opposite was also true, wherein young people disengaged from support that did not offer them choices, empowerment or had a restricted view of what support would be useful.

### ***Building agency***

There are different ways to build and enhance agency amongst young people who experience family adversities, for instance through increasing young people’s participation in decision making about support (van Bijleveld et al., 2020), to peer group-based approaches (Callaghan, Fellin, & Alexander, 2019). The latter was a community approach built on the strengths and skills that young people had developed during their experiences of parental intimate partner violence and abuse, including strategies to build a sense of safety, develop trust in themselves and others, and build positive self-identity. One way that was suggested and somewhat highly prioritised as providing opportunity for agency within support for those whose parents use substances was by developing digital interventions that allowed young people to choose what content they wanted to engage with, when they wanted to access it, and how they wanted to speak to a practitioner. This was felt to be especially important for adolescents and young adults whose needs were often missed in current support. A review of the literature around developing mental health interventions for young people found that providing a tailored

experience, through having customisable features on a digital intervention, can promote a sense of agency amongst young people (Achilles et al., 2020). Within the qualitative fieldwork, many young people and practitioners felt that there was currently a lack of digital interventions available for young people whose parents use substances, which is reflected in available interventions for young people (McGovern, Smart, et al., 2021), where only one computer-based self-help intervention was identified (Gustafson, McTavish, Schubert, & Johnson, 2012). It was discussed that digital interventions could include and combine content specific to parental substance use, but to primarily focus on building young people's strengths, including activities for addressing emotional wellbeing, opportunities for social connection with peers in similar situations, and text support with a practitioner. Having a variety of options within one digital resource was thought to help empower young people to access the support they would need in any given moment.

Digital interventions and tools are becoming popular approaches to address a range of health and wellbeing objectives for adolescents and young adults, as well as a strategy to address the shortcomings within the health and social care system such as a lack of access to in person support (WHO, 2019b). Some of the main barriers to accessing support for young people within the qualitative findings included, not having or knowing about formal support options in their local area; not having access to formal support during times of highest need for instance during the evenings; long wait lists and referral times; and fear of disclosing to someone due to feelings of shame and stigma, which could be heightened when face-to-face. Digital interventions and online support can be accessible regardless of time and geographical location, opening up opportunities for young people to engage in support in a flexible manner (Griffiths, 2017). Digital interventions are therefore especially advantageous when there is currently a 'postcode lottery' to support across the country due to a lack of national policy and a lack of requirements to provide wellbeing support directly to young people whose parents use substances (POST, 2018). Additionally, in a recent systematic review, the anonymity and privacy provided to young people who seek mental health support digitally was a key benefit to online interventions, as well as affording young people a greater sense of control over their help-seeking journey (Pretorius, Chambers, & Coyle, 2019). Anonymity of online support was also found to ease young people's fear of stigma and shame, as they did not have to speak directly to a practitioner, affording a safer and less threatening approach to accessing support initially (Haner & Pepler, 2016; Pretorius et al., 2019). An example of a UK based online mental wellbeing service is Kooth, which is available for young people aged 11-25 years, allowing young people to chat with an experienced practitioner online (Prescott, Hanley, &

Ujhelyi, 2017). A small evaluation study found that Kooth provided an anonymous and controlled online place to disclose feelings and provided an accessible way to access support for young people (Hanley, 2009). Developing a digital intervention specifically with content and modules for those whose parents use substances alongside chat support with a practitioner, could offer a viable way to empower young people, particularly adolescents and young adults (Hollis et al., 2017), to take the first steps into seeking formal support. This would allow them to tailor the content to their specific needs and overcomes the barriers of limited access to direct support across the country.

However, what may be a concern is that research has shown that lower-income families can experience greater digital exclusion, including slower internet, having to share devices, or being disconnected due to missed payments (Enyioha & Cotman, 2021; V. S. Katz, 2017). There are often differences in how, not if, young people access the internet and use technology (George et al., 2020), but for instance sharing devices can be problematic if a young person needs to use a device privately, especially for young people whose parents use substances. A recent systematic review identified that digital mental health interventions can be a promising option for addressing the wellbeing needs of socio-economically and digitally marginalised young people, although the current evidence base was limited (Piers, Williams, & Sharpe, 2023). The authors recommended that researchers should include and engage with those most at risk of being digitally excluded (e.g., from lower socio-economic families) if and when co-designing digital interventions to promote wellbeing, ensuring access could be feasible and acceptable. There was acknowledgement by both young people and practitioners within the prioritisation study, that digital interventions may widen disparities amongst young people due to digital exclusion and digital inequality and therefore were prioritised lower than school-based approaches due to possible issues with equity. Further exploration would be needed to determine whether digital interventions could be a viable option within this population.

### **6.2.3 *Macrosystem changes***

Making improvements to young people's 'external resilience' by creating resilient systems surrounding young people could promote positive coping pursuits and resilience amongst young people whose parents use substances, as inferred by Liu et al. (2020) multi-system model of resilience. The qualitative fieldwork identified that the current macrosystem (e.g., cultural, and societal context) that children and young people are in has impacted on and compounded their experiences of parental substance use, including austerity measures

implemented by the government impacting on the support available for young people. Practitioners reported minimal recognition and investment into children of parents who use substances, with cuts to services, as well as reduced links between children and adult services. Practitioners discussed how this affected their work, with job insecurity and heavy caseloads, impacting their capacity to build ongoing and meaningful relationships with young people that young people expressed was important. Young people can perceive such limited practitioner capacity as a lack of genuine care from practitioners, which can contribute to increased feelings of rejection, lack of trust and the want to disengage from formal support (Brown, Alderson, Kaner, McGovern, & Lingam, 2019), yet practitioners were navigating a system that was receiving funding cuts and low prioritisation by government.

Taking the UK as an example, mental health and social care services have been historically underfunded during a time when the need for these services is increasing (Cooper & Whyte, 2017; Stuckler & Basu, 2013). For children and young people's services between 2010/2011 and 2017/2018, there was a 29% reduction in funding, equating to a decrease of £3 billion spent on supporting families in need (Britton, Farquharson, & Sibieta, 2019). These support services, when they thrived, generally benefitted disadvantaged children the most, but with cuts to funding, there is a disparate impact on young people from different socio-economic backgrounds (OECD Family database, 2019). Spending on children and young people's services in the most deprived local authorities has fallen almost five times faster than in the least deprived local authorities (OECD Family database, 2019). Additionally, there have been funding cuts to primary, secondary, and tertiary education, further impacting young people's access to support (Britton et al., 2019). Whilst recently there has been the 'largest ever increase in funding for drug treatment', which would include treatment for those who are parents, this has come at the same time as the Department for Health and Social Care confirmed a funding cut of £6 million for support specifically targeted at children of parents who use alcohol (Home Office, 2022). However, as this thesis demonstrates, young people report needing support in their own right alongside treatment for their parents to reduce substance use. Therefore, there is a need for changes across government investment, increasing spending for services directly for young people in their own right. Additionally, innovative strategies are needed that can address the social and emotional impacts of parental substance use on young people, accounting for a lack of funding and investment within the macrosystem.

Childhood adversities are commonly known to both cooccur and cluster with one another (Lacey, Howe, Kelly-Irving, Bartley, & Kelly, 2022; Lanier, Maguire-Jack, Lombardi, Frey, & Rose, 2018), with growing evidence that poverty is a reinforcing factor in the clustering and accumulation of adversity (Bywaters, Skinner, Cooper, Kennedy, & Malik, 2022; Lacey et al., 2022; D. Walsh, McCartney, Smith, & Armour, 2019). The qualitative findings demonstrated that children and young people experienced a clustering of adversities including parental mental health problems and intimate partner violence and abuse, as well as compounded impacts from experiences of socio-economic disadvantage or poverty. Adjei et al. (2022) demonstrated that parental mental health problems, as well as parental substance use to a lesser extent, interact with poverty, a structural risk factor, across childhood developmental stages with negative impacts on health outcomes and behaviour in later life. A systematic review of reviews exploring how to respond to the complex and interconnected issues experienced by vulnerable families identified that there were limited interventions that have addressed structural changes to promote wellbeing amongst young people, however those that have, show promising findings (Barrett et al., 2023). Interventions including income supplementation and welfare reform were found to reduce a variety of adverse childhood experiences and their impacts (Courtin, Allchin, Ding, & Layte, 2019; Marie-Mitchell & Kostolansky, 2019) yet support services and interventions rarely engage with the impact of income, employment, and housing conditions on families (Bywaters et al., 2022). Policies and interventions should therefore seek to address childhood socio-economic conditions such as poverty to ameliorate outcomes in children with experience of multiple adversities, including parental substance use. Such improvements could begin to mitigate some of the risks posed by parental substance use, including the exacerbated stigma experienced by young people who were also in socio-economically disadvantaged families. These would complement the development of child- and young person-focused interventions that address the enduring emotional and social impacts of parental substance use.

## **6.3 Strengths and Limitations**

### **6.3.1 Approach**

This research has built upon the current evidence base drawn from a wide range of countries regarding children and young people's experiences of parental substance use and their support needs. The selection of theories to aid my understanding was guided by the involvement of public and practice advisors, the qualitative systematic review findings, and the developing themes from the qualitative data, resulting in drawing upon aspects of multiple theories. This

approach ensured that my understanding reflected the pertinent issues of young people and practitioners. This research was primarily guided by the overarching theory of ecological systems theory (Bronfenbrenner, 1979, 1986) that has been applied to identify which changes across the system could address some of the underlying issues of parental substance use (e.g. loneliness and stigma), and to promote young people's resilience and wellbeing, rather than focusing only on the family system to affect change (Rothbaum et al., 2002). My findings contribute to the area of health promotion and prevention for young people whose parents use substances, identifying that young people and practitioners want early and consistent support for young people's emotional and social wellbeing. The underlying mechanisms of acceptable support included creating connections amongst young people whose parents use substances, raising awareness and understanding amongst others, and empowering young people through allowing for flexibility and personalisation. These approaches could address feelings of loneliness and social isolation, as well as associated stigma and shame, and promote and build upon young people's agency and strengths.

My findings have identified that children and young people feel a need for direct support in their own right, and that school-based programmes, across both primary and secondary school, as well as digital interventions could be acceptable and feasible approaches to address social and emotional wellbeing amongst young people. These interventions can span and target those across a range of ages from early childhood (primary school) to young adulthood (digital). Such interventions can also overcome structural barriers identified across the country, including inconsistent access to and funding of support directly for young people whose parents use substances (POST, 2018). However, there is a need for changes across multiple systems as direct interventions may not be enough, with initiatives to address poverty being especially important, as socio-economic deprivation can compound the experiences of loneliness and stigma for young people whose parents use substances.

This doctoral research has been grounded in a qualitative and co-production approach that has centralised the voices of children and young people whose parents use substances, an often hidden or silenced group. I took a young person focused approach to defining at what level of parental substance use impacted on young people, as it was based on their interpretation of harm and impact and not specific thresholds. Majority of the studies included in the qualitative systematic review recruited young people from adult treatment services therefore parents were likely to have dependent levels of substance use and were receptive to support. Whereas within the qualitative fieldwork, young people were recruited from young person

focused services and most young people reported that their parents had never received treatment. It is likely that some of these young people could have experienced non-dependent but risky levels of parental substance use as well as parents who were less receptive to support. The principles of co-production were applied to the approach taken to conducting this research, with lived experience experts and practice advisors being involved and engaged at each stage from as early as possible, including conceptualisation of research questions, development of methods and materials, data synthesis and analysis, prioritisation of interventions ideas, and dissemination of findings (Involve, 2016, 2018). Utilising a co-production approach to this research may have helped to develop findings that have the most potential to benefit young people whose parents use substances (Involve, 2018), and as it was used in the early development of interventions it may also likely lead to interventions that are acceptable and relevant to the young people it seeks to benefit (O'Cathain et al., 2019).

There have also been limitations and challenges to the co-production approach, including the COVID-19 pandemic impacting upon planned public involvement activities and the relationships I had developed with young people prior to the pandemic. Throughout the research I also had to take a pragmatic approach to the involvement of young people and practitioners as there was no clear and explicit guidance on how to integrate involvement and engagement activities within different elements of the qualitative research. For example, there was no guidance on how to incorporate involvement activities within the qualitative thematic synthesis (Thomas & Harden, 2008). Therefore, there is a need for either further iterations of this method which includes details of public and practice involvement or a specific paper documenting how such activities can contribute to qualitative systematic reviews, which could be similar to a paper written for stakeholder participation in systematic reviews of complex interventions (Harris, Croot, Thompson, & Springett, 2016). The management of relationships across both public and practice partners also took time and effort to establish and build trust and rapport. Trying to organise times when all young people could meet could be challenging and it was important to be flexible and adaptive to changing plans last minute. The time constraints on practitioners meant I often met with them separately, which was beneficial when needing specific tasks completing but difficult when I wanted to explore and understand different perspectives, for instance on how to approach services. These challenges are similar to ones published in an article discussing the 'dark side of co-production' (Oliver, Kothari, & Mays, 2019). Nevertheless, this research has provided the young people who were involved with opportunities to develop new skills through training, being involved in a group,



writing papers, and presenting at seminars, as well as empowering them, with a member of the YPAG reflecting:

*“It has been an absolute honour to be involved as part of this project. To use my ‘negative’ life experience and be able to turn it into a positive impact for other children like me in the future: to help speak for those who feel they don’t have a voice and aren’t seen by people around them in the position they are in.”*

The specific strengths and limitations relating to the methods of each of the components within this thesis will now be discussed.

### **6.3.2 Qualitative systematic review**

This is the first comprehensive systematic review combining qualitative literature to understand the lives of children and young people that have experienced both parental alcohol and drug use. The approach taken and synthesis of findings were informed by both young people with lived experience and practitioners within the field, who helped identify important areas to explore within the data (e.g., stigma and agency) that were relevant to the population. I undertook a rigorous approach to the methodology and review process. This included developing a robust search strategy that allowed for a balance between specificity and sensitivity. The review was not limited by language or country, as studies were translated ensuring the inclusion of a broad range of studies. This was also highlighted as a strength during the peer-review process of publication wherein I was acknowledged for identifying important but lesser-known studies within the field. I took additional steps to ensure the review process was robust, including dual screening, extraction, and quality appraisal. I also rated the included studies based on relevance and quality to allow for a form of sensitivity analysis where I gradually added in lower rated studies to the synthesis, which often had conceptually thin data.

The review drew on multiple qualitative studies, from a range of different countries, ethnicities, and ages, with mostly comparable and similar findings across different contexts, which is important for practice and policy implications globally and nationally. Four of the main differences identified across the included studies were that, (1) being associated with parental drug use was seen as more stigmatising than parental alcohol use which increased the social impacts experienced by young people; (2) siblings were often impacted differently depending on their birth order and age; (3) being from a culture that placed emphasis and

social norm on young people to support their aging parents (e.g., collectivist societies) found it harder to express agency in their familial relationships; and (4) being from a lower socio-economic background compounded the social impacts and stigma experiences for young people. These differences highlight important implications for developing support for young people, for instance ensuring young people whose parents use drugs are included in approaches tackling loneliness or social impacts, as currently support tends to focus on the needs of children whose parents use alcohol rather than those of parental drug use (Children's Commissioner's Office, 2018). By synthesising studies across different cultural and social contexts, the presented findings should be applicable beyond individual study populations and provide a breadth of understanding of children and young people's lived experiences. The qualitative systematic review process and findings fed into the design of my qualitative fieldwork and analysis of the generated data to further my insight into the topic.

Several limitations should be acknowledged in interpreting the findings. The qualitative review was limited to quotes that were selected for inclusion in the original studies that represent the authors' interpretations, so may not be fully inclusive of all perspectives. Included studies tended to report on the negative experiences and impacts, with only minor acknowledgement that not all children and young people experienced abuse and neglect. This is important to counter judgmental stereotyping and stigma towards parents who use substances, since not all parents who use substances become violent and abusive towards their children. Nevertheless, I found that the unpredictability in parental substance use and relationships can have emotional and social impacts on children and young people in the absence of such abuse.

There was also limited ethnic diversity across the included studies, with majority focusing on White or Caucasian samples. Whilst some studies did explore the experiences specifically of young people from ethnic minority backgrounds, only one of these studies was conducted within the UK (Ahuja et al., 2003). Extrapolation of the findings across ethnicities may therefore be problematic, especially as those from minority ethnicities can experience increased discrimination and poorer outcomes (Hackett, Ronaldson, Bhui, Steptoe, & Jackson, 2020). Furthermore, a related potential limitation to this study is the synthesising of findings from multiple countries and across different timeframes. For example, the USA, UK, and Asian health and social care systems are inherently different and provide different support to children and young people whose parents use substances. Likewise, policy and practice contexts have changed over the past three decades of which these studies cover. This poses

challenges in terms of the potential impact of contextual factors within studies on individual experiences that may not be relevant to policy and practice within England today.

Children and young people were defined up to the ages of 25 for this thesis, however some studies included those older (up to the age of 30). This raises issues of retrospective accounts and recall bias, as well as viewing experiences through a young adult-lens that can alter how childhood experiences are interpreted (Gil-González, Vives-Cases, Ruiz, Carrasco-Portiño, & Álvarez-Dardet, 2007). Where I could and the authors had distinguished between participants or experiences based on age, I prioritised the accounts of those aged under 25 years. However, as explored in the findings, differences in experiences based on age were often due to sibling birth order and the roles young people then took on in their families.

Additionally, the findings representativeness of different populations was dependent upon the samples of included studies. Most children and young people who were recruited into the studies were already known to social services with most studies also focusing recruitment of young people from adult treatment services. Therefore, the review only marginally captured the voices of those who had not had any support and it is likely that the views of those who experience lower non-dependent levels of parental substance use were also missed. Young people were also less often recruited through direct means that did not go through their parents first, and therefore it is likely that those young people who took part had parents who were receptive to support for their children. Likewise, authors of the included studies often presented limitations in terms of difficulty gaining parental consent for young people to participate. It is also possible that study samples consisted of individuals who were more open to discussing their experiences due to active involvement in services, and therefore those who had experienced deeper stigma, disappointment, and shame with services may not have participated due to a lack of trust.

### **6.3.3 *Qualitative fieldwork***

As this study aimed to explore the support needs of young people whose parents use substances and what interventions were needed the views of both young people with lived experience and practitioners who provide support have been explored. Including the practitioners' views was not based on validation of the young people's experiences but to add richness to the study and to aid understanding of contextual factors outside of the young person's immediate microsystem. This allowed for a broader understanding of what was viewed as important by both those who would receive an intervention and those who could

possibly deliver it. It also enabled a deeper understanding on the issues with support, through comparing and contrasting their accounts, enabling an ecological view of support needs across different systems that can be applicable to developing policy and practice recommendations (Eriksson, Ghazinour, & Hammarström, 2018).

Within this piece of research, I tried to counter some of the recruitment limitations of the included studies within the review by recruiting young people from services who directly support young people without the need for accessing young people through adult treatment services. I also applied for and was granted ethical approval for including those aged 14 and 15 years as being able to provide informed consent for themselves, instead of the commonly used 16 years and above (Medical Research Council, 2004), which supported the inclusion of young people in their own right. However, the young people who participated had received some form of support and therefore their experiences may differ from those who have never received support. Due to the known difficulties and barriers to accessing support for young people whose parents use substances, including fear and stigma, this can also extend to recruiting such 'hidden' young people into research. Further work is needed, utilising the knowledge and skills of both those with lived experience and professional expertise, to develop research strategies for identifying young people who have not had support. This would need to be a sensitive approach, addressing safeguarding concerns and possible stigma experiences. Working with young peer researchers could be one possible solution (Page, Cense, & van Reeuwijk, 2023).

Additionally, when speaking to gatekeepers I tried to communicate that they should not target individuals they deemed as 'resilient' for the interviews but provide opportunity for all young people from across their service to learn about the study and participate if they would like to. On the whole this was achieved well but there were limitations with using gatekeepers as the primary source of recruitment, as I did not have full input on who was approached. Whilst gatekeepers were briefed on the inclusion and exclusion criteria, there were some misunderstandings, as some young people who were approached were not eligible for the study, however this was noticed prior to arranging interviews. Some gatekeepers also acknowledged their own biases in initially approaching young people who they thought would provide detailed accounts and who had made good progress with support. With open discussion, these biases were often addressed, and there was increased inclusion within this study of young people who practitioners may not have deemed as resilient e.g., those who were currently using substances themselves. Furthermore, a lot of the services I contacted did

not have capacity to aid recruitment of young people because of the pandemic, this was especially the case for more universal children's services that did not already support young people for parental substance use. Children's social care and schools were also working to capacity, prioritising safety of families and education of children during the pandemic rather than inclusivity in research.

The results from the qualitative fieldwork with young people are limited to those who chose to take part. I am unaware of how many young people were approached by gatekeepers who chose not to take part. However, there were seven young people who chose not to take part after giving initial consent to contact. These young people who chose not to participate, may differ in regard to their support needs and experiences of support compared to those who chose to take part. Likewise, the COVID-19 pandemic may have impacted upon those who would have wanted to take part, with issues during this time including housing instability, increased severity of parental substance use, feeling unable to discuss parental substance use whilst at home, and issues with accessibility (Adfam, 2020). To address accessibility issues, I worked closely with gatekeepers to ensure those young people who did not have the means or a safe means to participate could take part if they wanted to. There was only one instance where this was the case, wherein the gatekeeper facilitated the young person's access by providing a laptop for the young person during school hours rather than when they were at home. This young person also chose to have the gatekeeper present during the interview.

Populations which proved difficult to recruit from included black, Asian, and minority ethnic groups, consistent with the included studies from the qualitative systematic review. Despite specific efforts to recruit those from a diverse ethnic sample, only three (out of twenty-one) took part in the study. When approaching services, a common finding was that they did not support many, if any, young people from diverse ethnic backgrounds. This may signify a larger issue within the field of young people's social and health support, particularly parental substance use support, in which those who are from diverse ethnic backgrounds may be underrepresented in support. Like limitations with the systematic review, there is a lack of representation in the qualitative fieldwork findings of young people from minority ethnicities who experience parental substance use. The applicability of the findings and identified interventions to more ethnically diverse populations may therefore be limited. This raises important questions for research, whether young people from different ethnicities know about services and support for parental substance use, whether they feel more stigmatised to access support, whether there are other barriers and facilitators to accessing support, and whether

current support is inclusive. This also demonstrates the need to improve and develop strategies to increase the involvement of young people from ethnic minorities in research to understand their participation needs and how to engage them in research in order to develop acceptable support (Powell et al., 2021; Waheed, Hughes-Morley, Woodham, Allen, & Bower, 2015). For instance, minority ethnic young people could be involved in the design of study methods and recruitment procedures and materials to ensure they are sensitive to different cultural beliefs (Babla, Akindolie, & Gupta, 2021) as well as researchers building relationships with community organisations that work specifically with those from minority ethnic communities to facilitate engagement with young people (Powell et al., 2021).

The measure of socio-economic status within this fieldwork was limited. Area measures were adopted that reflected the accumulative socio-economic properties of an individual's postcode, through the English indices of deprivation. This provided an indicator of the level of deprivation or affluence within the young people's local environment (Clelland & Hill, 2019). However, young people within this study experienced transience in their living situations, with some young people temporarily living between houses, or others having recently moved away for university, therefore accurate levels of deprivation may not have been accounted for.

Data from interviews and focus groups with young people and practitioners were rich with discussion on experiences and support needs. There was initial concern whether remote interviews would be adequate to provide rich data (Irvine, 2011). However, young people often acknowledged that they thought the remote nature of the interview was a positive, as they could express themselves more readily and found it helpful in articulating difficult experiences: *"My favourite way of speaking to someone is by call. Right now, I'm laid on my bed with you on speaker and I'm just talking to the air, pretty much. That's how I feel most comfortable talking about my things."* The anonymity the remote interview offered young people as well as being in the comfort of their own space may have aided in their discussions of traumatic and sensitive topics, and reduced some of the barriers regarding stigma and embarrassment (Trier-Bieniek, 2012; Whale, 2017). In addition, providing young people with the choice to take part in a telephone interview or video call may have increased their feelings of empowerment, as mirrored in this study's findings regarding young people's support needs. The remote interview approach, utilising both telephone and video call, proved a useful and effective way to engage young people whose parents use substances in research and for providing rich detailed accounts on sensitive topics. This adds to the literature within the

field, as a very limited number of studies have previously utilised this approach with young people whose parents use substances, with one study using telephone interviews alongside in-person interviews (Park et al., 2016).

Including practitioners from across different settings and with different roles provided a breadth of insights into supporting children and young people whose parents use substances. Whilst this heterogeneity meant that issues and approaches specific to particular practitioners and services could be examined through comparison between groups, it meant that these could not be understood in depth for a particular practitioner group. One of the key findings from this doctoral research and prioritised intervention ideas was the need for school-based approaches. Whilst practitioners within the education system were eligible to take part, attempts at recruitment were unsuccessful. Education practitioners, alongside those within social care and mental health services, proved difficult to recruit due to the COVID-19 pandemic, with constraints on their time and work priorities. As intervention development is iterative (O'Cathain et al., 2019), this doctoral research has identified a further potential research iteration; exploring the experiences of education practitioners, especially regarding developing training around supporting children and young people whose parents use substances. However, of those practitioners who did take part, many of them had previously worked within a school setting (e.g., primary school teacher, school counsellor, special educational needs co-ordinator) or had collaborated with schools in delivering support to young people, so had an awareness of the support needs of young people within a school setting. To respond to the limitations in recruitment identified within this study, I tried to ensure education practitioners attended the later prioritisation workshop.

This study took a national approach to recruitment, with young people and practitioners from across multiple regions in England. Therefore, this evidence is not based on the context of any one local region or service provider. This study adds to the evidence that is currently lacking in England, as the majority of qualitative studies within the UK with young people whose parents use substances were either conducted between 10-20 years ago or were conducted in Scotland. In comparison to England, Scotland has a different political context and statutory support provision for young people whose parents use substances (The Scottish Government, 2022). Therefore, there may be different support needs and requirements for young people across England where support is limited for young people whose parents use substances. Additionally, this approach is important for the development of UK/English-based

interventions, as often interventions for young people whose parents use substances originate from the USA.

#### **6.3.4 *Prioritisation and workshops***

To ensure that newly developed intervention(s) supporting young people whose parents use substances are relevant and acceptable to young people, and to those who support them, it was important that their voices were included in the decision-making and priority-setting process within this study (Craig et al., 2008; O'Cathain et al., 2019). The qualitative research formed the basis for the content in the prioritisation study and co-production workshops. As there are currently limited evidence-based interventions in this field, the intervention ideas that were prioritised were ones proposed by young people and practitioners during the qualitative fieldwork. This enabled a young person and practitioner focused account of what could be useful. However, had the systematic review exploring the effectiveness of interventions to promote resilience in children of parental alcohol use been published at the time of this study, this could have suggested further strategies to include in prioritisation (A. McLaughlin et al., 2014).

There is currently limited evidence and guidance on how to engage a diverse group of stakeholders in the intervention prioritisation phase of the research cycle. This study therefore utilised and combined different methodological approaches from studies that prioritised research topics for young people's mental health (Taylor et al., 2021) as well as interventions aimed at increasing young people's physical activity (Morton et al., 2017) to develop a pragmatic co-production approach to prioritisation within this study that met the needs of those involved (Lavalley et al., 2020). This study also took place towards the end of the COVID-19 pandemic and therefore needed to be flexible to an online platform. I adopted both individual rankings and then group-based consensus workshops to allow for individuals to first rate on their own accord and explain their reasoning, to then explore group consensus and acceptability. This approach helped young people to feel confident about their reasons for prioritisation and led to constructive discussions amongst the group. For those young people who were not in attendance at the workshop, I could feed into the group their reasons for prioritisation to allow for richer discussion. Practitioners also had opportunity to first explore their own prioritisation and reasoning, with live feedback from their peers allowing them to vote again to build consensus. However, like the qualitative work, this study is based on a small sample of young people whose parents use substances and the practitioners who support them, who were willing and comfortable to engage online and therefore further work is



needed to explore applicability of the prioritised interventions beyond this group. This is especially important given that development of a digital intervention was highly prioritised.

For practitioners, having a wider dissemination event and online workshop allowed for ease of attendance and a learning opportunity, however conversely the online platform changed the nature of exchange, possibly making it harder for participants to engage and offer their views (NCCPE, 2020). However, due to the anonymous ranking/scoring exercises, and chat function options, those who may have found it difficult to participate online were facilitated to be included. Feedback from after the event highlighted that practitioner's had benefitted from the workshop and live data from their peers. Furthermore, utilising an iterative approach between young people and practitioners, focusing on both voices separately, facilitated meaningful contribution for all stakeholders. As there was agreement between young people and practitioners regarding the highest-ranking intervention ideas, this adds strength that the intervention ideas prioritised could be acceptable and feasible within practice for both young people and practitioners within a UK setting. Having the practitioners workshop facilitated by young people with lived experience was a strength of this approach and allowed practitioners to hear from those with lived experience and allowed young people to have awareness of issues pertinent to practitioners.

Whilst the study explored multiple criteria for prioritisation (e.g., acceptability, safety), there was only one overall prioritised list produced which was based on discussion regarding each criterion. I did not obtain different prioritisation rankings against each criterion separately. Providing different rank orders based on different criterion could have offered further insight for practice and policy recommendations regarding specific criteria, as well as identifying different priorities across stakeholders (Forbes et al., 2022).

#### **6.3.5 *Applicability to other adverse experiences***

Focusing on a single-risk factor (e.g., parental substance use) throughout this doctoral research is both a strength and limitation of the research. Whilst this research adds valuable insights and contributions to the field regarding the experiences, support needs, and intervention priorities of children and young people whose parents use substances, there is also a national policy push for exploring multiple adversities and developing interventions for those who experience compounding and clustering family adversities (K. Allen et al., 2022; Barrett et al., 2023). Some of the children and young people within the included studies of the qualitative systematic review as well as those who participated within the qualitative

interviews had experience of other adversities, including parental intimate partner violence and abuse, parental mental health problems, and poverty, and therefore findings may be relevant across those who experience multiple adversities. Likewise, across this discussion findings have been demonstrated to be similar to studies that have explored other adversities as single-risk factors (Arai et al., 2021; Callaghan, Fellin, Alexander, et al., 2017; Reupert et al., 2021). However, it is important to note that I did not fully or specifically explore the compounding nature of adversities within the interviews with young people who had experienced multiple adversity. Therefore, further research is needed to explore young people's experiences of multiple adversities and how they interact to see whether loneliness, stigma, and agency are important targets for intervention and whether school-based programmes and digital interventions could also be acceptable approaches to address social and emotional wellbeing amongst young people with multiple adversities. Adjei et al. (2022) identified that the combination of parental mental health problems and poverty are strongly associated with adverse outcomes for children, particularly poor mental health, with parental alcohol use also being highly related to worse social and emotional problems in young people over time. Therefore, there is a need to address and tackle poverty to prevent family adversities from arising or escalating as well as focusing on support for those who have experienced impacts to their social and emotional wellbeing due to family adversity.

## **6.4 Implications for Policy, Practice, and Further Research**

### ***Policy and practice implications***

This doctoral research can help inform UK guidance for supporting young people whose parents use substances. Currently there is a very limited focus on what support should be directly offered to young people, with the national policy paper 'From Harm to Hope' identifying a specific focus on specialist substance misuse interventions for young people whose parents use substances (Home Office, 2022). Within the paper there is acknowledgement that local authorities could consider and meet the needs of young people whose parents use substances in their local area, but without specifying what that need could be. This doctoral research took a national approach and found similarities in young people's needs across the UK. These findings could contribute to and inform local authorities' assessment of local need. Young people wanted support to address the social and emotional impacts of parental substance use, mainly the feelings of loneliness, isolation, and stigma. These needs were further acknowledged by practitioners across the country. Both prioritised the development of resources and training within schools, as a way to meet the needs of

children and young people. This corresponds to a further acknowledgement within the policy paper that, “good outcomes can be achieved by building resilience through skills-based education” (Home Office, 2022, p. 43). This need to address loneliness and stigma identified amongst young people whose parents use substances coincides with another national policy, to address loneliness amongst young people, especially those who may experience stigma (HM Government, 2018) and embedding such resources into the curriculum (Department for Education, 2019). Findings from this doctoral research could therefore begin to inform and build links between two national policies, responding to calls on (1) how to address the needs of young people whose parents use substances, and (2) how to address loneliness amongst young people who are at increased risk.

Although the proposed intervention ideas within this doctoral research are currently in the early stages of development, due to the nature of the study being co-produced and informed by young people with lived experience and practice partners, the recommendations and intervention ideas suggested are likely to be acceptable and feasible within practice across the UK (O'Cathain et al., 2019). To summarise some of the findings and implications for practice outlined in section 6.2, there is a need for the provision of direct social and emotional support to young people, as impacts can extend beyond periods of parental substance use and young people are currently coping with and managing parental substance use often without formal support in place. Future interventions within this area should consider a school-based approach, with the development of resources that can be utilised universally, across the whole class, including the use of a storybook or animated video. These would depict the social and emotional experiences of young people whose parent uses substances and could model viable solutions to address feelings of loneliness, isolation, and stigma. Additionally, a digital intervention incorporating and tailoring content and modules on parental substance use, activities for addressing emotional wellbeing, opportunities for social connection with peers in similar situations, and text support with a practitioner, could help empower young people through allowing personalisation and flexible access. Moreover, teachers should receive training in identification of the impacts of parental substance use amongst children and young people. This would increase awareness of the experiences pertinent to young people and highlight how to respond to the needs of young people, especially regarding externalised behaviours and hidden or masked behaviours.

### ***Future research***

There are possible areas for further research. First, there is a need for a systematic review to explicitly assess the effectiveness of interventions that have directly targeted children and young people in addressing the social and emotional impacts of parental substance use, including interventions that have involved young people in possible digital interventions, school-based programmes, or family-based interventions. This could identify whether there are effective strategies targeting young people's resilience and wellbeing where young people have been involved in their own right. Alongside this, a realist review of possible evidence on the mechanisms of effective interventions for young people in their own right could also help determine how such interventions have brought about change or not. These, together, would add to the evidence within this area and help to develop effective interventions.

There is a need for UK based qualitative research that focuses on exploring the experiences of parental substance use and support needs of young people from ethnic minorities, as current research is predominantly focused on white British young people. This could help develop a more nuanced understanding of how the findings explored within this doctoral research may be experienced by those from different cultures and whether there are additional support needs. This can contribute to future strategies being more responsive to need. Moreover, as there is a policy interest in developing interventions for families and young people who experience multiple adversity (Barrett et al., 2023), there is a need for further qualitative research exploring how the compounding nature of different adversities may be experienced and how they may interact, as opposed to viewing experiences of young people through a single-risk factor lens.

Regarding the continuation of this doctoral research, there would be a need for the interventions and resources identified within this research to be co-produced. Further workshops would be required to co-design, refine, and build a prototype intervention, including for the children's storybook, animated video, teacher training, and/or digital intervention (O'Brien et al., 2016). During this process, there can be opportunity to recruit those who were not as well represented in the fieldwork, for instance teachers as well as children of primary school age for the storybook to ensure resources are appropriate and acceptable. Once an intervention has been developed sufficiently and the program theory has been developed and adapted accordingly, the intervention should be assessed for acceptability, feasibility, cost-effectiveness, and suitable evaluation design. This can be

carried out through a comprehensive feasibility study. If deemed suitable this can also inform an evaluation study, as advised by the medical research council (Craig et al., 2008).

Furthermore, as there was need for training for practitioners across a variety of statutory and non-statutory organisations, it is important to distil the learning from this project in a way that is accessible for practitioners that can have impact on their current work with young people. Co-producing a report or toolkit on the findings from this doctoral research alongside Adfam, a national organisation tackling the negative effects of drugs and alcohol on family members may be an effective strategy to share knowledge. This could include principles for supporting young people whose parents use substances, and awareness of different behaviours and impacts. Where appropriate, this resource could also help link up services across the country who are providing similar support to young people. Such a report could be evaluated for impact, as it would include educational materials and recommendations for practitioners which could impact and influence care provision. The impact could monitor google analytics for recording number of clicks and downloads of the resource; a pop-up evaluation survey on the website with qualitative and quantitative data gathering; and longer term follow up data including focus groups with practitioners who have used the resource and the young people they have supported.

## **6.5 Conclusion**

This thesis aimed to develop a child- and young person-focused understanding of their experiences of parental substance use and their support needs, that could inform the early development of future co-produced intervention(s) within this area. Qualitative methodology and co-production techniques were employed to address this aim. Together, the qualitative findings emphasised that children and young people lived highly disrupted and chaotic lives due to parental substance use, characterised by unpredictability and insecurity within their relationships. They were trying to manage and mitigate vulnerabilities and be resilient to the unpredictable, adverse, and often stigmatising experiences. Whilst young people showed agency in how they survived, often without formal support in place, many did not thrive. Unfortunately, some of their strategies or externalised behaviours were inconsistent with societal norms and/or failed to produce the desired results, often leaving young people feeling lonely and isolated. Current interventions provided to families affected by parental substance use, that focus on reducing parental risk or whole family approaches, can fall short of meeting children and young people's support needs. Children and young people wanted direct support

that promoted their social and emotional wellbeing. The prioritised intervention ideas indicated that schools could be an acceptable setting for support. Creating connections amongst young people in similar situations was important but not without risk, especially as it could potentially increase stigma within the school setting if approached in ways that singled them out. Therefore, there was a need for interventions and resources that could be used universally, across the whole class, aimed at increasing young people's recognition that they were not alone. For instance, co-producing storybooks or animated videos depicting the experiences of other young people whose parents use substances could facilitate conversations between young people and a trusted adult within the school. Likewise, such resources could also begin to reduce the often-taboo nature of parental substance use and the shame experienced due to this. Through specialised training for practitioners, particularly teachers, young people wanted increased awareness of their experiences and impacts regarding their externalised or hidden emotions, which could result in more understanding and supportive relationships. Moreover, developing digital applications or websites could address young people's need for agency, allowing them to tailor content and modules, access it at times of increased need, and empower them to engage in support earlier. Finally, there was also need for systemic changes to address the socio-economic conditions that families may experience in addition to parental substance use, and increased government investment in support for children and young people in their own right.

These findings, taken together, have therefore identified areas of possible future intervention and strategies for supporting young people whose parents use substances. They have addressed current issues within national policy around how to respond to the needs of young people whose parents use substances and how to address loneliness amongst those of increased risk. This research has been co-produced at each stage with young people who have lived experience of parental substance use and the practitioners who support them. Therefore, this research has addressed pertinent and important issues amongst young people and practitioners, making the findings likely to be acceptable and relevant within practice across the United Kingdom. Further work is needed to co-produce interventions directly for children and young people whose parents use substances, addressing their emotional and social wellbeing.

I would like to end on the words of a young person who was involved in the young person advisory group.

*“The main part of supporting young people is accessing them and communicating with them. Reaching out to young people in general about parental substance use issues, getting the knowledge out there about it is important. This in turn will help the young people experiencing parental substance use, as the subject isn’t so hidden anymore as it usually feels hidden in the home. And through that we must back up with access to different support links. Some children aren’t ready, some don’t want help, some we won’t reach, but to push and be as present for as many children as possible, for as long as possible and to reduce the isolation of the stigma around it is vital.”*

# Appendix A. Prospero Registration for the Qualitative Systematic Review

A systematic review of qualitative studies exploring lived experiences, impacts and coping strategies of children and young people affected by parental substance misuse

*Cassey Muir, Ruth McGovern, Eileen Kaner, Emma Geijer-Simpson, Debbie Smart, Judi Kidger, Lizzy Winstone, Vivienne Evans, Sophie Phillips, Domna Salonen, Emma Adams*

## Citation

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## Review question

1. What are children and young people's lived experiences of parental substance misuse?
2. What are children and young people's views on the impacts of parental substance misuse?
3. What approaches and strategies do children and young people use to manage adverse impacts of parental substance misuse?

## Searches

The following electronic databases will be searched from inception until July 2019: MEDLINE and PsycINFO (OVID), Cumulative Index to Nursing and Allied Health Literature (EBSCOhost), International Bibliography of the Social Sciences, Social Science Database, Sociology Collection and Applied Social Sciences Index and Abstracts (ProQuest), and Scopus; including grey literature searching: i.e. [www.opengrey.eu](http://www.opengrey.eu) and searching relevant journals. Reference lists and citations of included studies and relevant reviews and reports will be screened to identify any further papers.

Early scoping work of the qualitative literature has helped inform the development of the search strategy. Eight key studies have been identified that have informed the key terms and database specific filters. The sensitivity of the search strategy will be optimised by testing for inclusion of these known relevant articles. The search strategy includes combinations of the following key terms: children and young people; parental substance misuse; and lived experiences/qualitative research. Search terms will be adapted for use with each database, alongside appropriate database specific filters. There will be no language, year of study or publication status restrictions placed on the searches. The searches will be re-run prior to the final version of the review to identify and retrieve any further studies for inclusion.

## Types of study to be included

The review will include qualitative studies, reporting primarily narrative data concerned with the lived experiences, impacts and coping strategies of children and young people affected by parental substance misuse.

Studies with at least some qualitative data collection, analysis, and reporting will be included. Studies including only quantitative methods, analysis and reporting will be excluded.

## Condition or domain being studied

Lived experiences, attitudes, perspectives, impacts, and identified coping strategies of children and young people affected by parental substance misuse.

Parental substance misuse is defined as both dependent and non-dependent alcohol and/or illicit drug use by at least one primary caregiver that has the potential to cause harm to a child in their care.



### Participants/population

Inclusion:

Children and young people aged below 25 years (or where the mean age is less than or equal to 25 years) who have at least one primary carer who misuses or has misused substances (alcohol and/or drugs).

Exclusion:

- Individuals over the age of 25 years.
- Looked-after children; children and young people who are currently in care including: living with foster parents for short period of time, living in residential children's homes or living in residential settings i.e. secure units.
- Children and young people who are currently in custodial criminal justice settings.
- Parents' or health or social care professionals' views of how children experience or are impacted by parental substance misuse without inclusion of young peoples' accounts

### Intervention(s), exposure(s)

Parental substance misuse refers to both dependent and non-dependent use including: hazardous and/or harmful levels of alcohol use; risky single occasion high intensity alcohol use (i.e. binge drinking); any classified or illicit drug use including the misuse of prescription drugs; alcohol or drug abuse; as well as alcohol or drug dependence.

Child-reported problematic parental substance misuse will be included.

Studies will be excluded if they focus on parental tobacco and/or caffeine misuse without any other substance misuse. Primary carer refers to anyone who has had a parenting role for a significant period of time (e.g. biological, step, adoptive parent/carer or kin care).

### Comparator(s)/control

Not applicable.

### Main outcome(s)

Qualitative narrative accounts focusing on the lived experiences, impacts and coping strategies of children and young people affected by parental substance misuse.

#### \* Measures of effect

Not applicable.

### Additional outcome(s)

None.

#### \* Measures of effect

Not applicable.

### Data extraction (selection and coding)

All identified articles will be imported into a referencing manager software (i.e. Rayyan/EndNote) and duplicates will be removed. The lead review author (CM) will split the titles and abstracts amongst the review team to identify studies that potentially meet the inclusion and exclusion criteria (CM, EG-S, DS, SP, LW, and DS). All studies will be screened by two independent reviewers. Any disagreement between the reviewers on the eligibility of particular studies will be resolved through discussion or a third reviewer. Full papers of potentially relevant studies will then be retrieved and screened independently by two members of the review team, to identify if they meet the eligibility criteria.

Data extraction from the relevant studies will be performed by two independent reviewers and findings will be discussed and explored amongst the review team. A detailed and specific data extraction form will be used

to extract data from the included studies for evidence synthesis. Extracted information will include but not be limited to: Author(s), publication year and country; Aims, objectives and research questions; Participant characteristics (age, sex, ethnicity, socioeconomic status); Parent characteristics (age, sex, caring role, substance misuse); method of data collection; method of data analysis; findings and themes; references. A data extraction form will be piloted with a few of the included studies and refined if necessary. Missing data will be requested from the study authors via email.

#### Risk of bias (quality) assessment

As this is a qualitative systematic review, a risk of bias assessment would not be appropriate. Studies will be assessed on their relevance to the research questions. To assess the quality of the included qualitative studies the Critical Appraisal Skills Programme (CASP) tool will be used, as recommended by Cochrane Guidance (Noyes et al, 2018). Two independent reviewers will assess the quality. Any disagreement between the reviewers on the eligibility of particular studies will be resolved through discussion or a third reviewer. Studies will not be excluded on the basis of quality, but will be retained on the basis of whether they contribute valuable or novel data to the review.

#### Strategy for data synthesis

While a method of synthesis will be selected that is most appropriate for the papers identified for inclusion from screening, it is likely that data will be synthesised through thematic synthesis (Thomas and Harden, 2008). Both data from individual participants (children and young people) quoted within the article, and the authors' interpretations and generalisations within the text will be synthesised. Identified themes will be compared, contrasted and grouped across studies. The stages will include: line by line coding; development of descriptive themes and; generation of analytical themes to determine the key messages.

The data synthesis will be performed primarily by the lead author (CM) with support from the supervisory team (RM, EK, JK, VE) to allow for discussion and the emergence of more abstract messages and themes that go beyond the content in the original studies.

Themes will also be discussed, explored and challenged with a group of young people who are within the age/experience of the target group. A thematic synthesis will allow for the generation of key messages and themes with regards to what children and young people's lived experiences are, their views on the impacts of PSM and their identified coping strategies.

#### Analysis of subgroups or subsets

As this is a qualitative synthesis, it may not be possible to identify subgroups. If appropriate, subgroups may include analysis by age or gender, or by parental substance misuse (i.e. non-dependent and dependent or alcohol and illicit drugs) or by parental gender (mother and father) or substance use by one or both parents.

#### Contact details for further information

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**Type and method of review**

Epidemiologic, Synthesis of qualitative studies, Systematic review

**Anticipated or actual start date**

20 May 2019

**Anticipated completion date**

01 September 2020

**Funding sources/sponsors**

The lead review author, Cassey Muir, is being supported by the National Institute for Health Research School for Public Health Research (NIHR SPHR) studentship (SPHR-PHD-FUS-002)

The NIHR SPHR is a partnership between the Universities of Sheffield; Bristol; Cambridge; Imperial; and University College London; The London School for Hygiene and Tropical Medicine (LSHTM); LiLaC - a collaboration between the Universities of Liverpool and Lancaster; and Fuse - The Centre for Translational Research in Public Health a collaboration between Newcastle, Durham, Northumbria, Sunderland and Teesside Universities

The views to be expressed will be those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

**Conflicts of interest**

**Language**

English

**Country**

England

**Stage of review**

Review Ongoing

**Subject index terms status**

Subject indexing assigned by CRD

**Subject index terms**

Adaptation, Psychological; Adolescent; Adolescent Health; Adverse Childhood Experiences; Alcoholics; Alcoholism; Child; Child Health; Drug Users; Humans; Parent-Child Relations; Parenting; Parents; Substance-Related Disorders; Young Adult

**Date of registration in PROSPERO**

10 June 2019

**Date of first submission**

10 June 2019

**Stage of review at time of this submission**

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

#### Revision note

This record has been revised to include a new member of the review team.

*The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.*

*The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.*

#### Versions

10 June 2019

07 July 2020

#### PROSPERO

This information has been provided by the named contact for this review. CRD has accepted this information in good faith and registered the review in PROSPERO. The registrant confirms that the information supplied for this submission is accurate and complete. CRD bears no responsibility or liability for the content of this registration record, any associated files or external websites.

## Appendix B. Full Search Strategy for the Qualitative Systematic Review

### ProQuest (International Bibliography of the Social Sciences, Social Science Database, Sociology Collection: Sociology Database)

#### *Children and Young People*

(ab(("young person" OR "young people" OR young\* OR child\* OR youth OR adolescen\* OR teen\* OR pre?teen OR "young adult\*" OR offspring OR juvenile\* OR pubescen\* OR "school child\*" OR student OR boy\* OR girl\* OR pupil)) OR (MAINSUBJECT.EXACT("Young adults") OR MAINSUBJECT.EXACT("Children of alcoholics") OR MAINSUBJECT.EXACT("Teenagers") OR MAINSUBJECT.EXACT("Children & youth"))) AND PEER(yes)

#### *Parental Substance Use*

(NOFT((((("alcohol consumption" OR "alcohol misuse" OR "alcohol use\*" OR "misuse alcohol" OR "alcohol intoxicat\*" OR "alcohol drinking" OR "alcohol disorder\*" OR "binge drinking" OR "social drinking" OR "risky drinking" OR "substance misuse" OR "substance use\*" OR "misuse substances" OR "substance disorder" OR "substance abuse" OR "hazardous drinking" OR "hazardous alcohol" OR "harmful alcohol" OR "harmful drinking" OR "alcohol dependen\*" OR "dependent drinking" OR alcoholic OR alcoholism OR "drug consumption" OR "drug misuse" OR "drug use\*" OR "misuse drugs" OR "drug disorder\*" OR "drug dependen\*" OR "illicit drugs" OR "alcohol or other drug\*") NEAR/2 (parent\* OR father\* OR paternal OR step?father OR mother\* OR maternal OR step?mother OR carer\* OR care?giver OR foster?parent\* OR grand?parent\* OR grand?mother\* OR grand?father\* OR family OR families)))) OR (MAINSUBJECT.EXACT("Children of alcoholics")))) AND PEER(yes)

#### *Qualitative Research*

(ab((interview\* OR theme\* OR "thematic analysis" OR qualitative OR "nursing research methodology" OR questionnaire OR ethnograph\* OR ethnonursing OR "ethnological research" OR phenomenol\* OR "grounded theor\*" OR "grounded stud\*" OR "grounded research" OR "grounded analys?s" OR "Life Stor\*" OR "Women's Stor\*" OR emic OR etic OR hermeneutic OR heuristic OR semiotic OR "data saturat\*" OR "participant observ\*" OR "social construct\*" OR Postmodern\* OR "Post structural\*" OR feminis\* OR interpret\* OR "action research" OR "co-operative inquir\*" OR Humanistic OR Existential OR Experiential OR Paradigm\* OR "field stud\*" OR "field research" OR "human science" OR "biographical method" OR "theoretical sampl\*" OR "Purposive sampl\*" OR "open-ended account\*" OR "unstructured account" OR narrative\* OR text\* OR "life world" OR "conversation analys?s"



OR "theoretical saturation" OR "lived experience" OR "life experience" OR "living with" OR "cluster sampl\*" OR "observational method\*" OR "content analysis" OR "constant comparative" OR "discourse analys?s" OR "discurs\* analys?s" OR "narrative analys?s" OR Heidegger\* OR colaizzi\* OR spiegelberg\* OR "Van manen\*" OR "Van Kaam\*" OR "merleau ponty\*" OR Husserl\* OR Foucault\* OR corbin\* OR strauss\* OR glaser\*)) OR (MAINSUBJECT.EXACT("Qualitative research") OR MAINSUBJECT.EXACT("Phenomenology") OR MAINSUBJECT.EXACT("Grounded theory") OR MAINSUBJECT.EXACT("Interviews") OR MAINSUBJECT.EXACT("Personal experiences") OR MAINSUBJECT.EXACT("Ethnography") OR MAINSUBJECT.EXACT("Focus groups") OR MAINSUBJECT.EXACT("Discourse analysis")) AND PEER(yes)

Above combined with AND.

Found 3/5 papers in database: does not find Bancroft et al. (2004) and Barnard & Barlow (2003) due to no abstract or thesaurus terms.

### **ProQuest (Sociology Collection: Sociological Abstracts)**

#### *Children and Young People*

(ab(("young person" OR "young people" OR young\* OR child\* OR youth OR adolescen\* OR teen\* OR pre?teen OR "young adult\*" OR offspring OR juvenile\* OR pubescen\* OR "school child\*" OR student OR boy\* OR girl\* OR pupil)) OR (MAINSUBJECT.EXACT.EXPLODE("Children") OR MAINSUBJECT.EXACT("Adolescents") OR MAINSUBJECT.EXACT("Young Adults"))) AND PEER(yes)

#### *Parental Substance Use*

(NOFT(((("alcohol consumption" OR "alcohol misuse" OR "alcohol use\*" OR "misuse alcohol" OR "alcohol intoxicat\*" OR "alcohol drinking" OR "alcohol disorder\*" OR "binge drinking" OR "social drinking" OR "risky drinking" OR "substance misuse" OR "substance use\*" OR "misuse substances" OR "substance disorder" OR "substance abuse" OR "hazardous drinking" OR "hazardous alcohol" OR "harmful alcohol" OR "harmful drinking" OR "alcohol dependen\*" OR "dependent drinking" OR alcoholic OR alcoholism OR "drug consumption" OR "drug misuse" OR "drug use\*" OR "misuse drugs" OR "drug disorder\*" OR "drug dependen\*" OR "illicit drugs" OR "alcohol or other drug\*") NEAR/2 (parent\* OR father\* OR paternal OR step?father OR mother\* OR maternal OR step?mother OR carer\* OR

care?giver OR foster?parent\* OR grand?parent\* OR grand?mother\* OR grand?father\* OR family OR families))) OR (MAINSUBJECT.EXACT("Drug Addiction") OR MAINSUBJECT.EXACT("Alcoholism")) AND PEER(yes)

### *Qualitative Research*

(ab((interview\* OR theme\* OR "thematic analysis" OR qualitative OR "nursing research methodology" OR questionnaire OR ethnograph\* OR ethnonursing OR "ethnological research" OR phenomenol\* OR "grounded theor\*" OR "grounded stud\*" OR "grounded research" OR "grounded analys?s" OR "Life Stor\*" OR "Women's Stor\*" OR emic OR etic OR hermeneutic OR heuristic OR semiotic OR "data saturat\*" OR "participant observ\*" OR "social construct\*" OR Postmodern\* OR "Post structural\*" OR feminis\* OR interpret\* OR "action research" OR "co-operative inquir\*" OR Humanistic OR Existential OR Experiential OR Paradigm\* OR "field stud\*" OR "field research" OR "human science" OR "biographical method" OR "theoretical sampl\*" OR "Purposive sampl\*" OR "open-ended account\*" OR "unstructured account" OR narrative\* OR text\* OR "life world" OR "conversation analys?s" OR "theoretical saturation" OR "lived experience" OR "life experience" OR "living with" OR "cluster sampl\*" OR "observational method\*" OR "content analysis" OR "constant comparative" OR "discourse analys?s" OR "discurs\* analys?s" OR "narrative analys?s" OR Heidegger\* OR colaizzi\* OR spiegelberg\* OR "Van manen\*" OR "Van Kaam\*" OR "merleau ponty\*" OR Husserl\* OR Foucault\* OR corbin\* OR strauss\* OR glaser\*)) OR (MAINSUBJECT.EXACT("Group Research") OR MAINSUBJECT.EXACT("Phenomenology") OR MAINSUBJECT.EXACT("Grounded Theory") OR MAINSUBJECT.EXACT("Discourse Analysis") OR MAINSUBJECT.EXACT("Qualitative Methods") OR MAINSUBJECT.EXACT("Interviews") OR MAINSUBJECT.EXACT("Social Policy")) AND PEER(yes)

Above combined with AND.

Found 5/5 papers in database.

### **ProQuest (Sociology Collection: Applied Social Sciences Index and Abstracts)**

#### *Children and Young People*

(ab(("young person" OR "young people" OR young\* OR child\* OR youth OR adolescen\* OR teen\* OR pre?teen OR "young adult\*" OR offspring OR juvenile\* OR pubescen\* OR "school child\*" OR student OR boy\* OR girl\* OR pupil)) OR (MAINSUBJECT.EXACT("Adult children") OR MAINSUBJECT.EXACT("Adolescents") OR

MAINSUBJECT.EXACT("Young adults") OR MAINSUBJECT.EXACT("Young people")  
OR MAINSUBJECT.EXACT("Children")) AND PEER(yes)

#### *Parental Substance Use*

(NOFT(("alcohol consumption" OR "alcohol misuse" OR "alcohol use\*" OR "misuse  
alcohol" OR "alcohol intoxicat\*" OR "alcohol drinking" OR "alcohol disorder\*" OR "binge  
drinking" OR "social drinking" OR "risky drinking" OR "substance misuse" OR "substance  
use\*" OR "misuse substances" OR "substance disorder" OR "substance abuse" OR  
"hazardous drinking" OR "hazardous alcohol" OR "harmful alcohol" OR "harmful drinking"  
OR "alcohol dependen\*" OR "dependent drinking" OR alcoholic OR alcoholism OR "drug  
consumption" OR "drug misuse" OR "drug use\*" OR "misuse drugs" OR "drug disorder\*"  
OR "drug dependen\*" OR "illicit drugs" OR "alcohol or other drug\*") NEAR/2 (parent\* OR  
father\* OR paternal OR step?father OR mother\* OR maternal OR step?mother OR carer\* OR  
care?giver OR foster?parent\* OR grand?parent\* OR grand?mother\* OR grand?father\* OR  
family OR families))) OR (MAINSUBJECT.EXACT.EXPLODE("Problem drinkers") OR  
MAINSUBJECT.EXACT.EXPLODE("Abusers") OR  
MAINSUBJECT.EXACT.EXPLODE("Drug addicts")) AND PEER(yes)

#### *Qualitative Research*

(ab((interview\* OR theme\* OR "thematic analysis" OR qualitative OR "nursing research  
methodology" OR questionnaire OR ethnograph\* OR ethnonursing OR "ethnological  
research" OR phenomenol\* OR "grounded theor\*" OR "grounded stud\*" OR "grounded  
research" OR "grounded analys?s" OR "Life Stor\*" OR "Women's Stor\*" OR emic OR etic  
OR hermeneutic OR heuristic OR semiotic OR "data saturat\*" OR "participant observ\*" OR  
"social construct\*" OR Postmodern\* OR "Post structural\*" OR feminis\* OR interpret\* OR  
"action research" OR "co-operative inquir\*" OR Humanistic OR Existential OR Experiential  
OR Paradigm\* OR "field stud\*" OR "field research" OR "human science" OR "biographical  
method" OR "theoretical sampl\*" OR "Purposive sampl\*" OR "open-ended account\*" OR  
"unstructured account" OR narrative\* OR text\* OR "life world" OR "conversation analys?s"  
OR "theoretical saturation" OR "lived experience" OR "life experience" OR "living with" OR  
"cluster sampl\*" OR "observational method\*" OR "content analysis" OR "constant  
comparative" OR "discourse analys?s" OR "discurs\* analys?s" OR "narrative analys?s" OR  
Heidegger\* OR colaizzi\* OR spiegelberg\* OR "Van manen\*" OR "Van Kaam\*" OR  
"merleau ponty\*" OR Husserl\* OR Foucault\* OR corbin\* OR strauss\* OR glaser\*)) AND  
PEER(yes)) OR ((MAINSUBJECT.EXACT("Qualitative data") OR  
MAINSUBJECT.EXACT("Qualitative methods") OR MAINSUBJECT.EXACT("Emotional  
experiences") OR MAINSUBJECT.EXACT("Life experiences") OR



MAINSUBJECT.EXACT("Personal experiences") OR  
 MAINSUBJECT.EXACT("Qualitative analysis") OR MAINSUBJECT.EXACT("Focus  
 groups") OR MAINSUBJECT.EXACT("Discourse analysis") OR  
 MAINSUBJECT.EXACT("Focus group interviews") OR MAINSUBJECT.EXACT("Group  
 interviewing") OR MAINSUBJECT.EXACT("Grounded theory") OR  
 MAINSUBJECT.EXACT("Qualitative research") OR  
 MAINSUBJECT.EXACT.EXPLODE("Phenomenology") OR  
 MAINSUBJECT.EXACT.EXPLODE("Action research") OR  
 MAINSUBJECT.EXACT("Structured interviews") OR  
 MAINSUBJECT.EXACT("Semistructured interviews")) AND PEER(yes))

Above combined with AND.

Found 4/5 papers: does not find Bancroft et al. (2004) due to no abstract.

## **OVID (Medline)**

### *Children and Young People*

("young person" or "young people" or young\* or child\* or youth or adolescen\* or teen\* or  
 pre?teen or "young adult\*" or offspring or juvenile\* or pubescen\* or "school child\*" or  
 student or boy\* or girl\* or pupil).mp.

adolescent/ or young adult/ or exp child/

### *Parental Substance Use*

((("alcohol consumption" or "alcohol misuse" or "alcohol use\*" or "misuse alcohol" or  
 "alcohol intoxicat\*" or "alcohol drinking" or "alcohol disorder\*" or "binge drinking" or  
 "social drinking" or "risky drinking" or "substance misuse" or "substance use\*" or "misuse  
 substances" or "substance disorder" or "substance abuse" or "hazardous drinking" or  
 "hazardous alcohol" or "harmful alcohol" or "harmful drinking" or "alcohol dependen\*" or  
 "dependent drinking" or alcoholic or alcoholism or "drug consumption" or "drug misuse" or  
 "drug use\*" or "misuse drugs" or "drug disorder\*" or "drug dependen\*" or "illicit drugs" or  
 "alcohol or other drug\*") adj2 (parent\* or father\* or paternal or step?father or mother\* or  
 maternal or step?mother or carer\* or care?giver or foster?parent\* or grand?parent\* or  
 grand?mother\* or grand?father\* or family or families)).mp.

alcoholics/ or "child of impaired parents"/ or drug users/

### *Qualitative Research*

1 (theme\$ or thematic).mp.

2 qualitative.af.

3 questionnaire\$.mp.  
 4 ethnological research.mp.  
 5 ethnograph\$.mp.  
 6 ethnonursing.af.  
 7 phenomenol\$.af.  
 8 (grounded adj (theor\$ or study or studies or research or analys?s)).af.  
 9 (life stor\$ or women\* stor\$).mp.  
 10 (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or (data adj1 saturat\$).tw. or participant observ\$.tw.  
 11 (social construct\$ or (postmodern\$ or post-structural\$) or (post structural\$ or poststructural\$) or post modern\$ or post-modern\$ or feminis\$ or interpret\$).mp.  
 12 (action research or cooperative inquir\$ or co operative inquir\$ or co-operative inquir\$).mp.  
 13 (humanistic or existential or experiential or paradigm\$).mp.  
 14 (field adj (study or studies or research)).tw.  
 15 human science.tw.  
 16 biographical method.tw.  
 17 theoretical sampl\$.af.  
 18 ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.  
 19 (account or accounts or unstructured or openended or open ended or text\$ or narrative\$).mp.  
 20 (life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp.  
 21 ((lived or life) adj experience\$).mp.  
 22 cluster sampl\$.mp.  
 23 observational method\$.af.  
 24 content analysis.af.  
 25 (constant adj (comparative or comparison)).af.  
 26 ((discourse\$ or discurs\$) adj3 analys?s).tw.  
 27 narrative analys?s.af.  
 28 heidegger\$.tw.  
 29 colaizzi\$.tw.  
 30 spiegelberg\$.tw.  
 31 (van adj manen\$).tw.  
 32 (van adj kaam\$).tw.  
 33 (merleau adj ponty\$).tw.  
 34 husserl\$.tw.  
 35 foucault\$.tw.  
 36 (corbin\$ adj2 strauss\$).tw.  
 37 glaser\$.tw.  
 38 living with.mp.

focus groups/ or interviews as topic/ or attitude/ or grounded theory/ or exp qualitative research/ or exp biography/ or Nursing Methodology Research/

Above combined with AND.

Found 1/1 papers in database.

## **OVID (PsycINFO)**

### *Children and Young People*

("young person" or "young people" or young\* or child\* or youth or adolescen\* or teen\* or pre?teen or "young adult\*" or offspring or juvenile\* or pubescen\* or "school child\*" or student or boy\* or girl\* or pupil).mp.

\*\*No thesaurus terms

### *Parental Substance Use*

((("alcohol consumption" or "alcohol misuse" or "alcohol use\*" or "misuse alcohol" or "alcohol intoxicat\*" or "alcohol drinking" or "alcohol disorder\*" or "binge drinking" or "social drinking" or "risky drinking" or "substance misuse" or "substance use\*" or "misuse substances" or "substance disorder" or "substance abuse" or "hazardous drinking" or "hazardous alcohol" or "harmful alcohol" or "harmful drinking" or "alcohol dependen\*" or "dependent drinking" or alcoholic or alcoholism or "drug consumption" or "drug misuse" or "drug use\*" or "misuse drugs" or "drug disorder\*" or "drug dependen\*" or "illicit drugs" or "alcohol or other drug\*") adj2 (parent\* or father\* or paternal or step?father or mother\* or maternal or step?mother or carer\* or care?giver or foster?parent\* or grand?parent\* or grand?mother\* or grand?father\* or family or families)).mp.

"children of alcoholics"/

### *Qualitative Research*

1 Qualitative Research.mp.

2 Interview.mp.

3 (theme\$ or thematic).mp.

4 qualitative.af.

5 Nursing Methodology Research.mp.

6 questionnaire\$.mp.

7 ethnological research.mp.

8 ethnograph\$.mp.

9 ethnonursing.af.

10 phenomenol\$.af.

11 (grounded adj (theor\$ or study or studies or research or analys?s)).af.

12 (life stor\$ or women\* stor\$).mp.

13 (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or (data adj1 saturat\$).tw. or participant observ\$.tw.

14 (social construct\$ or (postmodern\$ or post-structural\$) or (post structural\$ or poststructural\$) or post modern\$ or post-modern\$ or feminis\$ or interpret\$).mp.

15 (action research or cooperative inquir\$ or co operative inquir\$ or co-operative inquir\$).mp.

16 (humanistic or existential or experiential or paradigm\$).mp.

17 (field adj (study or studies or research)).tw.

18 human science.tw.

19 biographical method.tw.

20 theoretical sampl\$.af.

21 ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.

22 (account or accounts or unstructured or opened or open ended or text\$ or narrative\$).mp.  
 23 (life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp.  
 24 ((lived or life) adj experience\$).mp.  
 25 cluster sampl\$.mp.  
 26 observational method\$.af.  
 27 content analysis.af.  
 28 (constant adj (comparative or comparison)).af.  
 29 ((discourse\$ or discurs\$) adj3 analys?s).tw.  
 30 narrative analys?s.af.  
 31 heidegger\$.tw.  
 32 colaizzi\$.tw.  
 33 spiegelberg\$.tw.  
 34 (van adj manen\$).tw.  
 35 (van adj kaam\$).tw.  
 36 (merleau adj ponty\$).tw.  
 37 husserl\$.tw.  
 38 foucault\$.tw.  
 39 (corbin\$ adj2 strauss\$).tw.  
 40 glaser\$.tw.  
 41 Living with.mp.

exp qualitative methods/ or exp "experiences (events)"/

Above combined with AND.

Found 6/6 papers in database.

## **EBSCOhost (Cumulative Index to Nursing and Allied Health Literature)**

### *Children and Young People*

"young person" or "young people" or young\* or child\* or youth or adolescen\* or teen\* or pre?teen or "young adult\*" or offspring or juvenile\* or pubescen\* or "school child\*" or student or boy\* or girl\* or pupil

(MH "Child+") OR (MH "Adolescence+") OR (MH "Young Adult")

### *Parental Substance Use*

("alcohol consumption" or "alcohol misuse" or "alcohol use\*" or "misuse alcohol" or "alcohol intoxicat\*" or "alcohol drinking" or "alcohol disorder\*" or "binge drinking" or "social drinking" or "risky drinking" or "substance misuse" or "substance use\*" or "misuse substances" or "substance disorder" or "substance abuse" or "hazardous drinking" or "hazardous alcohol" or "harmful alcohol" or "harmful drinking" or "alcohol dependen\*" or "dependent drinking" or alcoholic or alcoholism or "drug consumption" or "drug misuse" or "drug use\*" or "misuse drugs" or "drug disorder\*" or "drug dependen\*" or "illicit drugs" or

"alcohol or other drug\*") N2 (parent\* or father\* or paternal or step?father or mother\* or maternal or step?mother or carer\* or care?giver or foster?parent\* or grand?parent\* or grand?mother\* or grand?father\* or family or families))  
 (MH "Children of Alcoholics") OR (MH "Substance Abusers+")

### *Qualitative Research*

1. Ethnonursing
2. ethnograph\*
3. phenomenol\*
4. grounded N1 theor\*
5. grounded N1 study
6. grounded N1 studies
7. grounded N1 research
8. grounded N1 analys?s
9. life stor\*
10. women's stor\*
11. emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$
12. data N1 saturat\*
13. participant observ\*
14. social construct\* or postmodern\* or post-structural\* or post structural\* or poststructural\* or postmodern\* or post-modern\* or feminis\* or interpret\*
15. action research or cooperative inquir\* or co operative inquir\* or co-operative inquir\*
16. humanistic or existential or experiential or paradigm\*
17. field N1 stud\*
18. field N1 research
19. human science
20. biographical method
21. theoretical sampl\*
22. purpos\* N4 sampl\*
23. focus N1 group\*
24. account or accounts or unstructured or openended or open ended or text\* or narrative\*
25. life world or life-world or conversation analys?s or personal experience\* or theoretical saturation
26. lived experience\*
27. life experience\*
28. cluster sampl\*
29. theme\* or thematic
30. observational method\*
31. questionnaire\*
32. content analysis
33. discourse\* N3 analys?s
34. discurs\* N3 analys?s
35. constant N1 comparative
36. constant N1 comparison
37. narrative analys?s
38. Heidegger\*
39. Colaizzi\*
40. Spiegelberg\*
41. van N1 manen\*
42. van N1 kaam\*

43. merleau N1 ponty\*
44. husserl\*
45. Foucault\*
46. Corbin\* N2 strauss\*
47. glaser\*

48. living with

(MH Interview+) OR (MH audiorecording) OR (MH Interviews+) OR (MH "Grounded theory") OR (MH "Qualitative Studies") OR (MH "Research, Nursing") OR (MH Questionnaires+) OR (MH "Focus Groups") OR (MH "Discourse Analysis") OR (MH "Content Analysis") OR (MH "Ethnographic Research") OR (MH "Ethnological Research") OR (MH "Ethnonursing Research") OR (MH "Constant Comparative Method") OR (MH "Qualitative Validity+") OR (MH "Purposive Sample") OR (MH "Observational Methods+") OR (MH "Field Studies") OR (MH "theoretical sample") OR (MH Phenomenology) OR (MH "Phenomenological Research") OR (MH "Life Experiences+") OR (MH "Cluster Sample+")

Above combined with AND.

Found 5/5 papers in database.

## **Scopus**

### *Children and Young People*

TITLE-ABS("young person" OR "young people" OR young\* OR child\* OR youth OR adolescen\* OR teen\* OR pre?teen OR "young adult\*" OR offspring OR juvenile\* OR pubescen\* OR "school child\*" OR student OR boy\* OR girl\* OR pupil)

### *Parental Substance Use*

TITLE-ABS(((("alcohol consumption" OR "alcohol misuse" OR "alcohol use\*" OR "misuse alcohol" OR "alcohol intoxicat\*" OR "alcohol drinking" OR "alcohol disorder\*" OR "binge drinking" OR "social drinking" OR "risky drinking" OR "substance misuse" OR "substance use\*" OR "misuse substances" OR "substance disorder" OR "substance abuse" OR "hazardous drinking" OR "hazardous alcohol" OR "harmful alcohol" OR "harmful drinking" OR "alcohol dependen\*" OR "dependent drinking" OR alcoholic OR alcoholism OR "drug consumption" OR "drug misuse" OR "drug use\*" OR "misuse drugs" OR "drug disorder\*" OR "drug dependen\*" OR "illicit drugs" OR "alcohol or other drug\*") W/2 (parent\* OR father\* OR paternal OR step?father OR mother\* OR maternal OR step?mother OR carer\* OR care?giver OR foster?parent\* OR grand?parent\* OR grand?mother\* OR grand?father\* OR family OR families))))

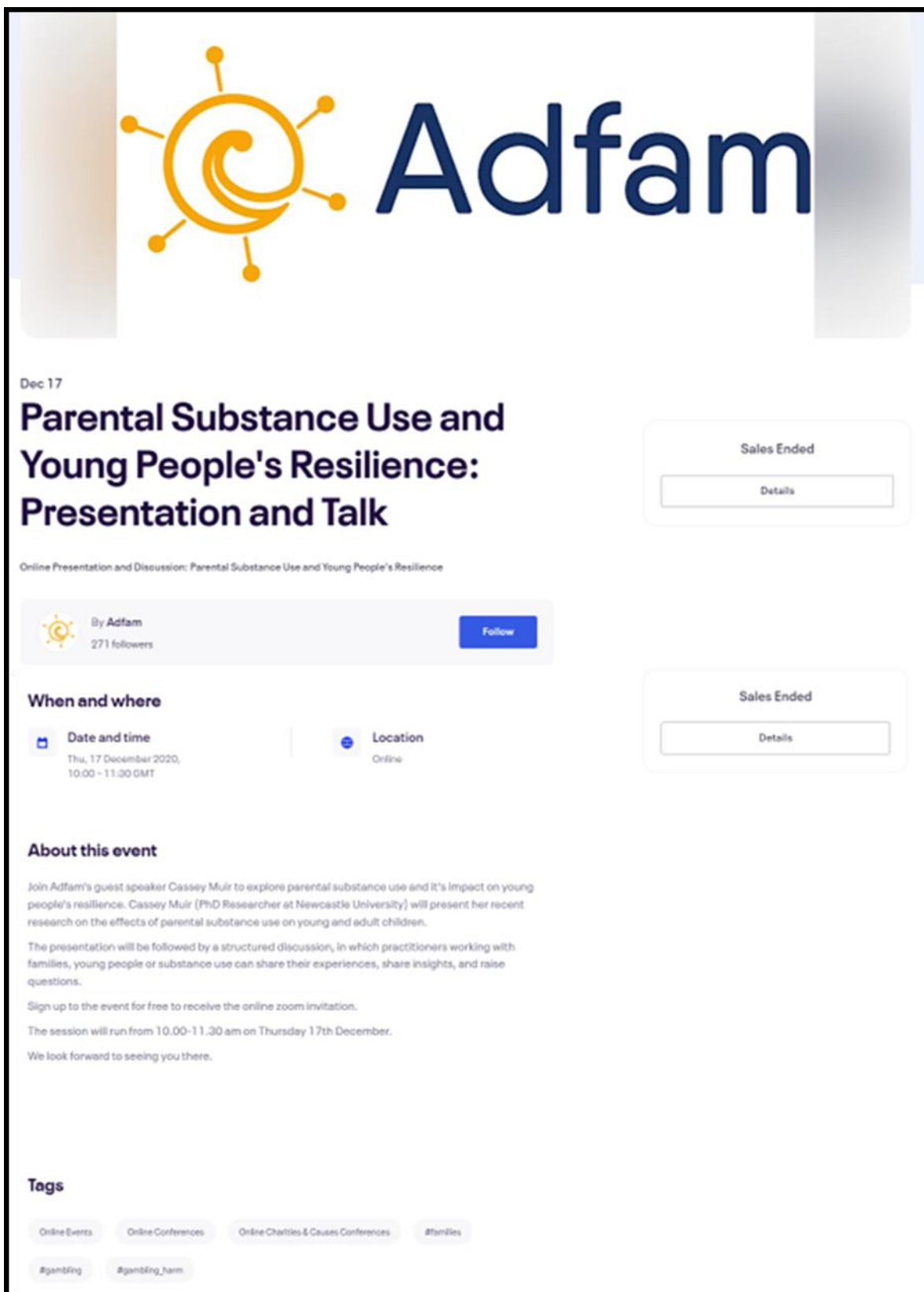
### *Qualitative Research*

TITLE-ABS(interview\* OR theme\* OR "thematic analysis" OR qualitative OR "nursing research methodology" OR questionnaire OR ethnograph\* OR ethnonursing OR "ethnological research" OR phenomenol\* OR "grounded theor\*" OR "grounded stud\*" OR "grounded research" OR "grounded analys?s" OR "Life Stor\*" OR "Women's Stor\*" OR emic OR etic OR hermeneutic OR heuristic OR semiotic OR "data saturat\*" OR "participant observ\*" OR "social construct\*" OR Postmodern\* OR "Post structural\*" OR feminis\* OR interpret\* OR "action research" OR "co-operative inquir\*" OR Humanistic OR Existential OR Experiential OR Paradigm\* OR "field stud\*" OR "field research" OR "human science" OR "biographical method" OR "theoretical sampl\*" OR "Purposive sampl\*" OR "open-ended account\*" OR "unstructured account" OR narrative\* OR text\* OR "life world" OR "conversation analys?s" OR "theoretical saturation" OR "lived experience" OR "life experience" OR "living with" OR "cluster sampl\*" OR "observational method\*" OR "content analysis" OR "constant comparative" OR "discourse analys?s" OR "discurs\* analys?s" OR "narrative analys?s" OR Heidegger\* OR colaizzi\* OR spiegelberg\* OR "Van manen\*" OR "Van Kaam\*" OR "merleau ponty\*" OR Husserl\* OR Foucault\* OR corbin\* OR strauss\* OR glaser\*)

Above combined with AND.

Found 7/7 papers in database.

## Appendix C. Practitioner Involvement and Engagement Event Details for the Qualitative Systematic Review Findings



The screenshot shows an Eventbrite event page for Adfam. At the top is the Adfam logo, which consists of a stylized orange sun-like icon with a spiral center and the word "Adfam" in a large, dark blue sans-serif font. Below the logo, the date "Dec 17" is displayed. The event title is "Parental Substance Use and Young People's Resilience: Presentation and Talk" in a bold, dark blue font. To the right of the title, there are two buttons labeled "Sales Ended" and "Details". Below the title, a subtitle reads "Online Presentation and Discussion: Parental Substance Use and Young People's Resilience". The event is organized by "Adfam", which has 271 followers, and there is a "Follow" button. The "When and where" section shows the date and time as "Thu, 17 December 2020, 10.00 - 11.30 GMT" and the location as "Online". The "About this event" section provides details about the guest speaker, Cassey Muir, a PhD Researcher at Newcastle University, and describes the event as a structured discussion followed by a Q&A session. It also mentions that the session will run from 10.00-11.30 am on Thursday 17th December. The "Tags" section includes "Online Events", "Online Conferences", "Online Charities & Causes Conferences", "#families", "#gambling", and "#gambling\_harm".

Dec 17

# Parental Substance Use and Young People's Resilience: Presentation and Talk

Online Presentation and Discussion: Parental Substance Use and Young People's Resilience

By Adfam  
271 followers

Follow

**When and where**

**Date and time**  
Thu, 17 December 2020,  
10.00 - 11.30 GMT

**Location**  
Online

**Sales Ended**  
Details

**About this event**

Join Adfam's guest speaker Cassey Muir to explore parental substance use and its impact on young people's resilience. Cassey Muir (PhD Researcher at Newcastle University) will present her recent research on the effects of parental substance use on young and adult children.

The presentation will be followed by a structured discussion, in which practitioners working with families, young people or substance use can share their experiences, share insights, and raise questions.

Sign up to the event for free to receive the online zoom invitation.

The session will run from 10.00-11.30 am on Thursday 17th December.

We look forward to seeing you there.

**Tags**

Online Events Online Conferences Online Charities & Causes Conferences #families #gambling #gambling\_harm

Link: <https://www.eventbrite.co.uk/e/parental-substance-use-and-young-peoples-resilience-presentation-and-talk-tickets-131468073547?aff=ebdsoporgprofile>



## Appendix D. Summaries of Studies Included within the Qualitative Systematic Review

Table Apx D.1. Extended descriptive summaries of included studies within the qualitative systematic review

Author, Year and Country	Main Focus	Aim	Sample: Total N, Age (mean), Gender	Parental substance use	Data collection; recruitment; and analysis	Author-identified key themes
<b>Ahuja et al. (2003)</b> UK (England)	Impacts; Coping strategies	To investigate the experiences of a sample of wives of Sikh men with alcohol problems living in the English West Midlands, and sub-samples of their daughters and husbands. The focus was upon the ways in which wives and daughters respond to or cope with their husbands/fathers' excessive drinking.	N = 7 Age = 17-23 7 females	Father's alcohol use	Semi-structured interviews; Specialist addiction treatment service for parents; Grounded theory	None included
<b>Alexanderson &amp; Näsman (2016)</b> Sweden	Impacts; Coping strategies	To describe and problematise, from a child perspective, the role of the other parent in relation to the children when one parent has addiction problems.	N = 23 Age = 6-19 Gender unknown	Parental substance use	Semi-structured interviews; Social services/support groups for children; Grounded theory	When parents live together; When parents have separated
<b>a) Bancroft et al. (2004)</b> <b>b) Backett-Milburn et al. (2008)</b> <b>c) Wilson et al. (2008)</b> <b>d) Wilson et al. (2012)</b> UK (Scotland)	a/b) ALL c/d) Impacts; Coping strategies	a) To explore older children of substance-using parents' accounts of their childhoods, their pathways to independence and the daily practices which might constitute survival, coping or resilience. b) To explore older children of substance-using parents' accounts of their childhoods and the daily practices that might be seen to constitute survival, resilience or coping, examining both the children's own agency and the help they said they grew upon. c) To identify ways in which the piecemeal nature of current policy approaches to parental substance use and youth transitions highlights the situation of some, while obscuring that of others particularly those who, while not 'care leavers', lack parental support. d) To focus on the difficult family experiences of young people affected by parental substance use.	a/b) N = 38 Age = 15-27 (19) 20 females; 18 males  c) N= subsample of 7 Age = 16-21 (18) 3 females; 4 males  d) N = subsample of 14 Age = 16-25 (18.8) 8 females; 6 males  (retrospective accounts of childhood)	Parental substance use	Semi-structured interviews with life grid; Multiple services, organisations and universities; Analysis unknown	a) Living with parental substance misuse; What helps? What hurts? Managing and getting by; Growing out of family substance misuse b) The overall picture; Children's agency and ways of 'getting by' within the home; Ways of 'getting by' outside the home: what did children do and whom did they turn to; Holding yourself together: the importance to children of beliefs, caring, loving and trusting c) Parental substance use policy: the relative invisibility of young people d) Young people's accounts of their 'families of origin'; Young people's accounts of developing family-like relationships

<b>Barnard &amp; Barlow (2003)</b> UK (Scotland)	Lived experience; Impacts	To represent the experience of parental problem drug use by children and young people.	N = 36 Age = 8-22 (14.8) 20 females; 16 males	Parental drug use (mainly heroin)	Semi-structured interviews; Treatment services/secure unit/rehabilitation unit for YP; Analysis unknown	Discovering parental drug dependence; Keeping it in the family; Responding to the discovery
<b>Bickelhaupt et al. (2019)</b> USA	ALL	To provide a novel, in-depth perspective to some of the positive and adaptive developmental strategies used by emerging Adult Children of Alcoholic's which contribute to their successful functioning as an emerging adult in terms of internalizing and externalizing behaviors.	N = 13 Age 21-25 (retrospective accounts of adolescence) 9 females; 4 males	Parental alcohol use	Semi-structured interviews; Local state University; Constant comparative analysis	Family of Alcoholism; Exhibited Adolescent Behaviors; Resiliency path to functional development; Current parent-emerging adult relationship
<b>Christensen (1997)</b> Denmark	Impacts; Coping strategies	To examine the significance of parental alcohol problems for the everyday life of the children, as seen from the children's perspective.	N = 32 Age = 5-16 14 females; 18 males	Parental alcohol use	Interviews; Alcohol abuse treatment institution for parents; Analysis unknown	A Stressful Life; Reactions to Parental Drinking; Help for Children; The Children want Attention and Help; Children Need a Break
<b>D'Costa &amp; Lavalekar (2021)</b>	Coping strategies	To explore the coping strategies of Goan adolescents living with an alcohol dependent parent	N = 15 Age = 17-19 11 females; 4 males	Parental alcohol use	Semi-structured interviews; Treatment services for parents; Thematic analysis	Seeking support; Engaging in problem-solving behavior; Practicing self-improvement techniques; Adapting to changes in perception
<b>Dundas (2000)</b> Norway	Impacts'; Coping strategies	To explore how children experience and cope with interpersonal distance in families with an alcoholic parent.	N = 17 Age = 10-21 8 females; 9 males	Parental alcohol use	Semi-structured interviews; Out-patient clinic for parents' alcohol problems; Analysis unknown	None
<b>Fraser et al. (2009)</b> UK (England)	Impacts; Coping strategies	To explore the views of parents/carers and children and young people about the impact of parental substance use and implications for services.	N = 8 Age = 4-14 4 females; 4 males	Parental alcohol use (one used drugs)	Draw & write semi-structured interviews; Social services; Phenomenological perspective	Impact on family life; Experiences of support

<b>Hagström &amp; Forinder (2019)</b> Sweden	ALL	To investigate what it means to grow up in an alcoholic family environment.	N = 19 Age = Time 1: 6-12 (8.5); Time 2: 10-16 (12.7); Time 3: 15-24 (19.4) 8 females; 11 males	Parental alcohol use (three used drugs)	Three interviews; young people who participated in the Children are People Too (CAP) programme; Narrative methods	The children's social situation; The two faces of the alcohol-dependent parent; Positioning oneself as a 'vulnerable victim'; Positioning oneself as a 'competent agent'
<b>M. Hill et al. (1996)</b> UK (Scotland)	ALL	To ascertain family members and professionals' views about needs and services. To examine children's experiences and needs from their own points of view, as a basis for the development of services and health education.	N = 27 Age = 5- 12+ Gender unknown	Parental alcohol use	Interviews; Multiple agencies and services; Analysis unknown	Children's experiences and needs; Suggestions about services needed
<b>L. Hill (2015)</b> UK (Scotland)	Lived experience; Impacts	To engage with children and young people who have been affected by parental (or significant carer) alcohol problems and to explore, from their perspectives, the impact on their lives and their experiences of support. Exploring participants' own nuanced ways of choosing to communicate about parental alcohol problems.	N = 30 Age = 9-20 16 females; 14 males	Parental/ significant carer alcohol use (1 used drugs)	Flexible methods-group work, interviews, task-based activities; voluntary organisations; Thematic analysis	Choosing to talk; All in the past...perhaps; Use of treatment services; Where I live; Choosing to talk indirectly
<b>Holmila et al. (2011)</b> Finland	Impacts; Coping strategies	To describe the lives of children with problem drinking parents from children's own perspective, emphasizing their experiences, agency and coping.	N = 70 Age = 12-18 58 females; 12 males	Parental alcohol use	Online survey with open-ended questions; Two websites for children with substance-misusing parents; Content analysis	The drinking parent and the harms caused by his/her drinking; Children's strategies of coping with the everyday life and their distress; Searching for help; Friends, relatives and professionals; The obstacles of seeking help; Experiences of successful search for help; General recommendations for children in similar situations; Help for the whole family; Separation from the family; Information, support and therapy for the children

<b>a) Houmøller et al. (2011)</b> <b>b) Bernays et al. (2011)</b> UK (England)	a) ALL b) Impacts; Coping strategies	a) To understand the processes of coping for young people affected by parents' substance misuse by focusing on the influence of family dynamics on their experiences and coping strategies. b) This booklet is based on research with young people, whose parents have problems with drugs or alcohol, to find out more about what it is like living in a family affected by parental substance misuse and what helps them cope.	N = 50 Age = 10-18 (13) 30 females; 20 males	Parental substance use	Semi-structured interviews (16 young people had follow-up interviews over 20 months); Specialist services for young people; Thematic analysis	a) Navigating substance misuse; Coping in the context of relationships; Getting support from friends and professionals b) Learning about parental substance misuse; Caring for the family; What do I appreciate in the people that I talk to?
<b>Johnson (2013)</b> USA	Lived experience; Impacts	To explore youth reports of their interactions with their substance-using mothers to determine whether the interactions: (1) shape youths' perceptions of maternal influence, (2) reveal patterns of communication, (3) lead youth to assume specific roles within the family, and (4) affect youths' involvement with other social support networks.	N = 14 Age = 14-17 (15.36) 6 females; 8 males	Biological mother's substance use (problematic use, abuse, or dependence)	Semi-structured interviews; Social services and schools; Content analysis	Influence (of mothers and fathers); Communication; Assumed Roles; Support Networks
<b>McGuire (2002)</b> UK (Scotland)	Impacts; Coping strategies	To complete a comprehensive identification of needs for children in Govan affected by parental drug use. To identify gaps in service for children of parents in Greater Govan who use drugs.	N = 7 Age = 3 under 16 and 4 over 16 Gender unknown	Parental drug use	Semi-structured interviews; Social work services and addiction treatment services; Analysis unknown	Chapter 5: Part 1-The Impact of drug use on parent's ability to care for their children; Part 2-The impact of being a parent on drug use; Part 3-The effect on children of their parents' drug use Chapter 6: Part 3-Schools and Nurseries; Part 4-Youth Provision; Part 5-The Police; Part 7-Social Work Services
<b>McLaughlin et al. (2015)</b> UK (Northern Ireland)	Coping strategies	To investigate child outcomes (substance use, mental health and education/employment) in the context of parental drinking. Phase 1: to identify/understand the factors that help a child to be resilient based on the perspectives of children currently living with parental alcohol misuse Phase 2: to elicit children who currently live with parental alcohol misuse's views on recommendations for practitioners and other professionals who work with children potentially affected by 'hidden harm'.	N = 23 Phase 1: N = 12 Age = 7-14 (10) 7 females; 5 males Phase 2: N = 11 Age = 7-14 (11) 7 females; 4 males	Parental alcohol use (hazardous or harmful drinking, dependence and alcohol use disorders)	Co-production participatory workshops; Pharos service at Barnardos; Thematic analysis	Phase 1: Living with an alcoholic parent; Sources of social support for children affected by 'hidden harm'; Coping with a parent's drinking; Leisure activity (and involvement in the community) – as a means of distraction; Childs Attitudes (the importance of being positive) Phase 2: Support from others; Activities that can act as a distraction; Coping strategies; Children's recommendation for policy and practice

<b>a) Moore et al. (2010)</b> <b>b) Moore et al. (2011)</b> Australia	a) ALL b) Impacts	a) To contribute to an understanding of how best to support children and young people and intervene effectively to redress any negative effects that may occur as a result of their parents' substance use. b) To develop and understand the experience of caring for a parent with an alcohol or other drugs issue.	N = 15 Age 11-17 8 females; 7 males	Parental substance use	Semi-structured interviews with activities for engagement; Services and organisations for young people; a) Grounded theory, b) Meaning-focused approach	a) Young people's needs; Young people's experiences of the service system; Barriers to support; What needs to be done b) Level of caring; The need to capture the expanse of the caring role (not just the level of care); Type of caring; Impact of the caring role; The needs of these young people; To be or not to be: labelling these young people as 'young carers'; Re-conceptualising young caring
<b>Mudau (2018)</b> South Africa	Impacts	To explore challenges faced by young people living with alcoholic parents at Mamokgadi village.	N = 8 Age = 14-25 4 females; 4 males	Parental alcohol use	Interviews; Mamokgadi village including schools; Thematic narrative analysis	Challenges faced by young people living with alcoholic parents; Relationships between alcoholic parents and their children; Emotional challenges; Financial challenges; Physical challenges; Educational challenges; Coping strategies used by children living with alcoholic parents; Possible solutions to challenges faced by children living with alcoholic parents
<b>Murray (1998)</b> Canada	ALL	To explore and understand the experience of parental alcoholism from an adolescent's perspective who have lived with an alcoholic parent.	N = 5 Age = 13-19 3 females; 2 males	Parental alcohol use	Three interviews over 4 months; Al-Anon, school, personal contact; Constant comparative analysis	The nightmare; The lost dream; The dichotomies: continuing the nightmare vs. pursuing the dream; The awakening
<b>Nattala et al. (2020)</b> India	ALL	To provide an in-depth account of experiences, perceptions and reactions of adolescents to their fathers' drinking, in the context of home environments affected by paternal drinking.	N = 15 Age = 10-19 (14.6) 10 females; 5 males	Father's alcohol use	Semi-structured interviews; outpatients for fathers in treatment and snowballing; Analysis unknown	Explanations of fathers' drinking; Experiences related to father's drinking; Reactions to father's drinking

<b>O'Connor et al. (2014)</b> UK (Wales)	ALL	To provide retrospective perspectives on the experiences of children and young people living in families with parental substance misuse.	N = 13 Age = 13-21 Gender unknown	Parental substance use (3 families also with parental mental health needs)	Interviews (5 YP directly and 8 YP with their parents); Crisis intervention service (child protection register); Thematic analysis	Living with neglect, trauma and violence; Living with tension; Attachments and consistency; Childhood & adulthood difficulties; Protective role & sense of agency; Aspiration, success & helpful interventions
<b>a) Offiong et al. (2020)</b> <b>b) Lewis et al. (2021)</b> <b>c) Powell et al. (2021)</b> USA	a) Impacts; Coping strategies b) Lived experience; Impacts c) Coping strategies	a) To understand connectedness among Black youth affected by parental drug use in Baltimore, Maryland USA, and identify the consequences of when connectedness is missed. b) To describe the housing experiences of youth who are affected by parental substance use. c) To describe why some strategies may be more effective in overcoming barriers to recruitment and retention efforts with Black adolescents affected by parental drug use in prevention research.	N = 14 Age = 18 – 24 (21) 6 females; 8 males	Parental drug use	Semi-structured interviews; local organisations; Content analysis	a) Missing parental connections; The desire for consistent, trusted adults; The consequences of missed connections b) Frequent and unpredictable housing transitions; Repeated trauma exposures related to housing instability; The lasting effects of housing instability. c) Safe people and places minimize re-traumatization; Teaming up with community partners increases acceptability; Addressing a range of needs helps adolescents survive; Relatable facilitators
<b>a) Park et al. (2016)</b> <b>b) Park &amp; Schepp (2017)</b> <b>c) Park &amp; Schepp (2018)</b> South Korea	a) Lived experience; Impacts b/c) Impacts; Coping strategies	a) To understand the lives of children of alcoholics who had grown up in Korean alcoholic families under the influences of the Korean traditional culture (Confucianism). b) To determine the psychosocial adaptation process of Korean children who grew up with a father with alcohol dependency. c) To suggest a theoretical model of resilience capacity by validating and extending one of the existing nursing theories of resilience—the society-to-cell model.	a & b) N = 20 Age = 19-30 (24.55) 13 females; 7 males  c) N = 22 (2 additional to paper's a/b) Age = 19-30 (25) 14 females; 8 males	a & b) Father's alcohol use  c) Parental alcohol use (inclusion of two mothers)	Two semi-structured interviews; Two universities, one college, online self-help groups, siblings; a) Thematic analysis, b) Grounded theory, c) Content analysis	a) Losing family; Life with holding a bomb; My life ruined; Being bound b) Being trapped; Awakening; Struggling; Blocking; Understanding; Separating c) Social-level factors; Community-level factors; Family-level factors; Individual-level factors
<b>Ramirez et al. (2014)</b> Mexico	Lived experience; Impacts	To understand the social construction and personal meaning of having an alcoholic father from the child's perspective.	N = 4 Age = 20-22 (21) 3 females; 1 male	Father's alcohol use	Life Stories method with interview; One University; Content analysis	Change in perspective of a child and his/her participation in the family

<b>Reupert et al. (2012)</b> Australia	Impacts; Coping strategies	To identify the issues when engaging children whose parents have a dual diagnosis into research, and present their needs and preferred supports.	N = 12 Age = 8-15 (11.7) 6 females; 6 males	Parental substance use (and co-occurring mental health diagnosis)	Semi-structured interviews; Service for dual diagnosis families; Interpretative phenomenological analysis	Meaning of family; Understanding the parent and his or her 'illness'; Coping and reacting; Preferred supports
<b>a) Ronel &amp; Haimoff-Ayali (2010)</b> <b>b) Ronel &amp; Levy-Cahana (2011)</b> Israel	Impacts; Coping strategies	a) To examine the adolescent children of parents addicted to drugs and alcohol as "persons-in-context" who were brought up against the background of a parent's addiction. b) To re-analyse the findings of a comprehensive study of the children of substance-dependent parents, to identify subjective risk and protective factors.	N = 19 Age = 13-22 (18) 7 females; 12 males	Parental substance use	Semi-structured interviews; Treatment services for parents and services for young people; Qualitative–constructivist method	a) Yearning—The Vision of the Ideal Family; Strong or Not There? The Role of the Nonaddicted Mother; Seeking Support from Other Family Members b) Subjective Risk Factors; Subjective Protective Factors;
<b>a) Silva &amp; Padilha (2013a)</b> <b>b) Silva et al. (2013b)</b> Brazil	Lived experience; Impacts	a) To describe adolescents' social representations on alcoholism and the habit of consuming alcoholic drinks and to analyze alcoholism's implications in the adolescents' life histories. b) To identify the social representations of adolescents about alcohol from their life stories; To analyse the attitudes of teenagers facing the reasons that lead them to drink or not alcoholic beverages.	N = 40 Age = 15-20 30 females; 10 males	Parental alcohol use	Life history- semi-structured interviews; Urban Tribes Project; Thematic analysis	a) Alcoholism and its consequences in the family b) Living with an alcoholic family and alcohol in family daily life
<b>Tamutienė &amp; Jogaitė (2019)</b> Lithuania	Impacts; Coping strategies	To learn to whom children disclose experiences of harm caused by their parents' or carers' substance abuse.	N = 23 Age = 8-18 18 females; 5 males	Parental alcohol use (3 used drugs)	Semi-structured interviews; Social services; Thematic analysis	Disclosure of alcohol-related harm to informal networks; Disclosure of alcohol-related harm to formal networks; Specialists' role
<b>Tinnfält et al. (2011)</b> Sweden	Coping strategies	To describe adolescent children of alcoholics' perspectives on disclosure and support.	N = 27 Age = 12-19 24 females; 3 males	Parental alcohol use	Interviews/focus groups; Support groups; Content analysis	Designing a Story, and Risk Assessment of Adults; Support from Adults, Trust—Distrust
<b>Tinnfält et al. (2018)</b> Sweden	ALL	To explore the consequences for a child of having an alcoholic parent.	N = 18 Age = 7-9 8 females; 10 males	Parental alcohol use (some also used substance)	Interviews; Treatment center for parents' addiction; Content analysis	Feeling Sad When My Parents are Fighting; Trying to Control the Situation; Having Bad Experiences; Wishing for Change; Despite Problems, Doing Things Together with a Loving Parent

<b>Turning Point (2006)</b> UK (England & Wales)	Impacts; Coping strategies	To understand the destructive impact alcohol misuse can have on the entire family.	N = unknown Age = 12-18 Gender unknown	Parental alcohol use	Interviews; Turning Point services; Analysis unknown	The impact of alcohol misuse on families; What stops children and parents getting help; What must be done for children, parents and families
<b>a) Velleman &amp; Reuber (2007)</b> England, Germany, Poland, Spain, and Malta <b>b) Templeton et al. (2009)</b> UK (England)	Impacts; Coping strategies	a) To hear from young people across Europe what it was like for them to live in an environment where both of these parental problems were present (domestic violence and abuse and alcohol problems). b) To talk to young people aged 12–18 years in an English city about their experiences of living with parental alcohol misuse and parental domestic abuse.	a) N = 45 (Germany (n = 21), Poland (n = 10), Spain (n = 6), England (n = 5) and Malta (n = 3)) Age = 12-18 (14.89) 29 females; 16 males  b) N = 8 (3 additional to England sample) Age = 12-18 7 females; 1 male	Parental alcohol use (and domestic violence/abuse)	Mixed method interview- standardized questionnaire with open ended questions (Alcohol Violence Teenager Version); Treatment services for parents, support services for the young person; Thematic analysis	a) Coping; Support; Support about the alcohol and domestic abuse problems; What has helped in the past; What would have helped in the past; Help in the present b) Experiences and effects; Coping; Support
<b>a) Wangensteen et al. (2019a)</b> <b>b) Wangensteen et al. (2019b)</b> <b>c) Wangensteen et al. (2020)</b> Norway	ALL	a) To explore young people's perceptions and reflections about growing up with parents who have substance use disorder. b) To explore the narratives of young people regarding the circumstances that protected and supported them as they grew up around parental SUD during their childhood. c) To explore how young people with parents with substance use problems and patients in treatment conceptualized and understood substance use problems and to discuss the impact of experiences of stigma and shame as they are related to substance use problems.	a) N = 12 Age = 13-26 9 females; 3 males  b) N= subsample of 5 Age = 21-26 (23.6) 4 females; 1 male  c) N= subsample of 7 Age = 13-26 5 females; 2 males	Parental substance use (mostly use of illegal substances)	a) Semi-structured interviews; Treatment services for parents; a) Interpretative phenomenological analysis b/c) Narrative paradigmatic analysis	a) Mixed and contradictory emotions; Struggling with closeness and distance; Lack of professional support b) Safe living conditions; Significant relationships; Respectful and caring conversations with professionals c) Incomprehensible behavior and situations; Trying to understand the development and maintenance of substance use problems; Attitudes of others
<b>Yusay &amp; Canoy (2019)</b> Philippines	Impacts; Coping strategies	To examine the struggles described by the young Filipino family members about their parent's drug use, surrendering, and recovery. Focusing on identifying and acknowledging the emotional consequences of parental drug use for young people living in the Philippines.	N = 13 Age = 13-19 10 females; 3 males	Parental drug use	Interviews; Community-based intervention program for parent's substance use; Narrative analysis	Community narrative of shaming; Anger and hurt as forms of active resistance; Narrative of surrender: re-appropriating fear of death and shame



## Appendix E. Full Quality Appraisal for the Qualitative Systematic Review

Table Apx E.1. Full quality appraisal of included studies within the qualitative systematic review, organised by relevance, including Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist answers and narrative summary of quality and relevance

→ CASP	1. Aims	2. Method	3. Design	4. Recruitment	5. Data collection	6. Researcher Bias	7. Ethics	8. Analysis	9. Findings	10. Value	Narrative Summary on quality and relevance
Authors ↓											
<b>Key Paper A:</b> Most relevant and conceptually rich, no or few issues with quality											
<b>Index Paper:</b> <b>Bancroft et al. (2004)</b> UK (Scotland) Substance Misuse  Linked to Backett-Milburn et al. (2008), Wilson et al. (2008) and Wilson et al. (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Bancroft et al (2004) and Backett-Milbuen et al. (2008): Reporting is clear and consistent. This study, presented as a report, was important as older children who have grown up with parental substance misuse were an understudied group due to falling between child and adult service provision. Some justification and detail were missing regarding data collection and analysis but findings and implications were extensive and valuable to the review. Only concern would be the impact the researchers had on the results. The following three papers were based on this report. Wilson et al. (2008): The authors explore transitions and policy in a sub-sample of the participants from the main report. Wilson et al. (2012): The authors explore difficult family dynamics in a sub-sample of the participants from the main report.
<b>Bickelhaupt et al. (2019)</b> USA Alcohol Use	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Reporting of the study design, method and data analysis were clear and explicit. Authors included detailed information regarding recruitment, inclusion and exclusion criteria with justifications, example of their topic guide questions, as well as use of audio recordings. There is explicit discussion on the analysis process, a reflexive journal was kept and used alongside analysis and data collection, triangulation and member checks were undertaken, and a table is included to show how the authors got to their themes. Variety of participants' experiences are also presented. This is valuable research, as it suggests avenues for practice, presents a conceptual model of the theme findings, as well as focuses on the relationship with the parent who uses alcohol. To note, the sample does not include young people under the age of 18.
<b>Hagström &amp; Forinder (2019)</b> Sweden Alcohol Use	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Yes	A lot of clarity and detail regarding reporting of methods and analysis. More detail needed to be reported with regards to follow up recruitment. There are explicit findings, with rich contextual data about participants. A longitudinal study offers valuable insights in how experiences may change over time. Limited implications reported.
<b>Index Paper:</b> <b>Houmøller et al. (2011)</b> UK (England) Substance Misuse  Linked to Bernays et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes	Houmøller et al. (2011): Reporting of the design and methods were clear and somewhat transparent, with justifications. However, there was a lack of reporting on the interview topic guide. The data analysis lacked clear detail, but the use of multiple analysts was discussed. There was no reflexivity reported, to account for biases in data collection and analysis. There was a large explicit and relevant findings section, with rich contextual data for participants. Within a UK based population, there was a lot of practical implications discussed. Bernays et al. (2011): Due to the nature of this paper, a report with a specific purpose of communicating findings to young people, parents and professionals, areas of the design and methods were not reported on. The entire report focuses on findings as it is a narrative of the thoughts shared by the young people interviewed. For the purpose of the systematic review it is a relevant report as it covers all of the main topics of interest.

<b>Index Paper:</b> <b>Moore et al. (2010)</b> Australia Substance Misuse  Linked to Moore et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moore et al. (2010): Considerations for this study were to the most part detailed and justified. There are multiple data collection methods, some which have been explained and others that have not (e.g. topic guide). Data analysis was explicit, but no reflexivity mentioned. However, there were efforts to triangulate, with multiple analysts and respondent validation in the form of a workshop with young people. The findings were clear and explicit, and well supported by data, and relevant for the systematic review. The authors gave valuable practical implications for intervening. Moore et al. (2011): The focus of this paper is narrow, exploring the caring role of these young people and therefore less relevant to the scope of the review.
<b>Murray (1998)</b> Canada Alcohol Use	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Reporting was generally explicit and justified, with only a few details missing surrounding the methods e.g. recruitment strategies. The author discusses the use of field notes throughout the process, and how their ideas, prejudices etc. may bias the analysis. Quotes were provided, supporting a thick description of the findings, as well as reporting a conceptual map of adolescents' experiences. The authors have also discussed implications for practice.
<b>Nattala et al. (2020)</b> India Father's alcohol dependence	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes	Reporting of aims, recruitment strategies and data collection were clear and explicit. There was a lack of reporting regarding the analysis method. Potential biases from the researchers, and the credibility of the findings were not discussed. However, the findings were clear and well presented, with rich contextual quotes that covered all aspects of the review.
<b>Tinnfält et al. (2018)</b> Sweden Alcohol Use	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Most details were reported allowing for some transparency. Reflexivity was not reported, but would have been important with three researchers undertaking the study. The findings are explicit, and rich with a mixture of long and short quotes and relevant to the scope of the review. Some practical implications reported, with exploration of possibility of transferability to children in similar situations.
<b>Key Paper B: Relevant but with limited themes or data, and/or some issues with quality</b>											
<b>Barnard &amp; Barlow (2003)</b> UK (Scotland) Drug Dependence: Heroin	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Can't tell	Yes	Yes	Reporting of the design and methods of the study lacked transparency e.g. justification of interviews, the topic guide, data collection. Limitations were not explored, and nor were any biases from the research team and potential implications (especially as the authors were interviewing the parents too, bias from knowing both sides). Ethical considerations were also not mentioned, but consent was taken. A major issue within this paper is that the authors have not reported any data analysis- there is a clear lack of transparency as to how they got to the themes. However, this is a valuable paper as there are limited papers in this review that look solely at parental drug dependence (heroin) from the young person's perspective. It provides a perspective that might be missed otherwise. The researcher has discussed the contribution the study makes to practice, as well as transferred to other populations, e.g. children living with alcohol misuse unacknowledged by family members.
<b>D'Costa &amp; Lavalekar (2021)</b> India Alcohol Use	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Reporting of design and method were generally explicit and justified, with acknowledgment of reflexivity. However, reporting of data analysis lacked clarity and there was no contextual information provided for participant quotes. Study mainly focused on one area of the review; coping strategies.
<b>Fraser et al. (2009)</b> UK (England) Substance Use	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes	Reporting of the design and methods were generally explicit and justified, with only a few details missing surrounding data collection. However, reporting of data analysis lacks some clarity and transparency, with no reflexivity. There were two analysts but discussion was based on key areas of interest identified by the commissioning agency. Some interesting findings with regards to experiences and impacts with images included, but the findings also include parents' perspectives. This paper reports one of the youngest samples included in the review (4-14 years).

<b>Johnson (2013)</b> USA Mother's Substance Misuse	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Reporting of design and methods were clear and somewhat transparent, including recruitment and data collection, but justifications were limited. The data analysis lacked some details, but the authors included other researchers outside of the primary team to aid analysis. There was no reflexivity reported, to account for biases in data collection and analysis. The findings are somewhat limited, exploring mainly interactions with the substance using parent. This study also covers a specific subset of young people in that it is focused on African Americans. Practical implications were discussed.
<b>McGuire (2002)</b> UK (Scotland) Drug Use	Yes	Yes	Yes	Yes	Can't tell	No	Yes	Can't tell	Yes	Yes	Lack of explicit and transparent reporting of the sample and their respective parental drug use. The sample size is also quite small (7 young people) but highlights the difficulty in recruitment. No data analysis or reflexivity reported. Findings are detailed, but also includes parents' and professionals' perspectives amongst young peoples' perspectives. However, this is a relevant and important study as it focuses on parental drug use within a UK context, with specific recommendations.
<b>McLaughlin et al. (2015)</b> UK (Northern Ireland) Alcohol Use	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Can't tell	Yes	Reporting of design and methods were detailed and had some justifications. However, there was a lack of detail with regards to analysis, and the findings were limited. Valuable in terms of approaches and strategies, and lots of recommendations.
<b>O'Connor et al. (2014)</b> UK (Wales) Substance Misuse	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes	The methods of the study were mainly explicitly reported, with some justifications missing. The researchers do not explore their own biases and assumptions, and any impact of this on data collection, analysis and reporting. There was a lack of some details in reporting of data analysis (e.g. how the thematic framework was produced) but multiple analysts were employed. The findings presented have rich contextual data, but also include parents' perspectives. The findings were relevant to the scope of the review but there was also a focus on child protection interventions.
<b>Index Paper: Offiong et al. (2020)</b> USA Drug use  Linked to Lewis et al. (2021) and Powell et al. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Offiong et al. (2020): Clear and explicit reporting throughout. Transparent data collection and analysis methods, with discussion on reflexivity and the credibility of findings; using triangulation, negative case analysis, and peer debriefing. However, the findings reflect the narratives of parents and professionals, as well as young people with a focus on relationships. Lewis et al. (2021): This study focuses on one narrow element of young people's experiences and impacts; housing instability. Powell et al. (2021): The main aim of this study is to explore recruitment and retention of young people whose parents use drugs. However, there is inclusion throughout the results section of some relevant data for the scope of this review.
<b>Index Paper: Park et al. (2016)</b> South Korea Father's Alcohol Use  Linked to Park et al. (2017) and Park & Schepp (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Park et al. (2016): Reporting of recruitment and data collection were transparent, with some justifications missing. The data analysis was satisfactory but lacked some details. There is no mention of potential bias from the researchers, however the use of two interviews allowed for participant validation. This study was focused on one specific cultural population and only father's alcohol use, transferability may be questionable. To note, the sample does not include young people under the age of 18. Park et al. (2017): A conceptual map of adaptation was produced. Park & Schepp (2018): This paper included both father's and mother's alcohol use. A theoretical model of resilience capacity was produced.
<b>Reupert et al. (2012)</b> Australia Substance Misuse (& Mental Health Disorder)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Reporting was to the most part explicit and justified. Some mention of reflexivity during data collection, but potential bias from the authors during analysis was not discussed. However, multiple authors analysed the data, and they used respondent validation to check for accuracy. The findings were well supported with rich quotes, and contextual information was provided. However, this study presented findings on young peoples' experiences of dual diagnosis: parental mental health and parental substance use, and not just parental substance misuse alone, issues with transferability to other study populations may be present.

<b>Index Paper: Ronel &amp; Haimoff-Ayali (2010)</b> Israel Mainly drugs with alcohol  Linked to Ronel & Levy-Cahana (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	The methods of the study were mostly explicitly stated, but justification was lacking. The research team did not explore their biases through reflexivity. Data analysis was explicit, with examples of codes, themes and how the present paper was presenting only one of those themes. There were multiple analysts included. The authors reported a rich, clear findings section, with contextual data regarding the participants. The findings mainly focused on experiences, and not impacts or coping strategies, of a specific population in Israel.
<b>Tinnfält et al. (2011)</b> Sweden Alcohol Use	Yes	Yes	Can't tell	Can't tell	Can't tell	No	Yes	Yes	Yes	Yes	Most details were reported for the methods and design, but with limited justification. Clear explicit data analysis reported, with examples of how codes became themes. However, no report of reflexivity. Clear findings section with rich quotes, but limited to a narrow focus of disclosure and support. The authors also proposed practice implications.
<b>Turning Point (2006)</b> UK (England & Wales) Alcohol Use	Yes	Yes	Can't tell	Can't tell	Can't tell	No	Can't tell	Can't tell	Yes	Yes	Reporting lacked clarity and transparency across all main areas: this may be due to the publication type, a report. There was an explicit findings section with relevant data for the review- but the young people's perspectives are mixed with the author's interpretations and parents' and service providers' views.
<b>Index Paper: Wangenstein et al. (2019a)</b> Norway Substance Misuse  Linked to Wangenstein et al. (2019b) and Wangenstein et al. (2020)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes	There was a lack of clarity and justification with regards to the design and methods, especially with regards to the recruitment strategy. There was satisfactory description of the interview topics. Data analysis was carried out by two analysts but there was no reflexivity and potential researcher bias reported. The reported findings were rich, including contextual information, and some practical implications are reported. All young people were at some point in foster care but not at the point of interview (independent living), the findings reflect these experiences. Wangenstein et al. (2020): Findings include both young peoples' and parents' narratives, and is therefore quite limited in detail and richness.
<b>Yusay &amp; Canoy (2019)</b> Philippines Drug use	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Most details were reported clearly and satisfactorily, with the exception of data collection, whereby there was limited reporting on the interview process and topic guide. A rich findings section was presented with considerable reporting of potential interventions based on the findings. However, the context is very specific to the Philippines Anti-Illegal Drugs Campaign (i.e. drug war) and those who surrendered to the police as a first step to stop their illegal activities.
<b>Satisfactory:</b> Less relevant to review with few or major issues with quality OR relevant but major issues with quality											
<b>Ahuja et al. (2003)</b> UK (England) Father's Alcohol Use	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Limited	While the aim was clear, it was focused on the wives of alcohol users rather than the children (in this case daughters). There is lack of transparency with some reporting of the design and methods, including how the interviews were managed, and ethical considerations around interviewing YP in their family home, with the substance user around. Data analysis lacked clarity, and again was more focused on analysis of the wife's data. There are limited findings and implications for young people, with focus on the role a daughter can have in their father's treatment. However, this is a UK based study, and focuses on Sikh families, adding a cultural diversity to this review.
<b>Alexanderson &amp; Näsmän (2016)</b> Sweden Substance misuse	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Limited	Detailed and somewhat explicit reporting, with some justification. Limited detail on reflexivity and potential bias from the researcher (especially with some personal contacts). Some contextual information missing around participants. Valuable in terms of exploring the role of the non-using parent as support and coping strategy, but limited with regards to experiences, impacts and other coping strategies.

<b>Christensen (1997)</b> Denmark Alcohol Use	Yes	Yes	Can't tell	Can't tell	Can't tell	No	Can't tell	Can't tell	Can't tell	Yes	Reporting lacked sufficient detail and transparency in many areas, such as methods of recruitment, data collection and analysis. There was no reflexivity mentioned or potential biases explored. Findings were supported with rich quotes with some contextual information. This study is valuable in its application for understanding the lived experience, impacts, and flaws with current approaches and strategies for supporting children but major issues with quality.
<b>Dundas (2000)</b> Norway Alcohol Use	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	No	Yes	Limited	Lack of clarity reported for recruitment strategy and data analysis. Inconsistencies with data collection and findings, wider topics covered in the interview but only limited findings presented. Some reflexivity mentioned during data collection, but no triangulation for analysis. Limited quotes to illustrate findings, mainly for the author's hypotheses. Very specific focus on cognitive/affective distancing as a coping strategy. Limited implications discussed but coping mechanisms useful for intervention development.
<b>M. Hill et al. (1996)</b> UK (Scotland) Alcohol Use	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	No	Can't tell	Yes	Lack of clarity reported for recruitment strategy, including the ages of the young people recruited. Reporting for data collection and analysis lacked transparency, with no reflexivity. Team of researchers analysed the findings, but unclear how, which undermines the findings presented. However, there are many practical implications explored within a UK context.
<b>L. Hill (2015)</b> UK (Scotland) Alcohol Use	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes	Reporting of the study design and methods lacked some explicit detail, especially with regards to the 'flexible research methods' used. However, justification of the varied and creative methods was explored and allowed for various opportunities for children to provide input and feedback. The author has not reported on their reflexivity and potential bias, which may be important due to their range of flexible/creative methods. There is not an in-depth description of analysis, and it is not clear how the themes were derived from the data. The findings are thin and more to do with the methods used than exploring young people's experiences and views.
<b>Holmila et al (2011)</b> Finland Alcohol Use	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Can't tell	Yes	Yes	Reporting lacked clarity in places, especially around the area of parental substance misuse of interest, with contradictions in reporting. The focus was on problem drinking parents but recruitment and data collection included young people who experience parental substance use (alcohol and drugs). As this was a web-based survey, there was limited qualitative analysis and thin results reported, without contextual participant data. However, the area of interest was around coping.
<b>Mudau (2018)</b> South Africa Alcohol Use	Yes	Yes	Yes	Can't tell	Can't tell	No	Yes	Can't tell	Can't tell	Yes	Reporting lacked transparency, with regards to the design and methods (e.g. topic guides). There were also inconsistencies in recruitment and sampling (e.g. time or data saturation). There were no references to any efforts to triangulate or establish reliability of findings, including no reflexive measures, which would have been important due to the author residing in the community of the young people. Reporting of the data analysis lacked transparency, making it hard to understand how themes were derived from the data. The findings were thin and descriptive of the quotes provided. The author reported practice implications and recommendations that are valid but context specific, maybe less transferable. While this paper lacks transparency it offers a divergent cultural perspective to the UK studies (predominantly white British participants).
<b>Ramirez et al. (2014)</b> Mexico Father's Alcohol Use	Yes	Yes	Yes	Can't tell	Can't tell	No	Can't tell	No	Yes	Yes	Reporting lacked clarity and detail, especially with regards to the recruitment, data collection and analysis, this may be due to the nature of translation. Furthermore, while the findings were detailed, they focused on experiences of 4 young people from one further education establishment in Mexico.
<b>Index Paper: da Silva &amp; Padilha (2013a)</b> Brazil Alcohol Use	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Limited	Reporting lacked some detail in areas for both papers, including recruitment procedures, data collection and analysis. While there may be fewer issues with regards to quality, the findings were limited and less relevant to the scope of the review- with a focus on adolescence use of alcohol. The focus on parental alcohol use was not clear – the authors focus on living with family alcohol use but they do state the family member was: 'in most cases, the mother or father'.

Linked to da Silva et al. (2013b)											
<b>Tamutienė &amp; Jogaitė (2019)</b> Lithuania Alcohol Use	Yes	Yes	Can't tell	Yes	Yes	No	Yes	Yes	Yes	Yes	Most details were reported, allowing for transparency, but limited justifications. Reporting was not reflexive, and no triangulation of methods were reported. There was a rich findings section, with contextual information but limited to a narrow focus of disclosure- less relevant for the scope of the review. The authors also proposed practice implications, but again this was mainly with regard to supporting disclosure.
<b>Index Paper: Velleman &amp; Reuber (2007)</b> England, Germany, Poland, Spain, and Malta Alcohol Use (& Violence)  Linked to Templeton et al. (2009) UK (England)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	No	Limited	Velleman & Reuber (2007): Reporting of qualitative data collection and analysis lacked clarity and transparency, authors included more detail for the quantitative aspects of the questionnaire. The findings included are satisfactory, with limited contextual information, and with a focus on domestic violence and parental alcohol problems. Practical implications have been explored. Templeton et al. (2009): Findings are thin and supported with notes the authors took during the process.

## Appendix F. Included Studies within Each Theme of the Qualitative Systematic Review

Table Apx F.1. Table showing which included studies within the qualitative systematic review are related to each theme and sub-theme.

First Author (Year)	Theme 1: Unpredictability				Theme 2: Impacts				Theme 3: Control/agency		Theme 4: Coping/resisting		Theme 5: Support		
	1	2	3	4	1	2	3	4	1	2	1	2	1	2	3
Ahuja (2003)	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓			✓	
Alexanderson (2016)	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓	✓		✓
Bancroft (2004)*	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
* <i>Backett- Milburn, 2008</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
* <i>Wilson, 2008</i>		✓		✓	✓	✓					✓	✓	✓	✓	
* <i>Wilson, 2012</i>	✓			✓		✓	✓		✓			✓	✓		
Barnard (2003)	✓					✓	✓	✓	✓	✓	✓	✓		✓	
Bickelhaupt (2021)	✓	✓			✓	✓	✓		✓		✓			✓	✓
Christensen (1997)	✓	✓				✓	✓		✓	✓		✓			✓
D'Costa (2021)	✓	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓	✓	✓
Dundas (2000)				✓	✓	✓	✓		✓	✓	✓		✓	✓	

Fraser (2009)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓
Hagström (2019)		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Hill (1996)	✓	✓	✓		✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
Hill (2015)	✓	✓		✓	✓	✓		✓		✓		✓	✓	✓	✓
Holmila (2011)			✓		✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
Houmøller (2011)*	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
<i>*Bernays, 2011</i>	✓	✓	✓	✓		✓	✓		✓	✓		✓	✓		✓
Johnson (2013)	✓	✓	✓	✓	✓	✓		✓	✓			✓	✓		✓
McGuire (2002)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓		✓
McLaughlin (2015)			✓	✓		✓			✓			✓	✓	✓	✓
Moore (2010)*	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<i>*Moore, 2011</i>	✓	✓	✓	✓		✓		✓	✓	✓				✓	✓
Mudau (2018)		✓			✓	✓	✓	✓		✓		✓	✓	✓	✓
Murray (1998)	✓	✓	✓	✓		✓	✓				✓	✓			✓



Nattala (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
O'Connor (2014)	✓	✓	✓	✓	✓	✓	✓		✓		✓		✓	✓	✓
Offiong (2020)*		✓	✓	✓	✓	✓	✓	✓			✓		✓		
<i>*Lewis, 2021</i>			✓	✓	✓	✓		✓			✓		✓	✓	✓
<i>*Powell, 2021</i>					✓					✓		✓	✓		✓
Park (2016)*	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
<i>*Park, 2017</i>	✓	✓			✓	✓	✓		✓	✓				✓	✓
<i>*Park 2018</i>				✓	✓			✓		✓		✓		✓	✓
Ramirez (2014)	✓	✓	✓		✓	✓		✓	✓	✓				✓	
Reupert (2012)	✓		✓	✓	✓	✓	✓	✓	✓			✓			✓
Ronel (2010)*			✓	✓	✓	✓	✓		✓	✓	✓		✓	✓	
<i>*Ronel, 2011</i>			✓			✓		✓			✓		✓	✓	
Silva (2013a)*		✓			✓	✓		✓		✓					
<i>*Silva, 2013b</i>	✓	✓						✓							

Tamutiené (2019)				✓	✓	✓	✓	✓			✓	✓	✓	✓	✓	✓
Tinnfält (2011)						✓					✓	✓	✓	✓	✓	
Tinnfält (2018)	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓				✓
Turning Point (2006)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Velleman* (2008)		✓			✓	✓			✓	✓	✓	✓				✓
<i>*Templeton, 2009</i>		✓	✓	✓	✓	✓		✓	✓	✓	✓	✓		✓	✓	
Wangensteen (2019a)*	✓	✓			✓	✓	✓		✓			✓				✓
<i>*Wangensteen, 2019b</i>	✓	✓		✓	✓	✓	✓		✓				✓	✓		
<i>*Wangensteen, 2020</i>		✓			✓		✓					✓				✓
Yusay (2019)		✓			✓	✓	✓	✓	✓	✓		✓				

## Appendix G. NHS Ethical Approval, HRA Approval, and COVID-19 Amendment

*Figure Apx G.1. Letter from Research Ethics Committee (REC) with favourable opinion  
subject to minor conditions/alterations*



### Yorkshire & The Humber - Leeds West Research Ethics Committee

NHSBT Newcastle Blood Donor Centre  
Holland Drive  
Newcastle upon Tyne  
NE2 4NQ

Telephone: 0207 972 25 04  
Fax:

**Please note:** This is the  
favourable opinion of the  
REC only and does not allow  
you to start your study at NHS  
sites in England until you  
receive HRA Approval

20 January 2020

Ms Cassey Muir  
PhD Student  
Population Health Sciences Institute, Newcastle University  
Baddiley-Clark Building, Newcastle University  
Richardson Road  
Newcastle upon Tyne  
NE2 4AX

Dear Ms Muir

<b>Study title:</b>	<b>Qualitative research to inform development of an intervention to promote resilience in young people affected by parental substance misuse.</b>
<b>REC reference:</b>	<b>20/YH/0010</b>
<b>IRAS project ID:</b>	<b>270744</b>

The Research Ethics Committee reviewed the above application at the meeting held on 10 January 2020. Thank you for attending to discuss the application.

### **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Number	Condition
1.	The PIS should add a sentence to explain travel expenses.
2.	The consent form should have a sentence added to explain confidentiality and when information may need to be shared with other services, such as the Police.
3.	The Professional Information Sheet should have the phrase 'substance use' changed to say 'substance misuse'.
4.	The Chief Investigator, Cassie Muir, should not conduct any interviews with children under the age of 18 until she has completed Safeguarding training either face to face or online. The Chief Investigator should send a copy of her certificate to the Committee after completion of the formal training.
5.	The PIS must explain that a transcription service will be used and that they have a confidentiality agreement with the sponsor.
6.	The prototype should be submitted as an amendment. This should be done after workshops 1, 2 and 3 but before workshop 4. This is Workshop 4: 'Road-test' the prototype (Young people and possibly professionals) as defined in document SPRing_Workshop Guide_ALL (26_11_19) V1.0

**You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

#### Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee ( see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

#### Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **After ethical review: Reporting requirements**

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

## Ethical review of research sites

### NHS/HSC Sites

The favourable opinion applies to all NHS/HSC sites taking part in the study taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

## Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment poster for young people- Interview]	V1.0	02 December 2019
Copies of advertisement materials for research participants [Recruitment poster for young people- Workshop]	V1.0	02 December 2019
Copies of advertisement materials for research participants [Recruitment poster for professionals- Workshop]	V1.0	02 December 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter for Insurance & Idemnity]	V1.0	25 July 2019
Interview schedules or topic guides for participants [Interview topic guide for 11-17 year olds]	V1.0	26 November 2019
Interview schedules or topic guides for participants [Interview topic guide for 18-25 year olds]	V1.0	26 November 2019
Interview schedules or topic guides for participants [Optional activities to facilitate interviews]	V1.0	26 November 2019
Interview schedules or topic guides for participants [Workshop Guide]	V1.0	26 November 2019
IRAS Application Form [IRAS_Form_05122019]		05 December 2019
Letter from funder [Studentship Letter]	V1.0	19 September 2018
Letter from sponsor [Sponsorship Letter from Newcastle Univeristy (Kay Howes)]	V1.0	27 November 2019
Non-validated questionnaire [Demographics form for 11-17 year olds]	V1.0	26 November 2019
Non-validated questionnaire [Demographics form for 18-25 year olds]	V1.0	26 November 2019
Participant consent form [Consent form to contact parents]	V1.0	26 November 2019
Participant consent form [Consent form to contact young people]	V1.0	26 November 2019
Participant consent form [Consent form for over 14 years - Interview]	V1.0	26 November 2019
Participant consent form [Consent form for over 14 years -	V1.0	26 November 2019



Workshops]		
Participant consent form [Consent form for professionals workshop]	V1.0	26 November 2019
Participant consent form [Assent form for under 14 years and consent form for parents - Interview]	V1.0	26 November 2019
Participant consent form [Assent form for under 14 years and consent form for parents - Workshop]	V1.0	26 November 2019
Participant information sheet (PIS) [Information leaflet for young people- Interview]	V1.0	26 November 2019
Participant information sheet (PIS) [Information leaflet for parents- Interview]	V1.0	26 November 2019
Participant information sheet (PIS) [Information leaflet for young people- Workshop]	V1.0	26 November 2019
Participant information sheet (PIS) [Information leaflet for parents- Workshop]	V1.0	26 November 2019
Participant information sheet (PIS) [Information leaflet for professionals- Workshop]	V1.0	26 November 2019
Referee's report or other scientific critique report [Project approval for this study from panel of assessors, head of school and Dean ]	V1.0	19 November 2019
Research protocol or project proposal [Qualitative Protocol for SPRing study]	V1.0	02 December 2019
Summary CV for Chief Investigator (CI) [CI and Student Cassey Muir CV]	V1.0	
Summary CV for student [CI and Student Cassey Muir CV]	V1.0	
Summary CV for supervisor (student research) [Supervisor Eileen Kaner CV]	V1.0	
Summary CV for supervisor (student research) [Supervisor Ruth McGovern CV]	V1.0	
Summary CV for supervisor (student research) [Supervisor Judi Kidger CV]	V1.0	
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of study]	V1.0	26 November 2019

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

**20/YH/0010**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely  
pp



**Dr Rhona Bratt**  
**Chair**

E-mail: [nrescommittee.yorkandhumber-leedswest@nhs.net](mailto:nrescommittee.yorkandhumber-leedswest@nhs.net)

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Ms Kay Howes, Sponsor's Representative



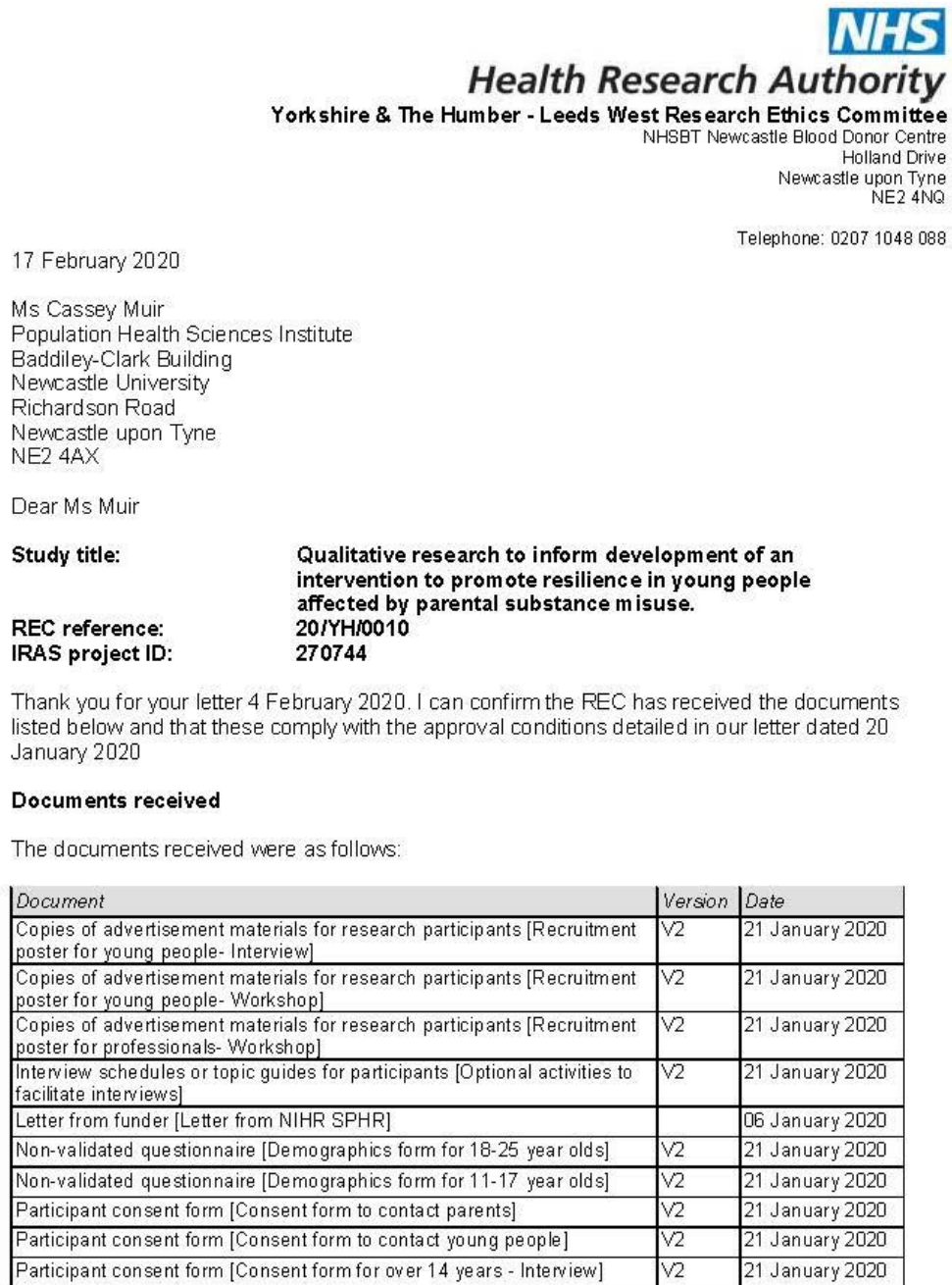
Yorkshire & The Humber - Leeds West Research Ethics Committee

Attendance at Committee meeting on 10 January 2020

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Nathan Beebe	Support Assistant	No	
Dr Rhona Bratt	Retired Multimedia Project Manager	Yes	
Mr Jon Cohen	Partner (Pharmacist)	Yes	
Mrs Kerrie Davies	Principal Clinical Scientist	Yes	
Dr Martin Elliott	Consultant Paediatric Oncologist	Yes	
Miss Aikaterini Katsouraki	Junior Associate	No	
Ms Sarah Kirkland	Clinical Studies Officer	Yes	
Dr Vera Neumann	Retired Consultant in Rehabilitation Medicine	Yes	
Mrs Hannah-Claire Newman	Cardiology Research Nurse	Yes	
Dr Bing-Chiu Pang	GP	Yes	
Dr Susan Partridge	Teaching Fellow in Biomechanics	Yes	
Miss Sarah Prothero	REC Assistant	No	
Dr Vishal Sharma	Research Fellow/PhD Student	Yes	
Mr Anthony Warnock-Smith	Retired solicitor	Yes	

Figure Apx G.2. Favourable opinion from the REC for approval of conditions being met



A Research Ethics Committee established by the Health Research Authority

Participant consent form [Consent form for over 14 years - Workshops]	V2	21 January 2020
Participant consent form [Consent form for professionals workshop]	V2	21 January 2020
Participant consent form [Assent form for under 14 years and consent form for parents - Interview]	V2	21 January 2020
Participant consent form [Assent form for under 14 years and consent form for parents - Workshop]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for young people- Interview]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for parents- Interview]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for young people- Workshop]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for parents- Workshop]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for professionals- Workshop]	V2	21 January 2020
Research protocol or project proposal [Qualitative Protocol for SPRing study]	V2	21 January 2020

### Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment poster for young people- Interview]	V2	21 January 2020
Copies of advertisement materials for research participants [Recruitment poster for young people- Workshop]	V2	21 January 2020
Copies of advertisement materials for research participants [Recruitment poster for professionals- Workshop]	V2	21 January 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter for Insurance & Idemnity]	V1.0	25 July 2019
Interview schedules or topic guides for participants [Interview topic guide for 11-17 year olds]	V1.0	26 November 2019
Interview schedules or topic guides for participants [Interview topic guide for 18-25 year olds]	V1.0	26 November 2019
Interview schedules or topic guides for participants [Workshop Guide]	V1.0	26 November 2019
Interview schedules or topic guides for participants [Optional activities to facilitate interviews]	V2	21 January 2020
IRAS Application Form [IRAS_Form_05122019]		05 December 2019
Letter from funder [Studentship Letter]	V1.0	19 September 2018
Letter from funder [Letter from NIHR SPHR]		06 January 2020
Letter from sponsor [Sponsorship Letter from Newcastle Univeristy (Kay Howes)]	V1.0	27 November 2019
Non-validated questionnaire [Demographics form for 11-17 year olds]	V2	21 January 2020
Non-validated questionnaire [Demographics form for 18-25 year olds]	V2	21 January 2020
Participant consent form [Consent form to contact parents]	V2	21 January 2020
Participant consent form [Consent form to contact young people]	V2	21 January 2020
Participant consent form [Consent form for over 14 years - Interview]	V2	21 January 2020
Participant consent form [Consent form for over 14 years - Workshops]	V2	21 January 2020

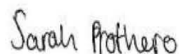
A Research Ethics Committee established by the Health Research Authority

Participant consent form [Consent form for professionals workshop]	V2	21 January 2020
Participant consent form [Assent form for under 14 years and consent form for parents - Interview]	V2	21 January 2020
Participant consent form [Assent form for under 14 years and consent form for parents - Workshop]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for young people-Interview]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for parents-Interview]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for young people-Workshop]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for parents-Workshop]	V2	21 January 2020
Participant information sheet (PIS) [Information leaflet for professionals-Workshop]	V2	21 January 2020
Referee's report or other scientific critique report [Project approval for this study from panel of assessors, head of school and Dean ]	V1.0	19 November 2019
Research protocol or project proposal [Qualitative Protocol for SPRing study]	V2	21 January 2020
Summary CV for Chief Investigator (CI) [CI and Student Cassey Muir CV]	V1.0	
Summary CV for student [CI and Student Cassey Muir CV]	V1.0	
Summary CV for supervisor (student research) [Supervisor Eileen Kaner CV]	V1.0	
Summary CV for supervisor (student research) [Supervisor Ruth McGovern CV]	V1.0	
Summary CV for supervisor (student research) [Supervisor Judi Kidger CV]	V1.0	
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of study]	V1.0	26 November 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>20/YH/0010</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



**Sarah Prothero**  
**Approvals Officer**

E-mail: [leedswest.rec@hra.nhs.uk](mailto:leedswest.rec@hra.nhs.uk)

Copy to: *Ms Cassey Muir*  
*Ms Lyndsey Dixon, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust*

*Lead Nation - England: [HRA.Approval@nhs.net](mailto:HRA.Approval@nhs.net)*

Figure Apx G.3. Approval letter from Health Research Authority



Ms Cassey Muir  
PhD Student  
Population Health Sciences Institute, Newcastle  
University  
Baddiley-Clark Building, Newcastle University  
Richardson Road  
Newcastle upon Tyne  
NE2 4AX

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

20 February 2020

Dear Ms Muir

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**

<b>Study title:</b>	<b>Qualitative research to inform development of an intervention to promote resilience in young people affected by parental substance misuse.</b>
<b>IRAS project ID:</b>	<b>270744</b>
<b>REC reference:</b>	<b>20/YH/0010</b>
<b>Sponsor</b>	<b>Newcastle University</b>

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **270744**. Please quote this on all correspondence.

Yours sincerely,  
Alex Thorpe

Approvals Manager

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Ms Kay Howes, Sponsor's Representative*



Figure Apx G.4. Approval letter for COVID-19 amendment

**From:** @hra.nhs.uk  
**To:** [Cassey Muir \(PGR\); Kay Howes](#)  
**Subject:** IRAS Project ID 270744. HRA and HCRW Approval for the Amendment  
**Date:** 10 September 2020 11:25:58

External sender. Take care when opening links or attachments. Do not provide your login details.

Dear Ms Muir,

<b>IRAS Project ID:</b>	270744
<b>Short Study Title:</b>	SPRing: Study exploring Parental substance use and Resilience V1.0
<b>Amendment No./Sponsor Ref:</b>	201920 06Muir
<b>Amendment Date:</b>	27 July 2020
<b>Amendment Type:</b>	Non Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

Please contact [amendments@hra.nhs.uk](mailto:amendments@hra.nhs.uk) for any queries relating to the assessment of this amendment.

Kind regards

**Kevin Ahmed**  
**Approvals Manager**  
**Health Research Authority**

Ground Floor | Skipton House | 80 London Road | London | SE1 6LH

[E.amendments@hra.nhs.uk](mailto:E.amendments@hra.nhs.uk)

[W. www.hra.nhs.uk](http://www.hra.nhs.uk)

Sign up to receive our newsletter [HRA Latest](#).

## Appendix H. Interview Information Leaflet for Young People

### SUPPORT AND SERVICES

If you are concerned by your parents drinking or drug use and you would like information on where to get help you can contact:

Freephone Childline: 0800 1111  
Freephone NACOA: 0800 358 3456

Useful websites include:

- [adfam.org.uk](http://adfam.org.uk)
- [www.childrensociety.org.uk/parental-alcohol-misuse](http://www.childrensociety.org.uk/parental-alcohol-misuse)

### ***What should I do if I have a suggestion or complaint about the study?***

Any suggestions or complaints about the study or how you were treated should be made in writing to:

Professor Allison Pollock  
Population Health Sciences  
Newcastle University  
Baddiley Clark Building  
Richardson Road  
Newcastle upon Tyne NE2 4AX

All complaints will be dealt with in writing within 7 working days. If you are not happy with the way your complaint has been handled, your complaint will be referred to the research sponsor, Newcastle University.

### GENERAL DATA PROTECTION REGULATION

#### **How will we use information about you?**

We (the research team & the sponsor: Newcastle University) will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

#### **What are your choices about how your information is used?**

• You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

• We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

#### **Where can you find out more about how your information is used?**

You can find out more about how we use your information

• at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/) or [www.ncl.ac.uk/data.protection/PrivacyNotice](http://www.ncl.ac.uk/data.protection/PrivacyNotice)

• our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)

• by asking one of the research team, or

• by sending an email to Newcastle University's Data Protection Officer: Maureen Wilkinson at [rec-man@ncl.ac.uk](mailto:rec-man@ncl.ac.uk).



## SPRing: Study exploring Parental substance use and Resilience in young people

### Participant Information

### Leaflet: Young People



Qualitative research to inform development of an intervention to promote resilience in young people affected by parental substance misuse. Participant information leaflet for 11-25 year olds approached for interviews. Version 2: 21/01/20. IRAS Project ID: 270744



## Information for you

Hi, my name is Cassey Muir. I would like to invite you to take part in a research study. Please take your time to read this leaflet, feel free to talk to others about this study if you wish. Also, please feel free to contact me if there is anything you are unsure about or if you want to ask questions.

### **What is the research about?**

I want to talk to young people aged 14-25, whose parents drink alcohol or use drugs. I want to ask these young people about the things that matter to them (for example how they get on at school, their health, friendships and family life) as well as what might help them with the things that are important to them. I will use your ideas to help other young people.

### **Am I eligible for this study?**

You need to be aged between 14-25 years and have a parent or carer who currently or previously used drugs or drank alcohol in a way that made you feel worried, sad or angry.

### **What will taking part involve?**

If you decide to take part, I will arrange to meet you at a time and appropriate place that is best for you. We will talk about your experiences and how best to help young people who experience parental substance use. This chat will last between 30 minutes to 1 hour. A trusted adult is able to attend with you if you choose. Interviews will be audio recorded.

You will receive a **£10 gift voucher** for taking part and any travel costs, outside of your normal activities, will be repaid.

### **Do I have to take part?**

**No.** It is up to you whether you would like to take part. If you do decide to take part, you can change your mind whenever you want and your future care will not be affected.



### **Are there any risks or benefits in taking part?**



Talking about your experiences may make you feel upset or angry. You can stop the chat at any time if you do not want to continue. You may feel happy to be able to share your experiences and have your views heard, and that your ideas may help other young people like you in the future.

If you lose capacity to consent whilst taking part you will be withdrawn and data already collected will be kept. No new data will be collected and you will not have to participate further.

### **Will my taking part be kept confidential?**

All the information you provide will be kept confidential. This means that what you tell me will not be shared with other people. You will not be named in anything written in the study.

The only time things you tell me will not be kept confidential is if you tell me that you or another person is at serious risk of harm. This is called safeguarding (this is to keep you safe).

Any information about you will be stored electronically on a secure, anonymous Newcastle University database for 10 years.

A transcription service will also be used, who will use the audio recording to write up what we talk about. The service have a confidentiality agreement with the University.

## THANK YOU

Thank you for taking the time to read this leaflet. Please get in touch to ask any questions or share any concerns you may have about the project at:

### Contact details:

Researcher: Cassey Muir

Tel: XXXXXX

You can also email me at:

SPRing@newcastle.ac.uk

Supervisor: Dr Ruth McGovern

Email: XXXXX

Or write to:

Population Health Sciences Institute,  
Baddiley Clark Building, Richardson Road,  
Newcastle Upon Tyne, NE2 4AX.

This research has been reviewed and approved by the Yorkshire & The Humber –Leeds West Research Ethics Committee.

### **Research Funding**

Cassey Muir is being supported by the National Institute for Health Research School for Public Health Research (NIHR SPHR) studentship (SPHR-PHD-FUS-002).



# THE SPRING STUDY

STUDY EXPLORING PARENTAL SUBSTANCE USE AND  
RESILIENCE IN YOUNG PEOPLE

**DO YOU  
SUPPORT YOUNG  
PEOPLE WHOSE  
PARENTS USE  
SUBSTANCES?**

We are looking to chat to young people, aged 14-25 years, whose parents drink alcohol or use drugs. This study is open to young people across England!

We will talk about what matters most to the young person (e.g. family, school/work, friendships) as well as what might help them and other young people in similar situations.

**£10 GIFT  
VOUCHER AS A  
THANK YOU!**

Get in touch to find out more:  
Cassey Muir  
xxx@newcastle.ac.uk/  
xxx@newcastle.ac.uk

Newcastle University fuse University of BRISTOL Adfam NIHR | School for Public Health Research



## Appendix J. Interview/Focus Group Information Leaflet for Practitioners

### ***What should I do if I have a suggestion or complaint about the study?***

Any suggestions or complaints about the study or how you were treated should be made in writing to:

Professor Allison Pollock  
Population Health Sciences  
Newcastle University  
Baddiley-Clark Building  
Richardson Road  
Newcastle upon Tyne NE2 4AX

All complaints will be dealt with in writing within 7 working days. If you are not happy with the way your complaint has been handled, your complaint will be referred to the research sponsor, Newcastle University.

### **GENERAL DATA PROTECTION REGULATION**

#### **How will we use information about you?**

We (the research team & the sponsor: Newcastle University) will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

#### **What are your choices about how your information is used?**

• You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

• We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

#### **Where can you find out more about how your information is used?**

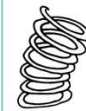
You can find out more about how we use your information

• at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/) or [www.ncl.ac.uk/data.protection/PrivacyNotice](http://www.ncl.ac.uk/data.protection/PrivacyNotice)

• our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)

• by asking one of the research team, or

• by sending an email to Newcastle University's Data Protection Officer: Maureen Wilkinson at [rec-man@ncl.ac.uk](mailto:rec-man@ncl.ac.uk)



## **SPRing: Study exploring Parental substance misuse and Resilience in young people**



### **Participant Information**

### **Leaflet: Practitioners**



Qualitative research to inform development of an intervention to promote resilience in young people affected by parental substance misuse. Participant information leaflet for professionals approached for workshops. Version 3. 27/07/20. IRAS Project ID: 270744

## Information for you

Hi, my name is Cassey Muir. I would like to invite you to take part in a research study. Please take your time to read this leaflet and feel free to contact me if you have any questions.

### **What is the research about?**

I am trying to find out the best way to support young people who have experienced or are currently experiencing parental substance misuse, including the use of alcohol and/or drugs. Your ideas will help to inform the best way to do this.

### **Am I eligible for this study?**

You need to be a practice or policy professional who supports young people and young adults between up to the age of 25 years. These young people need to be experiencing parental substance misuse, including the use of alcohol and/or drugs by at least one primary caregiver.

### **What will taking part involve?**

If you decide to take part you will have the choice to attend either a one to one interview or group discussion with other practice and policy professionals (remote or in person). You will discuss how best to support young people who experience parental substance misuse. You will be asked to talk about what this support would involve, who would deliver the support etc. This discussion will last between 60 and 90 minutes. This discussion will be audio recorded.

You will be reimbursed for any travel costs outside of your normal activities.

### **Do I have to take part?**

**No.** It is up to you whether you would like to take part. If you do decide to take part, you can change your mind whenever you want.



### **Will my taking part be kept confidential?**

All the information you provide will be kept **confidential**. You will not be named in anything written about the study.

The only time things you tell me will not be kept confidential is if you tell me that you or another person is at serious risk of harm. This is to uphold **safeguarding** protocol.

Any information about you will be stored electronically on a secure, anonymous Newcastle University database for 10 years.

A transcription service will also be used who have a confidentiality agreement with the University.

If you lose capacity to consent whilst taking part you will be withdrawn and data already collected will be kept. No new data will be collected and you will not have to participate further.



## THANK YOU

Thank you for taking the time to read this leaflet. Please get in touch to ask any questions or share any concerns you may have about the project at:

### Contact details:

Researcher: Cassey Muir

Tel: XXXXX

You can also email me at:

SPRing@newcastle.ac.uk

Supervisor: Dr Ruth McGovern

Email: XXXXX

Or write to:

Population Health Sciences Institute,  
Baddiley Clark Building, Richardson  
Road, Newcastle Upon Tyne, NE2 4AX.

This research has been reviewed and approved by the Yorkshire & The Humber-Leeds West Research Ethics Committee.

### **Research Funding**

Cassey Muir is being supported by the National Institute for Health Research School for Public Health Research (NIHR SPHR) studentship (SPHR-PHD-FUS-002).



## Appendix K. Topic Guides

Figure Apx K.1. Interview Topic Guide for Young People aged 14-17 years



**SPRing: Study exploring Parental substance use and Resilience in young people**



### Interview Topic Guide (14-17 years)

*Thank you for taking part in this study of young people whose parents drink alcohol or use drugs. I would like to ask you about the things that matter to you (for example how you get on at school, your health, friendships and family life) as well as what might help you with the things that are important to you. I will use your ideas to help other young people.*

*Reiterate issues of confidentiality and anonymity, the purpose of the study and what is going to happen to the data.*

*Complete Consent Forms*

*Switch on audio recorder (if young person has consented)*

#### Introduction

**So, tell me a little about yourself?** (Age, school/college, interests, family, friends, service)

#### Impacts

**Can you tell me what school life looks like for you?**

(Probe: How are you finding your classes? After school classes? How are the teachers? Achievements? Challenges?)

**Can you tell me about your different relationships?** (*Activity 1 optional for participants*)

*The participant will be asked to draw themselves in the middle, and then around that write people they connect with (people they connect with/see the most towards the middle) and how they know them? For those closest to the middle, what role do they take (friend, sister, son) and how do these roles/relationships make them feel?*

(Probe: School? Community groups? Services? Family? Online friends?)

**Can you tell me about your health and any times you might have been poorly in the past?**

(Probe: rate their health today on a scale from 0-10, optional use of a visual scale. Why number X? Is there a time when the number has been higher or lower? What number would you like your health to be in the future? What would need to happen to reach that number?)

**Have you ever drank alcohol or used drugs? If Yes- Can you tell me about your experiences of alcohol or drug use?**

(Probe: a typical day when you drink/use drugs, how often, do your friends drink/use drugs?)

#### Home Life

**Can you tell me what a typical day is like in your house?** (*Activity 2 optional for participants*)

*The participant will be asked to draw a house or have a picture of a house available. Once the picture has been drawn, ask the participant to mind map about the following;*

What is your house like at different times of day? (Probe: was it different during lockdown)

What is your house like if someone has had a drink or used drugs? – is it any different?

What about if no one has had a drink/used drugs? – is that different?

What would you like to change/keep the same?



### Mood/Feelings

**Can you tell me what makes you feel sad, worried, frustrated, or mad?**

(Probe: what was happening, how did you react/what do you do when feel like this, how often do you feel this way, what will you do next time you feel like this?)

**Can you tell me what helps you feel better when you feel sad, worried, frustrated, or mad?**

(Probe: why, how does that help? Does that always work?)

**Can you tell me what makes you feel happy, or safe?**

(Probe: what is happening, when do you experience them, how often do you feel this way?)

### Experiences of Support (iterative throughout interview)

**Who do you talk to about your feelings?** (Positive and negative feelings)

(Probe: easy/difficult to talk about? how do they help? How would you like them to help you?)

**Thinking about the people in your life, who is most important to you?** *(Activity 1 to support discussion)*

(Probe: Why? How do they help or support you? Do you help or support them, how?)

**Can you tell me about how other people help you when you feel sad, worried or mad?**

(Probe: friends, family, teacher, other adults, service providers, partner? How do they help, what do they do? Would you like them to anything else to help you?)

**Have you used any other types of help or support when you feel like this?**

(Probe: websites, books, services, phone lines? When would you use them? Do they help? What do you like/dislike about them? Challenges to accessing support?)

### Ideas for Support

**If a friend comes to you worried, sad, or angry about their parents drinking or drug use, what would you tell them to do?** *(Activity 3 optional for participants)*

*Participants will be given a person template, inside the template they will be asked to write down what might help their friend/young person, and on the outside, how they would feel about someone talking to them, and how they would respond to their friend.*

(Probe: what do you think would help them? What would help you if you wanted support? How would it make you feel if a friend told you how they felt? How would you respond to them?)

**If we wanted to help other young people who may feel worried, sad or angry about their parents drinking or drug use what would that help look like?**

(Probe: who would be involved? Family/friends/school? What would be difficult about this, what would help? Where would it take place? Who would deliver it? Face to face/online? What age?)

**Thinking to the future, where do you see yourself in 5-10 years?**

(Probe: how did you get there? What helped? Is it different/same to now? What are you doing?)

### Close

Is there anything that you think I have missed that you would like to add?

### *Switch off audio recorder*

*Thank interviewee. Offer reassurance that all responses will be anonymised and that participants will not be identified in the dissemination of results.*

*Ask if they are willing to be re-contacted to participate in a co-design workshop*

*Flag support services*

Figure Apx K.2. Interview Topic Guide for Young People aged 18-25 years



## SPRing: Study exploring Parental substance use and Resilience in young people



### Interview Topic Guide (18-25 years)

*Thank you for taking part in this study of young people whose parents drink alcohol or use drugs. I would like to ask you about the things that matter to you (for example how you get on at school, your health, friendships and family life) as well as what might help you with the things that are important to you. I will use your ideas to help other young people.*

*Reiterate issues of confidentiality and anonymity, the purpose of the study and what is going to happen to the data.*

*Complete Consent Forms*

*Switch on audio recorder (if young person has consented)*

#### Introduction

**So, tell me a little about yourself?** (Age, college/university/work, interests, family, friends, how long attended service)

#### Impacts

**Can you reflect back and tell me about your school life (also current work/university)?**

(Probe: How did you find your classes? After school classes? How were the teachers? Achievements? Challenges? How do you find your current position?)

**Can you tell me about your different relationships?** (*Activity 1 optional for participants*)

*The participant will be asked to draw themselves in the middle, and then around that write people they connect with (people they connect with/see the most towards the middle) and how they know them? For those closest to the middle, what role do they take (friend, sister, son) and how do these roles/relationships make them feel?*

(Probe: Community groups? Services? Family? Online friends? Partner? Colleagues?)

**Can you tell me about your health and any times you might have been poorly in the past?**

(Probe: rate their health today on a scale from 0-10, optional use of a visual scale. Why number X? Is there a time when the number has been higher or lower? What number would you like your health to be in the future? What would need to happen to reach that number?)

**Have you ever drank alcohol or used drugs? If Yes- Can you tell me about your experiences of alcohol or drug use?**

(Probe: a typical day when you drink/use drugs, how often, do your friends drink/use drugs?)

#### Home Life

**Can you tell me what a typical day is/was like in your house?** (*Activity 2 optional for participants*)

*The participant will be asked to draw a house or have a picture of a house available. Once the picture has been drawn, ask the participant to mind map about the following (reflect back to teenage years);*

*What is/was your house like at different times of day?*

*What is/was your house like if someone has had a drink or used drugs? – is it any different?*

*What about if no one has had a drink/used drugs? – is that different?*

*What would you like to change/keep the same?*

SPRing: Study exploring Parental substance use and Resilience: interview topic guide for 18-25 year olds;  
Version 1.0; 26.11.19, IRAS Project ID: 270744

### Mood/Feelings

**Can you tell me what makes you feel sad, worried, frustrated, or mad?**

(Probe: what was happening, how did you react/what do you do when feel like this, how often do you feel this way, what will you do next time you feel like this? Can reflect back to teenage years)

**Can you tell me what helps you feel better when you feel sad, worried, frustrated, or mad?**

(Probe: why, how does that help? Does that always work?)

**Can you tell me what makes you feel happy, or safe?**

(Probe: what is happening, when do you experience them, how often do you feel this way?)

### Experiences of Support (iterative throughout interview)

**Who do you talk to about your feelings?** (Positive and negative feelings, past and present)

(Probe: easy or difficult to talk about? how do they help? How would you like them to help you?)

**Thinking about the people in your life, who is most important to you?** (*Activity 1 to support discussion*)

(Probe: Now and then? Why? How do they help/ support you? Do you help or support them, how?)

**Can you tell me about how other people help you when you feel sad, worried or mad?**

(Probe: friends, family, teacher, other adults, service providers, partner? How do they help, what do they do? Would you like them to anything else to help you?)

**Have you used any other types of help or support when you feel like this?**

(Probe: websites, books, services, phone lines? When would you use them? Do they help? What do you like/dislike about them? Challenges to accessing support?)

### Ideas for Support

**If a friend comes to you worried, sad, or angry about their parents drinking or drug use, what would you tell them to do?** (*Activity 3 optional for participants*)

*Participants will be given a person template, inside the template they will be asked to write down what might help their friend/young person, and on the outside, how they would feel about someone talking to them, and how they would respond to their friend.*

(Probe: what do you think would help them? What would help you if you wanted support? How would it make you feel if a friend told you how they felt? How would you respond to them?)

**If we wanted to help other young people who may feel worried, sad or angry about their parents drinking or drug use what would that help look like?**

(Probe: who would be involved? Family/friends/school? What would be difficult about this, what would help? Where would it take place? Who would deliver it? Face to face/online? What age?)

**Thinking to the future, where do you see yourself in 5-10 years?**

(Probe: how did you get there? What helped? Is it different/same to now? What are you doing?)

### Close

Is there anything that you think I have missed that you would like to add?

*Switch off audio recorder*

*Thank interviewee. Offer reassurance that all responses will be anonymised and that participants will not be identified in the dissemination of results.*

*Ask if they are willing to be re-contacted to participate in a co-design workshop*

*Flag support services*



Figure Apx K.3. Interview/Focus Group Topic Guide for Practitioners



## SPRing: Study exploring Parental substance use and Resilience in young people



### Interview/Focus Group Topic Guide (Practitioner)

*Reiterate issues of confidentiality and anonymity, the purpose of the study and what is going to happen to the data.*

*Complete Consent Forms*

*(Focus group ground rules)*

*Switch on audio recorder (if consented)*

#### Introduction

1. **So, could you tell me a little about yourself?**
  - a. (Name, role, organisation, where you're based-location, how long you've worked there, past roles relevant to this study)

#### Current Practice

2. **Can you tell me about how you or your service currently support young people whose parents misuse substances?**
  - a. (Probe: how do you offer support (1:1, groups, families) and to whom? How many sessions? Content? Is support different for alcohol use, drug use or polysubstance use? Is it different if two parents use vs only one? How about if YP have social workers involved? Is it different across the organisation? Is it different for different ages? How do YP get referred to your service?)
  - b. Do you manage any staff- how do you support staff? What support is offered for key workers? Any training opportunities? Have staff come to you with suggestions for training?
3. **Thinking about the young people you work with/have worked with, what resources or techniques have they found useful and what do you find useful when supporting them?**
  - a. (Probe: For different ages, differences across services? What benefits do you think YP get from accessing your service?)
4. **On the flip side to that, what resources or techniques have young people not found very useful and what do you not find useful when supporting them?**
  - a. (Probe: different ages, substances etc.)
5. **Do you know of any other services or organisations who provide support for young people whose parents misuse substances, what do they offer young people?**
  - a. Is it different/similar to your work? How? Do you connect with them?
6. **What changes would you like to see to current practice (both within your organisation and on a broader level)?**

#### COVID-19

7. **How has the pandemic impacted current support for YP?**
  - a. Changes to service? Where did these changes come from (YP/workers/managers)? How have staff responded? How have YP found the change in service provision? Start of lockdown, during, now? Going forward?

- b. To what extent do you think the pandemic impacted young people's wellbeing (those you have supported? Positive or negative?)
- c. As we continue dealing with the effects of the pandemic, what are some of the hopes and fears you have for providing services? (especially as this is across England- different rules and tiers etc.)
- d. Is there anything that you changed about your service and will continue post-pandemic? (online/text support etc.)

#### YP's experiences of PSM

- 8. **Can you tell me about what you think young people whose parents misuse substances experience and how they are impacted?**
  - a. (Probe: Are there any specific cases you remember? What have young people told you about their experiences? Is it different for those whose parents use alcohol or drugs? Different ages? How are sibling groups impacted or experience PSM?)

#### Ideas for intervention development

- 9. **So, let's now think about if we were to develop a new intervention, whether that be a toolkit, resources or a service to promote resilience amongst young people whose parents misuse substances**
  - e. Firstly, do you know of any current resources to promote resilience? What are they and who delivers them?
  - f. If we were to develop resources as an addition to your current work, what resources or services would be of most help for you, and for your work with young people?
  - g. If this was something separate to your work, what would these resources look like?
- 10. **Whether thinking about resources in addition to your work or as a separate resource, what do you think the content should be of an intervention to promote resilience?**
- 11. **What would be the best mode of delivery for young people and practitioners?**
  - h. (Probe: online, face to face, groups, families, peers? How would young people find out about it? Do we include family members, friends, 1:1?)
- 12. **Who should deliver such an intervention or where should it be delivered?**
  - i. (Probe: School, social work, voluntary organisations, children's services, alcohol and drugs services.)
- 13. **Who do you think would benefit most from such an intervention to promote resilience?**
  - j. (Probe: what age range, what level of parental substance misuse, who should we target?)
- 14. **What challenges do young people face when accessing support?**
- 15. **How can we reduce stigma?**

#### Other

- 16. **What questions could our research seek to answer to most help you in your work with young people?**
- 17. **Is there anything that you think I have missed that you would like to add?**

#### *Switch off audio recorder*

*Thank participant(s). Offer reassurance that all responses will be anonymised and that participants will not be identified in the dissemination of results.*

*Ask if they are willing to be re-contacted to participate in a co-design workshop*

## Appendix L. Example Coding of Transcript with Young Person Advisory Group

### EXAMPLE

#### Emma: 15, Mum's Alcohol Use

*Interviewer: Do you want to reflect back and tell me what your home situation was like?*



Emma: It definitely wasn't the best. I think I was around 13/14 ish, Year 8 and 9, when it started to get a lot worse. I think at its peak- It was in the first lockdown when it was the worst. There was a lot of tension in the house, there were a lot of arguments and just falling-out. Just really, kind of, an uncomfortable place to be, that didn't feel as safe as it does now.

Experience conflict and tension

Experience lack of safety within home

Impacted on communication & relationships

*Interviewer: Yes. What do you think helped make it feel a bit better?*

Emma: I think, obviously we had some guidance and direction from [Service Name]. I think, mainly, what's helped is just, as a family, pulling together and helping each other and having more discussions and just communicating with each other more.

Useful: Changes in/support with family communication & relationships

## **Appendix M. Initial Codes Identified with Young Person Advisory Group**

### **Lack of safety / insecurity / unpredictability within the home**

Trauma experiences

Threat in environment - Trauma caused by different types of things (from parents)

Conflict and insecurity / stressful

Domestic violence (experience / observe / witness)

Parental mental health

Loss / death

Trauma at different stages / ages

Threat in environment (from those outside family e.g. new partners, drug dealers etc.)

Lack of boundaries within the home / family

YP's need for safety / security / predictability

Creating safety for self (Links to agency and choice – putting themselves first) – leave home

Support of others within the home (siblings, other parent)

### **Anticipation of next conflict / drinking situation (threat of something happening)**

Feeling anxious

Day vs Night

Strategies to reduce anxiety / anticipatory fear

How that links to support services (need for support during night/conflict/out of hours)

### **Safety or lack thereof – outside of the home**

Normative or abnormative comparison (internal confusion) – links to stigma / discrimination

Different types of support (help and hindrance)

Formal forms of support

Schools – poor at providing support – environment as being disappointing for YP

Schools adding to the confusion on normative experiences

Schools provide a lack of safety (bullying, discrimination, lack of support)

Schools offer safe place for YP (away from home)

Lack of trust

Informal forms of support (receive or generate)

Creating/ generating informal support for self (e.g. neighbours, peers)

Extended family members

Peers (going to a friend's house, or to be a 'normal' kid)

Trauma-informed practice

### **Process of awareness**

YP's experiences

Try to understand

Try to push it away / control (e.g. YP finding friendships in those similar to him – don't feel stigma / don't feel strange) – resistance to stigma (try to not be the poor kid, the bad kid, problem child) – try to demonstrate agency

### **Inappropriate relationships vs helpful relationships**

Risky people in the house (*linked to first section*)

Inappropriate role models (vs positive role models)

Lack of developed social skills

Relationships between parents (conflict/stress)

Non-using parent/extended family members – risk and protective (role of parents)

Control relationships (e.g. leave home, ignore communication)

### **How YP present themselves to others**

‘Not wanting to be seen as the problem child’ (linked to literature: these children are generally seen as problem child, not do well at school, have behavioural problems, relationship problems, own substance use problems)

Linked to interactions with practitioners e.g. police, school/teachers, and family

Feeling odd one out in social situations

Control - YP control how they are presented or perceived

(‘Sprinkle of trauma’) - Want people to see them as more than just trauma/parental substance use, but as someone who can cope, who can manage adversity

Resistance – resist impacts, stigma/identity, control the uncontrollable (Is it about YP coping or is it about YP wanting to present themselves like they are)

### **Caring responsibilities (young carer role)**

YP as ‘better carers’

Siblings – look after younger siblings vs. broken relationships – or risky siblings

Put themselves first – caring is not their responsibility

### **Mental health impacts**

Low self-esteem

Anxiety

Fear

Anger

At Parents / situation

At services / lack of support

### **Whole family support**

Include children in parents support/care

Work with family or individuals

Experience lack of safety (or safety?) in these situations

CYP understanding of safety may be different to professionals

### **Initial themes, codes and points of interest from the Young Person Advisory Group**

1. Young people compare them self to others (What is normal?)
2. Process of awareness around parents use
3. Impact on relationships
4. Young people adapt to meet parent's needs
5. Creating safe spaces
6. Resilience: Surviving or thriving (linked to agency and choice)
7. School as place for escapism but also risk (e.g. bullying)
8. Professional Support is not always supportive (what needs to be done – link to practice/policy recommendations)
9. Stigma and embarrassment



## Appendix N. Visual Representation of Ongoing Analysis







## Appendix O. Visual Representation of Final Themes Before Write-up



## Appendix P. Practitioner Workshop and Engagement Event Details for the Prioritisation of Intervention Ideas

**fuse**


Adfam

**NIHR** | School for Public Health Research

Nov 10


**Parental substance use and young people's resilience**


Findings from a recent research project exploring young people's experiences and impacts of living with parental substance misuse

By Adfam  
273 followers

Follow

**When and where**

 **Date and time**  
Wed, 10 November 2021,  
10:00 - 12:00 GMT

 **Location**  
Online

**Sales Ended**  
Details

**Sales Ended**  
Details

**About this event**

Wednesday 10th November, 10am-12pm

Join us for a free online event co-badged between Fuse, Adfam and NIHR School for Public Health Research (SPHR) presenting new research on the topic of parental substance use.

*Fuse, the Centre for Translational Research in Public Health, brings together the five North East Universities of Durham, Newcastle, Northumbria, Sunderland and Teesside delivering research to improve health and wellbeing and tackle inequalities. Fuse is also a founding member of the NIHR School for Public Health Research (SPHR).*

*Adfam is the national charity tackling the effects of alcohol, drug use or gambling on family members and friends.*

**What is the aim of this event?**

To share findings from a recent research project aimed at exploring young people's experiences and impacts of living with parental substance misuse. In addition, we will explore ideas for how we can best support young people whose parents drink alcohol or use drugs.

This event will bring together practitioners, policy makers, and academics for open discussion and workshop activities. In breakout rooms, you will be asked to provide feedback on the findings presented, and discuss what an intervention in this area would involve, and who would deliver it.

**Who is the event for?**

- Practitioners working with families, young people or substance use
- Commissioners and practitioners in Local Authority and other organisations who plan, commission, scrutinise or provide local health and wellbeing initiatives with young people and young adults in mind.
- Public health researchers and academics with an interest in substance use, families, and young people's mental health.

<https://www.eventbrite.co.uk/e/parental-substance-use-and-young-peoples-resilience-tickets-168251253027?aff=ebdsoporgprofile>

## Appendix Q. Practitioner Workshop and Engagement Event Programme



### Parental Substance Use and Young People's Resilience Wednesday 10<sup>th</sup> November, 10am-12pm

Programme	
5 minutes (10:00-10:05)	Welcome from Claire Hayward: National Hidden Harm Lead (Change, Grow, Live)
Chair: Claire Hayward, National Hidden Harm Lead (Change, Grow, Live)	
20 minutes (10:05-10:25)	Cassey Muir: NIHR SPHR PhD Researcher (Fuse – Newcastle University) with Aiden Quinn and Kira Terry (Lived Experience Experts) <i>The voices of young people and practitioners: parental substance use, resilience and stigma</i>
10 minutes (10:25-10:35)	Daniel Brocksopp: Young Person's Drug & Alcohol Intervention Worker (PROPS North East) <i>Supporting young people and families impacted by substance misuse</i>
30 minutes (10:35-11:05)	Cassey Muir: NIHR SPHR PhD Researcher (Fuse – Newcastle University) <u>Interactive audience participation activities:</u> (1) What ideas should we prioritise for supporting young people whose parents use substances? See 'Document A_Intervention Ideas (10_11_21)' for this activity (2) How can we support practitioners in their work with young people whose parents use substances?
10 minutes (11:05-11:15)	<i>Break</i>
Chair: Claire Hayward, National Hidden Harm Lead (Change, Grow, Live)	
10 minutes (11:15-11:25)	Virginia Wright: Programme Manager – Parents, Carers and Families (alcohol and drugs) Addictions and Inclusion (Department for Health and Social Care) <i>Parents with alcohol and drug problems: policy reflections and resources to support local authorities</i>
10 minutes (11:25-11:35)	Dr Ruth McGovern: Lecturer in Public Health Research (Fuse – Newcastle University) <i>The effectiveness of psychosocial interventions at reducing the frequency of alcohol and drug use in parents: findings of a Cochrane review and meta-analyses</i>
20 minutes (11:35-11:55)	Q&A Panel Discussion: Cassey Muir, Aiden Quinn, Kira Terry, Daniel Brocksopp, Virginia Wright, and Ruth McGovern
5 minutes (11:55-12:00)	Closing remarks from Claire Hayward: National Hidden Harm Lead (Change, Grow, Live)



## Appendix R. Example Personas

### What support might help me?



Hi, I'm Suzie, I'm 11 and I live with my Mum and older sister. My mum still drinks alcohol now, but her drinking was at it's worst a couple of years ago.

I've had some support from a service that was for young people who's parents drink alcohol. All of my family attended this support and I don't think it was that useful for me. There were issues with confidentiality and I didn't like that my mum was also part of this service so I stopped attending.

### What support might help me?



Hello, I'm Jamie, I'm 17 and I live in foster care. Both my mum and dad drink alcohol and use drugs and for a long time that was my normal.

I feel a lot of shame and like I am different to other people. I don't feel like I can talk about my experiences to anyone because they will judge me.

### What support might help me?



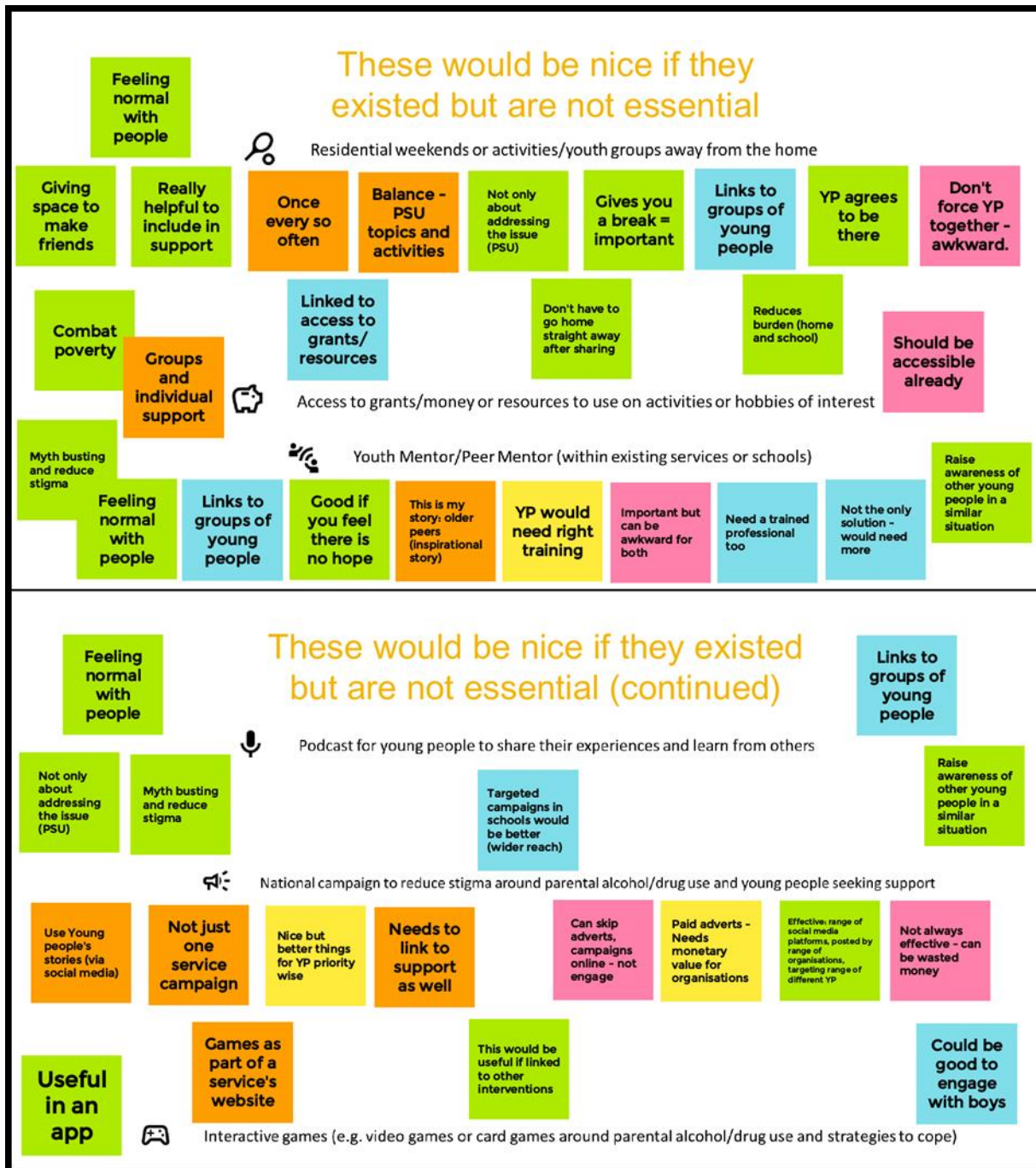
Hi, I'm Charlotte, I'm 24 and I live alone. My mum, dad and step-mum all drink alcohol. I still see them but only when I want to. I started drinking alcohol and using drugs when I was younger, to help cope with my experiences.

I never had any support when I was younger but I am pregnant now and want to do better for myself and my baby.

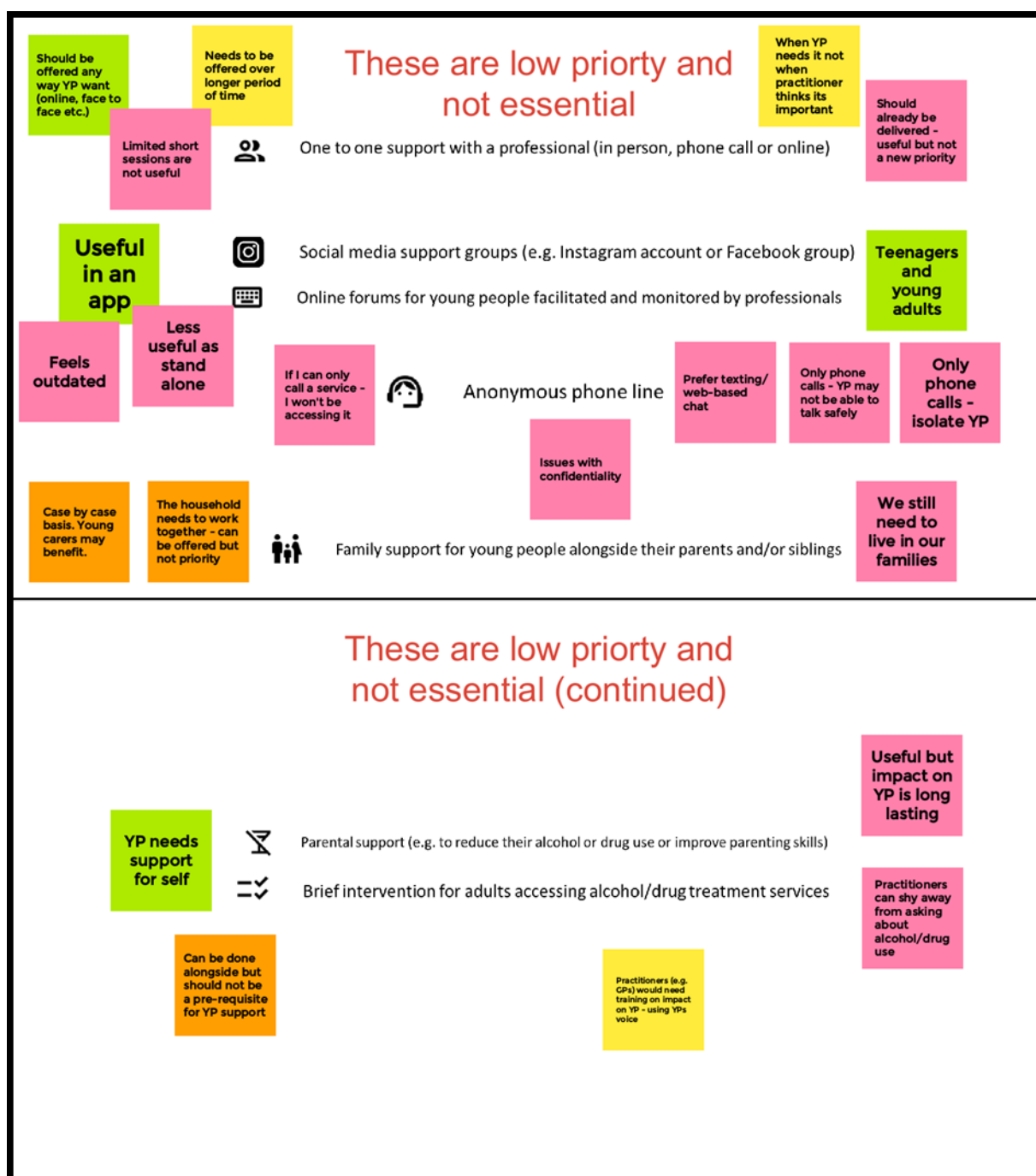
## Appendix S. Interactive Jamboard Slides for the Intervention Ideas

### Grouped as 'Nice if They Existed but Not Essential' by Young People

#### at the Group Consensus Workshop



## Appendix T. Interactive Jamboard Slides for the Intervention Ideas Grouped as 'Low Priority and Not Essential' by Young People at the Group Consensus Workshop

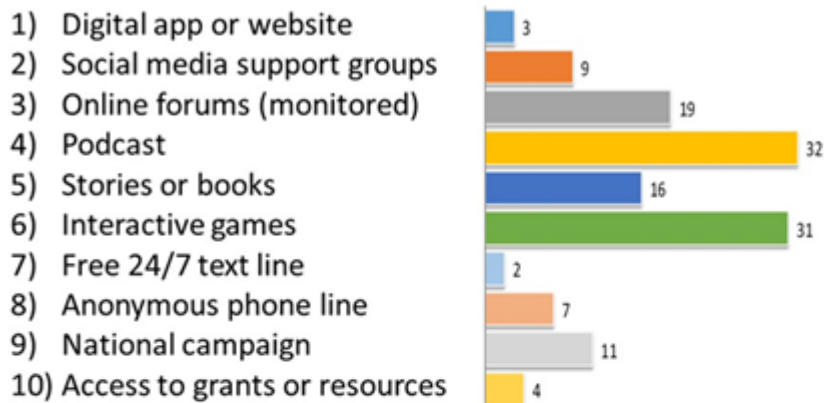


## Appendix U. OMBEA Response Live Graphs from the Practitioner Workshop for Low Priority Intervention ideas

Go to: [ra.ombea.com/](https://ra.ombea.com/)  
Enter Session ID: Spring21

Part 3 – What should we prioritise:

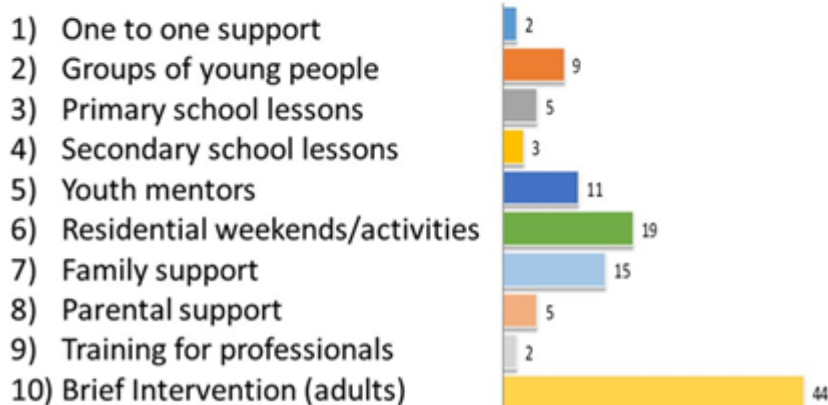
What two ideas would be least beneficial for supporting young people?



Go to: [ra.ombea.com/](https://ra.ombea.com/)  
Enter Session ID: Spring21

Part 4 – What should we prioritise:

What two ideas would be least beneficial for supporting young people?



## Appendix V. OMBEA Response Live Word Cloud from the Practitioner Workshop for Low Priority Intervention Ideas

Go to: [ra.ombea.com/](https://ra.ombea.com/)  
Enter Session ID: Spring21

From the top responses: which \*one\* would be the least  
beneficial? (Only use one word)

Podcast  
Games Brief  
residential  
Podcasts pod interventions  
breif



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