



A minority within a minority: An exploration into the prevalence of neurodevelopmental disorders in looked after children and the effects on health and social wellbeing.

Submitted to Swansea University in fulfilment of the requirements for the Degree of Doctor of Philosophy

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June 2022

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Declarations

I, Nicola Heady, confirm this thesis has not been submitted towards a previous degree or other qualification, and is intended for submission of a Doctor of Philosophy, awarded by Swansea University.

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Abstract

Looked after children (Lac) continue to be one of the most vulnerable groups in society and many go on to attain poor health and social outcomes. Research on neurodevelopmental disorders (NDDs) in the general population is relatively well documented, however, research on Lac with NDDs is extremely limited. The aims of this thesis were to explore the prevalence of NDDs in the Lac population and if feasible compare rates to children who are not looked after (non-Lac). It further aimed to explore the impacts, challenges, barriers or wider factors that the Lac with a NDD might encounter or experience.

To address the aims of this thesis, several methods have been used to collate data which are detailed in Chapters 2, 3, 4 and 5. Chapter 2 consists of a systematic review and meta-analysis which compares the prevalence of NDDs in Lac versus non-Lac and further explores the impacts on the Lac with a NDD. Twelve studies met eligibility. Six studies met eligibility for a meta-analysis and the remaining six studies are described as a narrative. In the review, there was a higher prevalence of ADHD and autism in the Lac population compared to their non-lac peers. The review also highlighted several adverse impacts and outcomes for the Lac with a NDD in the areas of care placement, criminal involvement, medication prescription, mental health services, emotional and physical abuse.

Chapter 3 describes a brief narrative review which examines five studies that were not eligible for the systematic review but were important to further explore as they highlighted adverse impacts for the Lac with a NDD. This chapter examines these studies in more detail and relates the findings to wider literature. Similar adverse outcomes and impacts like those found in the systematic review were found but several additional adverse impacts and outcomes in areas of sexual abuse, homelessness, suicidal ideation, learning difficulties and physical health difficulties were also identified for the Lac with a NDD.

As I could not interview Lac themselves, Chapter 4 describes a small q qualitative study, which was conducted to gain an insight into the perspectives and opinions of social workers on the little explored subject of NDDs in this population. Several broad topics were explored in areas of family, services and outcomes by means of interviews. Ten semi structured interviews were held, and a thematic analysis was utilised to analyse, code and identify themes. Themes involved perceptions of NDDs, perceptions of diagnosis, access to service

provision, impact on care settings, impacts on health and social wellbeing, parental factors and social worker challenges and needs.

Chapter five describes an electronic data linkage cohort study which investigates whether the prevalence rates attained from the meta-analysis for Lac reflect current prevalence estimates in Wales. It further examines whether there is similarity in several of the key findings detailed in the other chapters, in relation to services. Six health and administrative datasets held in the ‘Secured Anonymised Information Linkage (SAIL) databank at Swansea University were linked to explore and compare prevalence rates of NDDs and service usage in the Lac population compared to all children/young persons (Acyp) with a NDD in Wales. There was a higher prevalence of attention/deficit hyperactivity disorders, autistic spectrum disorders, developmental disorder of scholastic disorders, unspecified, eating disorders and reactive attachment disorders in Lac compared to Acyp in Wales. The results also highlight the mean age, gender of the first event/episode in which a NDD was identified within the dataset and the mean age, gender at time-of-service referrals to secondary health care services. In addition to this, results further highlight the educational support provision for both Lac and Acyp with a NDD who have been placed in the ‘educated other than school’ (EOTAS) setting. The final chapter integrates all the findings of this thesis into a brief discussion and highlights any similarities, parallels, or ambiguities, followed by recommendations for research, policy and practice.

My thesis proposes that more research is needed to support and understand the higher prevalence rates of NDDs in the already vulnerable Lac population. The identified impacts on the Lac with a NDD and the challenges, barriers and wider factors that these children may experience, or encounter may place these children at higher risk of adverse outcomes. More research in these areas would be beneficial to meeting the unique needs of the Lac with a NDD, particularly from a preventative and safeguarding perspective.

Acknowledgements

First and foremost, I would like to acknowledge my primary supervisor Professor Hayley Hutchings. There are no words that can fully express my gratitude to her. She has supported me tirelessly throughout this PhD and has not only met my expectations of what is expected of an excellent supervisor and mentor but exceeded them and gone beyond the remits of her role on an academic and pastoral level. I would also like to acknowledge Professor Alan Watkins and Professor Ann John for also being an integral part of this PhD and providing me with support and helping me with this journey.

I would like to also mention a close colleague named Bruce Burnett who I know, will remain a close friend and colleague for life. He has not only supported me throughout this thesis but continuously encouraged me, even when things got tough.

Finally, and equally important, I would like to thank all those involved in this PhD from admin, social workers, social care professionals, SAIL support, librarians, there are too many to name, for giving up their valuable time and supporting me on this journey
Thank you.

Dedication

I would like to dedicate this thesis to three amazing individuals who are the centre of my world. My wonderful husband, who has always supported me endlessly throughout this journey. Without him I could not have completed this PhD. And to my two special, intelligent and beautiful daughters who inspire me every day with their courage, strength and unique perspectives in life. I hope that what I have learnt has helped me become a better mother to you both. Thankyou x Love Nicky & Mammy

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Abbreviations

ACE = adverse childhood experience

Acyp = All children and young people

ADHD = attention deficit hyperactivity disorder

ALF_PE = Anonymised linking field

AS = Asperger's syndrome

ASD = autism spectrum disorder

CAMHS – Child and adolescent mental health services

DDMF = Specific developmental disorder of motor function

DDSS = Developmental disorder of scholastic skills

DSM - Diagnostic and Statistical Manual of Mental Disorders

EDUW = Education Wales Dataset

FASD = Foetal Alcohol Spectrum Disorder

FEC = Further education college

FEE = Pupil attending provision not maintained by the authority, or outside of the authority, for which the authority pays fees

GAT = Youth Gateway

ICD - International Classification of Diseases

IGRP - Information Governance Review Panel

IND = Independent schools

Lac = Looked after child/children

LACW = Looked after children in Wales dataset

SCH = Maintained primary, middle, secondary or special school

NDD = Neurodevelopmental disorder

NICE = National Institute for Health and Care Excellence

NIP = Awaiting provision or not currently in provision

NMS = non-maintained special school

Non-Lac = Children that are not looked after

OCD = obsessive compulsive disorder

OPRD = Outpatient Referral Dataset

OTH = Other

PEDW = Patient Episode Database for Wales

PRU = Pupil Referral Unit

PSP = Bought in private sector provision

RAD = Reactive Attachment Disorder

SAIL = Secured Anonymised Information Linkage databank

SEN = Special educational need

TPR = Training providers

TUI = Individual tuition and tuition at pupils' homes or at hospital

USA = United States of America

VOG = Voluntary organisations

WDSD = Welsh Demographics Service Dataset

WLGP = Welsh Longitudinal General Practice Dataset

WRE = Work related education

Academic Contributions

Publications

Heady, N., Watkins, A., John, A., & Hutchings, H. (2022). Prevalence of neurodevelopmental disorders and their impact on the health and social well-being among looked after children (LAC): a systematic review protocol. *Systematic Reviews*, 11(1), 1-10.

Heady, N.J., Watkins, A., John, A & Hutchings, H. (2022) 'The challenges that social care services face in relation to looked after children with neurodevelopmental disorders. A unique insight from a social worker perspective' Accepted and in print: *Adoption & Fostering*, Sage (2022)

Conferences

Poster Presentation, 'Exploring the Enigmatic Paradigm of Mental, Developmental & Learning Disorders in the Looked After Population': Swansea University Medical School PGR Conference, 2019. Awarded joint winner for 'Best Poster Group 2' (2019)

Poster Presentation, 'Exploring the Enigmatic Paradigm of Mental, Developmental & Learning Disorders in the Looked After Population': Research Corner, National Social Care Conference (2019)

Power point Presentation, 'The new age of research: How can health and social care data create a more REAL TIME, positive impact for our most vulnerable groups in society?': Health and Care Research Wales Digital Conference (2020)

Wider engagement

Participated in the Three-Minute Thesis (3MT) Competition held at Swansea University. Competition finalist. (2020)

Delivered a three-minute talk to members of the public held by Fame Lab which is an international competition and partnership between the UK's Cheltenham Science Festival and the British Council for STEM researchers (2019)

Undergraduate Workshop, 'Mental Health, Wellbeing & Autism', School of Social Justice & Inclusion, University of Wales Trinity Saint David (2019)

Chapter 1: Introduction

1.1 Background, rationale and thesis objectives

Note: It is important to note that the preferred terminology expressed by this population is to be referred to as a care experienced child but for consistency and clarity purposes, this thesis has chosen to use the acronym Lac which coincides with Welsh governmental legislation, policy and third sector terminology for definition of this population (NSPCC, 2021; Welsh Government, 2021).

This thesis uses a mixed methods approach to explore the prevalence of neurodevelopmental disorders (NDDs) in looked after children and what impacts they may have on the Lac with a NDD. Lac remain to date, one of our most vulnerable populations in society, positioned at the forefront of government policy and legislation (Cardiff University, 2022). However, they continue to attain poor health and social outcomes associated with mental health, suicide, criminal system involvement, teenage parenthood, substance misuse and poor educational attainment on both a national and international level (Ford et al., 2007, Hill et al., 2017; Kääriälä & Hiilamo, 2017; Lightfoot et al., 2011; Meltzer et al., 2003, Teyhan et al., 2018). In view of their poor outcomes, there is still limited literature on them on as a population (Carlson et al., 2020; Rock et al., 2015; Thomas, 2011). The same applies for research on many NDDs, as they are relatively new to the field of psychiatry (Cassidy et al., 2016; Gray & Climie, 2016; Rappolt-Schlichtmann et al., 2018). NDDs are life-long disorders that create challenges in the biological processes associated with both the brain and/or nervous system. They are a complex, multifaceted subject area of which we are only at the tip of exploration and can cross a wide clinical spectrum (Schork et al., 2017; Thapar et al., 2017). Children with NDDs are also suggested to experience poor health and social outcomes in areas of mental and physical health, self-harm, suicidal ideation, eating disorders, family breakdown, low educational attainment (Bargiela et al., 2016; Fleming et al., 2020; Hatton, 2018; Hirjak et al., 2018; Kääriälä et al., 2017; Tierney et al., 2016). Considering the vulnerabilities associated with children with a NDD and Lac, there is even less literature that explores the Lac population with a NDD.

Prevalence of a medical disorder provides policy and services with an insight into the burden on a population and provides them with knowledge to enable and secure funding for specific

support and interventions (Noordzij et al., 2012). NDDs have been notably increasing in the general population which might be attributed to increased awareness of these disorders and the improvements in diagnostic assessment accuracy (Dimitropoulos et al., 2013; Guthrie et al., 2013; Madsen et al., 2018). Yet, there has been limited research applied to the prevalence of NDDs in respect of Lac. They have often been noted in Lac research but under researched and omitted from results or not elaborated upon for varying reasons, such as low sample numbers (Kääriälä & Hiilamo, 2017; O’Higgins et al., 2015; Sebba et al., 2015). A recent study found that neurodevelopmental (ND) problems were highly prevalent in the Lac population and a recent systematic review found that ADHD was higher in Lac compared to those individuals not in the care setting (non-Lac) (Ogundele, 2020; Willis et al., 2017). Although a significant finding, the systematic review used a national estimated prevalence from each country of study to compare rates. They also acknowledged that the results should be interpreted with some caution as ADHD shares similar behavioural symptomology with other conditions (Willis et al., 2017). While early diagnosis and intervention are important, overdiagnosis and misdiagnosis can be just as detrimental to the child and have serious implications on what specific support and interventions they receive (Giuliano & Geyer, 2017; Marangon et al., 2015; Merten et al., 2017). Considering the adversity and vulnerabilities associated with Lac, attaining an estimated prevalence of NDDs in this population would be useful to inform policy and services for future funding purposes. Therefore, the overall aims of this thesis were to explore the prevalence of NDDs in the Lac population at an international and national level and further explore what impacts they may have on the Lac.

The legal term or definition for a ‘Looked After Child’ (Lac) varies on a national and international level and can cross a wide range of children with varying, complex and safeguarding needs (Kääriälä & Hiilamo, 2017; RCPCH, 2022; Sebba & Luke, 2019). Lac can represent children placed in a variety of settings such as institutions, residential care, kinship care, pre-adoptive settings, foster care and respite care. However, in the UK, there are two legal pathways that lead to a child becoming ‘looked after’ (a) they have either been voluntarily placed in a care setting by those that care for them [Section 20, Children Act, 1989] or (b) have been removed from their biological home as the result of a Care Order [Section 3, Children Act 1989] (NSPCC, 2019; SCIE, 2012; Sebba & Luke, 2019). These children are perceived as the most vulnerable within the Lac population as they have been placed in a care setting for over 24 hours for varying reasons (NSPCC, 2019; Sebba & Luke,

2019). In this thesis, the term ‘Lac’ represents these children but due to the scope of the thesis, does not include children who are defined as children in protection, children in need or children who have transitioned into adoption.

When the child is removed from the home voluntarily or involuntarily the local authority assumes the first role of the collective ‘corporate parent’, responsible for caring, protecting and safeguarding the child (Hodges, 2020a). These children can be placed in various short, long term or fixed care settings where reunification with their biological parent/s is the primary objective. However, for varying reasons reunification may be delayed or not always possible and during this process, many children are placed in the care of wider family members, residential or foster care or transition into a pre-adoptive care setting (Carlson et al., 2020; Fernandez et al., 2019).

There are many reasons why children become ‘looked after’ which can vary on a national and international level (Côté et al., 2018; Pecora et al., 2009). Parental incarceration, disability, death or abandonment are just some of the contributory factors (Clarke et al., 2020; RCPCH, 2022). In countries such as the United Kingdom (UK) and United States of America (USA), the most prominent reasons for referral into services are abuse and neglect (Clarke et al., 2020; RCPCH, 2022). This broad term of ‘abuse and neglect’ includes complex areas such as physical abuse, emotional abuse, sexual abuse, not meeting basic needs, emotional or medical neglect (RCPCH, 2022). However, in Finland, children are more often placed in a care setting due to parental physical or mental illness or a child’s special care/special educational need (Côté et al., 2018). This is also reflected in another study where 18% of children had entered care because of behavioural problems and not as a result of abuse or neglect (Pecora et al., 2009).

In Wales, proactive Welsh legislation and policies such as the ‘Social Services and Well-being Act’ (2016) have been introduced to better support this population and policies on a global level have strived to attain similar objectives. Yet, many still continue to attain poor health and social outcomes (Cardiff University, 2022; Ford et al., 2007, Hill et al., 2017; Kääriälä & Hiilamo, 2017; Lightfoot et al., 2011; Meltzer et al., 2003, Teyhan et al., 2018).

Situated within these poor health and social outcomes and well documented in literature are the high prevalence of mental, behavioural and developmental disorders in the looked after population, often attributed to the developmental impact of Adverse Childhood Experiences (ACEs) or poor socioeconomic environments (Kääriälä & Hiilamo, 2017; Ford et al., 2007;

Meltzer et al., 2003). However, these prevalence studies, although significant, are often depicted and categorised under broad headings. Limited within primary and secondary literature is a more in-depth, individual analysis of what specific disorders represent these broad categories (Hill et al., 2017; Meltzer et al., 2003; NHS, 2018).

Neurodevelopmental disorders can span across a broad clinical spectrum. Some NDDs such as Prader-Willi Syndrome can be diagnosed with a medical test, however many NDDs are diagnosed solely based on behaviour (Dimitropoulos et al., 2013; Madsen et al., 2018).

Neurodevelopmental disorders such as Attention-deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) are examples of such disorders, which are diagnosed based on behavioural symptomology and can manifest in children regardless of socioeconomic environment and affect those who have or have not experienced ACEs (Ozawa et al., 2018). Furthermore, many of these NDDs can frequently co-occur with other NDDs such as Foetal Alcohol Spectrum Disorder (FASD), Reading and written Disorder (Dyslexia), Speech and Language Impairment, Social (Pragmatic) Communication Disorder, Tic Disorder, Stereotypic Movement Disorder (Dyspraxia) (Harrison et al., 2019; Thapar et al., 2017).

To add to complexities, these NDDs can be multifaceted but they do share similar behavioural symptomology in areas of impairment in social communication and interaction, sensory and motor dysfunctions, sleeping, eating difficulties, attachment issues and attention problems (Bargiela et al., 2016; Emmons & Anderson, 2005; Hirjak et al., 2018; Madsen et al., 2018; Thapar et al., 2017). As a result of these complex but similar behaviours, early support and diagnosis can often be difficult to attain. Many NDDs are often misdiagnosed, over-diagnosed or can be inadvertently overlooked by the clinician or professional as the urgency to treat or provide the child with services overrides further exploration of the underlying behavioural symptomology (Chasnoff et al., 2015; Merten et al., 2017; Pritchett et al., 2016). This lack of specific early diagnosis and intervention can leave the child struggling in the home, school and social setting with no support or understanding (Green et al., 2019; Hamed et al., 2015; Hosozawa et al., 2020). For the Lac who is already vulnerable and enshrouded in complexities, it was hypothesised that the challenges often associated with a NDD could place these children at an even greater disadvantage.

Therefore, chapter 2 and chapter 5 explore the prevalence of some of these NDDs (see table 1.1), which can only be diagnosed based on behaviour using two methods: a systematic review and an electronic cohort study.

Table 1.1 The NDDs of interest for this thesis (APA, 2016; ICD, 2022).

Neurodevelopmental disorder
Schizophrenia
Bipolar disorder
Social phobia, unspecified
Obsessive compulsive disorder
Eating disorders, unspecified
Mild intellectual disability
Social pragmatic communication disorder
Developmental disorder of speech and language, unspecified
Specific reading disorder
Mathematics disorder
Specific developmental disorder of motor function
Autistic disorders
Attention Deficit Hyperactivity disorder
Reactive attachment disorder
Tic disorder
Stereotyped movement disorder
Foetal alcohol syndrome

The majority of these NDDs are categorized as NDDs in the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) and International Classification of Diseases (ICD 11) and some are still classified under the broad heading of mental disorder (APA, 2016; ICD, 2022). However, they all share commonality affecting the development of the brain and/or nervous system. These diagnostic systems significantly influence the clinical sector and are the most up to date and authoritative guidelines for professionals and research. Yet, it is also common knowledge that the DSM and ICD manuals can take over ten years to be updated (APA, 2016; ICD, 2022). As an example, ADHD was classified as a disruptive, behavioural disorder for decades in previous manuals and autism spectrum disorder as ‘childhood schizophrenia’ (Harris, 2014; Kulage et al., 2020; Stein et al., 2020). Therefore, as the nosology of psychiatry continues to evolve, many of these NDDs fall under new categories as is in the instance with ADHD now being categorised as a NDD in the ICD 11 and many have

been grouped and labelled as NDDs in genetic and neuropsychiatry literature (Schork et al., 2017; Thapar et al., 2017). Therefore, this thesis explores these NDDs to ensure there is no missed important information and to prevent the under-identification of these disorders in this vulnerable population.

Once the child has been placed in a 'looked after' care setting, they become legally protected and the collective 'corporate parent' who is made up of a multi-disciplinary group of public bodies and wider partner agencies take full responsibility for the safeguarding and care of the child (RCPCH, 2022). Safeguarding these children is a pivotal and paramount objective for both health and social services. However, factors such as adverse childhood experiences (ACEs), psycho-social problems, poor socioeconomic status (SES), multiple residential and educational moves and complexities in the consent process are just some of the dynamics that affect safeguarding and frequently prohibit the child from early support and intervention which impacts on their overall health and social wellbeing (Häggman-Laitila et al., 2018; Morris et al., 2015; Sanders et al., 2014). These dynamics have placed significant pressures on health and social care services, on the parent/carer and wider family supporting the child (Hodges, 2020a). Due to the increasing demand, access to service provision for both Lac and children with these NDDs are often very difficult to attain which can often lead to crisis situations (Crane et al., 2016; Sayal et al., 2015). If we incorporate a NDD into the complexities that encompass Lac lives; it was further hypothesised that there might be issues around safeguarding as result of their impairments and challenges that are often associated with these disorders (Hirjak et al., 2018; Tierney et al., 2016).

Therefore, the second primary aim of the thesis was to explore the impacts on the Lac with a NDD. Chapter 2 and 3 explore some of these impacts using a review of the literature.

Another initial aim was to use a qualitative method to gain an insight into the lived experiences of this population. However, accessibility to this population was made very difficult due to varying factors such as the unprecedented coronavirus pandemic and the potential repercussions from interviewing these already vulnerable children from a safeguarding and protective perspective. Several communications were sent to charities such as 'Barnardos' and organisations such as 'Voices from care Cymru' but to no avail.

Therefore, this thesis had to adapt and focus on the perceptions and opinions of social work professionals who are often the first point of contact for these children when they enter the care system and have to quickly navigate processes and systems to best help and protect the child. Interviews with social workers from two local social care services are detailed and

discussed in chapter 4. Although, they could not provide a real lived experience, they could at least provide some insight, based on their experiences and perceptions into the challenges and barriers that might impact on the Lac with a NDD.

With rates of children entering the care system increasing on a national level, demands on services are placing immense pressures on government funding, third sectors, front line services, families and more importantly on the children themselves (Hodges, 2020a). This thesis aims to contribute to existing literature on Lac with a NDD and address several questions:

- What is the prevalence of NDDs in Lac compared to those not looked after (non-Lac)?
- What are the impacts on the Lac who has a NDD?
- What are the challenges and barriers for Lac with a NDD, based on social worker perceptions and opinions?

To answer these questions the thesis aimed to:

- Conduct a systematic review and meta-analysis (if feasible) to compare prevalence rates of NDDs between Lac and non-Lac and identify if there are any impacts on the Lac with a NDD.
- Conduct a brief narrative review to explore if any other impacts exist for the Lac with a NDD.
- Conduct interviews with social worker professionals to explore the challenges and barriers associated with the Lac who has a NDD, based on their perceptions and opinions.
- Link health and administrative datasets held in the ‘Secured Anonymised Information Linkage (SAIL) databank at Swansea University to explore if (a) if prevalence rates in Wales reflect the results of the systematic review (b) explore any other findings that might derive from the results of the chapters.

This thesis explores these aspects in an aim to fill some gaps in the literature that might provide some deeper insight into Lac with a NDD. Attaining the prevalence rates of NDDs will contribute to providing policy and services with knowledge of the burden, these disorders may have on this population to secure relevant and specific funding for service provision. From a safeguarding perspective, understanding what impacts may arise for the Lac with a NDD will contribute to providing health, education and social professionals with a better understanding of how Lac with a NDD may be at more risk of adverse outcomes compared to both their Lac and non-Lac peers. Although, the voice of the Lac is not present in this thesis, the interviews held with social work professionals do provide some insight into the challenges and barriers that Lac with a NDD experience, but this is only based on their perceptions and opinions. The findings may contribute in some way to future research conducted on this population.

1.2 Research Paradigm

This next two sections of this chapter outline the philosophical framework which include the research paradigm and theoretical influences that have underpinned this thesis.

A research paradigm forms the basis and underpins a piece of research before it is conducted with the aim to create a map of what needs to be understood and addressed based on a researchers' basic belief systems and values (Brad, 2011; Khaldi, 2017; Kuhn, 1962). It involves exploring the relationships between ontology, epistemology, theoretical perspectives, methodology, methods and sources needed to explore the truth or reality of something (Scotland, 2012). This thesis uses a variety of approaches that relate to positivism, subjectivism and interpretivism, however, it leans more to the pragmatic paradigm, even with its suggested limitations (Feilzer, 2010; Morgan, 2014). Dewey proposed that this approach was needed due to the ever-changing dynamics that are evolving in society (Kaushik & Walsh, 2019).

As the population of interest is shrouded in complexities, unpredictability, and dynamic environments; the thesis required a more diverse, flexible research paradigm that could explore the utilisation of different research methods to address the overall research questions (Feilzer 2010; Morgan, 2014). This approach enables a more holistic, enriched information/data to be captured using varied methodological approaches and/or combining

both ‘quantitative and qualitative’ methods (Feilzer, 2010). All research paradigms have their methodologies and methods that aim to explore the ‘truth’ but the pragmatism approach focuses more on action, the consequences of those actions and uses that knowledge for action (Morgan, 2014). It enables a more integrated knowledge to be attained that will lead knowledge to action (Nowell, 2015). If we consider the needs of this vulnerable population of interest and the cross-disciplinary sections of society they transition, this ‘knowledge to action’ was a relevant approach to follow (Hothersall, 2016).

The thesis explored different epistemological and axiological elements of research. An etic and emic epistemological approach was utilised in this thesis to gain both a subjective and objective view of the research questions using mixed methods. The mixed methods approach is suggested to be a practice that enables the researcher to combine different methods to answer a research question (Anguera et al., 2018). The varying terminology for what defines a mixed method study has created much discourse and confusion over the last few decades (Anguera et al., 2018). Term such as multi methods or mixed methods have been used interchangeably. Hunter & Brewer (2015) suggest that multi method research can involve using a combination of varying methods to conduct a study but is not limited to quantitative or qualitative. Creswell (2014) proposes that mixed methods research is an approach that combines both quantitative data with qualitative data, but the qualitative data is based on the personal experience of the participants themselves. This study collates both qualitative and quantitative data and follows a mixed methods approach, however, the qualitative data in this instance is not based on the personal experience of the Lac which could also suggest that this study follows more of a multi methods approach (Anguera et al., 2018). Nevertheless, this study is defined as mixed methods as it collates both quantitative and qualitative data in an aim to integrate the findings and explore if any similarities or contradictions occur (O’Cathain et al., 2010).

This thesis used various methods including systematic review, meta-analysis, narrative review, electronic cohort study and interviews. The systematic review and meta-analysis are suggested to be one of the most reliable methods for exploring evidence-based information to provide a clearer picture of the literature already attained and what gaps exist, using a systematic approach with parameters (Akhter et al., 2019; Moola et al., 2015). Conversely, it has been suggested that this method can be laden with publication bias as it is suggested that journals place more focus on articles that have significant results which creates an imbalance in research findings and excludes equally important findings that did not find statistically

significant results (Akhter et al., 2019; Dwan et al., 2008). Biases within the individual studies such as selection, attrition, performance and detection should also be considered when conducting a systematic review (Higgins et al., 2020). Nevertheless, it is still considered one of the gold standard methods for exploring published research (Moola et al., 2015).

The electronic cohort study is suggested to be a valid and robust method for collating data in research (Coulton et al., 2015; Zhang et al., 2017). Yet with every method there are drawbacks that should be considered. Data is based around the quality of input and output and if incorrectly processed or not standardised, this can have detrimental impact on what is perceived to be true or exact (Menachemi & Collum, 2011). Selection, coverage bias and loss of data can additionally have a significant impact on the results attained, particularly if we consider the retrospective cohort study as it can often explore a group that is known to have the outcome of interest (Pescoe et al., 2021; Tam & Kim, 2018). Even with its limitations it is a method that is being used on a widespread basis and has shown to yield important, valid results in real time, especially for those hard-to-reach populations (Shah et al., 2015; Zhang et al., 2017).

Numerical data, however, can only provide research with a quantifiable and measurable portrayal of the issue at hand. Understanding how the data translates for the individual is equally important. Quantitative methodologies although perceived to be objective, are unable to provide research with the experiences of the participants that the research is aiming to explore. This thesis utilised a qualitative approach by means of interviews to gain an external perspective into the challenges and barriers that Lac with a NDD may have (Nigar, 2020). Qualitative research and methodology continue to evolve to meet the demands of the complex dynamics in society. However, it is always positioned within a qualitative paradigm which enables the researcher to explore theories that quantitative methods cannot (Clarke & Braun, 2013; O'Neill, 2002). Within the qualitative paradigm, literature suggests that there is a distinction between two types of qualitative research, the Big Q and little q (Clarke & Braun, 2013). Big Q qualitative research involves using qualitative techniques within a qualitative paradigm and the small q qualitative research utilises qualitative data collection and techniques. However, it has been suggested in research that this small approach is better placed within the quantitative paradigm (Clarke & Braun, 2013; O'Neill, 2002; O'Neill, 2002) although the aim was not to quantify the qualitative findings it does offer another alternative to conduct research in this area which might initiate future qualitative, quantitative, or mixed methods research in this field (Clarke & Braun, 2013; Merten, 2007).

Kuhn and Dewey propose that it is important to answer a research question by whatever methods are needed, as long as they remain within the normal assumptions of methodologies (Dewey, 1910; Hall, 2013; Kuhn, 1962; Morgan, 2014). This pragmatic approach lends itself well to mixed methods research as it is suggested that this way of conducting varying methods to collate data can enable the researcher to expand their philosophical creativity to address the research questions and not be limited to the often divisive qualitative and quantitative paradigms (Johnson & Onwuegbuzie, 2004; Sommer Harrits, 2011).

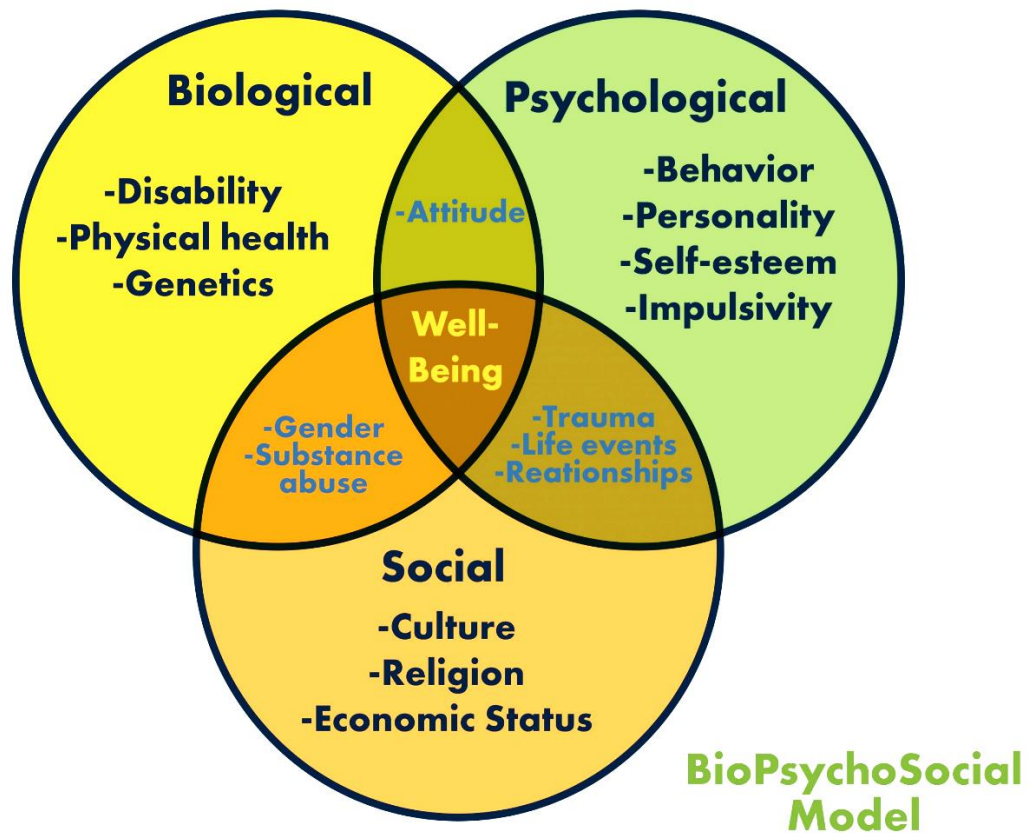
Nevertheless, it comes with its limitations and can be difficult to achieve because of varying epistemological challenges (Giddings, 2006; Migiro & Magangi, 2011). All methodologies and methods have their limitations; however, the pragmatism approach enables a unique set of data/knowledge to emerge that can often complement one another and enable the transferability of knowledge between them which can be adapted throughout the process to achieve a more holistic result (Hall, 2013; Shannon-Baker, 2016).

This thesis has used this pragmatic paradigm to conduct a mixed method approach to explore, analyse and interpret both qualitative and quantitative data simultaneously; enabling the study to attain subjective, objective and statistical data to address the research questions and provide as valid and reliable a result as is possible.

1.3 Theoretical Influence

The biopsychosocial model developed by George Engel in 1977, has underpinned the theoretical framework for this thesis. The theoretical model is an expansion of the psychosocial and systems theory models which are dominant models used in social work practice (Barkley, 2009; Ward et al., 2014). It was developed to provide a more holistic approach to explore the biological, psychological and social domains that exist in society, to better meet the dynamic, fast changing needs of the individual. (Lugg, 2021; Papadimitriou, 2017). (**Figure 1.1**).

Figure 1.1 The Biopsychosocial model of Wellbeing (MHDD, 2022)



This approach has been adopted by the World Health Organisation and has been used to inform the International Classification of Functioning, Disability and Health (ICF) which is used as a framework to classify health and health-related domains (Wade & Halligan, 2017, WHO, 2022b). All domains are independent but are intrinsically linked by related systems such as physical health (biological), emotional health (psychological) and environment (social). All of which require a multi and inter-disciplinary, holistic approach to achieve a good overall wellbeing, which cannot be attained until all three areas are supported (Gask, 2018; WHO, 2022b).

This model, however, comes with limitations and has been highly criticised in the field of medicine and psychiatry (Bolton & Gillett, 2019; Papadimitriou, 2017). It has been suggested that this approach can often blur the lines of treatment and intervention, when social factors are incorporated and considered (Papadimitriou, 2017; Bolton & Gillet, 2019). NDDs already affect the nervous system (biological), the brain (psychological) and social interaction and

communication (social). Therefore, gaining an understanding of the wider biological, psychological, social impacts and potential other determinants are important, even more so if we consider the frequent, additional adverse childhood experiences (ACEs) associated with Lac. (Basu & Parry, 2013; Gask, 2018; Thapar et al., 2017).

Chapter 2: Systematic Review & Meta-Analysis to explore the prevalence of NDDs and identify any risks associated for the Lac with a NDD

2.1 Introduction

To address part of the first research question in this thesis, this chapter explores what NDDs exist in the Lac population and compare prevalence rates to those children/young people who are not looked after (non-Lac) by means of a systematic review. It further explores if there are any impacts on the Lac with a NDD. A systematic review protocol which has subsequently been published, was designed a priori to this review and provides in-depth detail for the rationale and methods used in this review. However, due to the scope of the thesis and the wide range of terminology associated with a Lac, children who had been adopted were excluded from this systematic review. This was because the child is not always considered a Lac after completing the adoption process, even though a lot of these children would have previously been in foster care (Palacios et al., 2019; Paniagua et al., 2019).

In this chapter, a meta-analysis also highlights the prevalence rates of specific NDDs which cannot be medically tested for in the Lac population and compares rates to those defined as non-Lac. In addition, a narrative analysis explores the risks associated for the Lac with a NDD. The discussion examines all findings and makes reference to wider literature. Key findings are detailed, and recommendations made.

2.2 Systematic review objectives

The review aimed to:

- (a) attain an estimated prevalence of NDDs in Lac and if feasible compare with those children who are non-Lac.
- (b) identify if there are any impacts on Lac diagnosed with a NDD.

2.3 Methods

2.3.1 Search Strategy

The PI/ECO approach has been used to help define the primary research questions and formulate the search strategy.

(P) Population	All children/young persons
(I/E) Intervention or Exposure	Looked after
(C) Comparison	Non-looked after children/young persons
(O) Outcome	Neurodevelopmental disorders

This review was registered on PROSPERO (Identifier: CRD4201913103) and was reported in accordance with the guidelines outlined in the Preferred Reporting items for Systematic Reviews and Meta-Analyses (Page et al., 2021). A systematic review protocol was created prior to conducting the systematic review and meta-analysis (Heady et al., 2022). Articles were identified from PubMed, ASSIA, IBSS, Web of Science, PsychINFO, Scopus, Psych articles, Social Care Online. The databases were selected based on their relevancy and those identified in other peer reviewed studies that had explored similar outcomes of interest (Bronsard et al., 2016; Xu & Bright, 2018). Further articles were identified through systematically hand searching published and unpublished secondary, grey and governmental literature. Exploring citations and reference lists to further identify any new primary articles can be a rich information source and potentially alleviate publication bias (Ferguson & Brannick, 2012; Gough & Richardson, 2018). The key words ‘mental’, ‘developmental’, ‘disorder’, ‘looked after child’ and ‘prevalence’ were used to identify relevant literature. Synonyms were used to expand the results. The rationale for this was based on the extensive array of terminology that is often associated with both Lac and the NDDs that were being explored. A full representation of the key words and synonyms can be found in **Table 2.1** as the diagnostic codes and terminology for many of these NDDs have evolved over time (Harris. 2014; Reed et al., 2019). Searches were adapted in some databases due to the

difference in searching tools. See example of search strategy used in **Appendix 1**. The search strategy was verified by an experienced librarian in systematic reviews, employed at Swansea University.

Table 2.1 List of NDDs and synonyms included in the systematic review (APA, 2016; ICD, 2022).

Neurodevelopmental disorder	Synonyms
Schizophrenia	
Bipolar disorder	Paediatric bipolar disorder
Social phobia, unspecified	Social anxiety or social anxiety phobia
Obsessive compulsive disorder	OCD
Eating disorders, unspecified	Bulimia or anorexia
Mild intellectual disability	Developmental academic disorder or Learning difficulties
Social pragmatic communication disorder	Social communication disorder
Developmental disorder of speech and language, unspecified	Speech and Language disorder
Specific reading disorder	Reading disorder or written Disorder or Dyslexia
Mathematics disorder	Alcaculia or mathematic disability or Dyscalculia
Specific developmental disorder of motor function	Developmental coordination disorder or Dyspraxia
Autistic disorders	Autism spectrum disorder, pervasive development disorder, ASD and (including Aspergers syndrome)
Attention Deficit Hyperactivity disorder	ADHD
Reactive attachment disorder	RAD
Tic disorder	
Stereotyped movement disorder	
Foetal alcohol syndrome	Foetal alcohol spectrum disorder or FASD

*Both ICD and DSM diagnoses were included in the review

2.3.2 Eligibility Criteria

No restriction was placed on country, design or year of publication due to the anticipated low number of articles available for this review. Filters on language limits were applied to only include published articles in the English language. Databases that had distinctive processes that required adaptation in searching tools were guided and supervised by the residing university librarian to ensure consistency.

As detailed within the thesis already, Lac definition and terminology can vary on a national and international level. Therefore, Lac represented those children who had been removed voluntarily or involuntarily from their home and placed in an 'out of home care' setting. For the scope of this review, only those children who had been placed in either/or residential, foster or kinship were included (Bonevski et al., 2014; Jedwab & Shaw, 2017).

Non-Lac represented all those children who had not been placed in the care setting at the time when the articles had conducted their research. This included children who accessed respite care, often referred to a 'child in need' or 'child in protection' as they had not been removed from home and remained with the parent/s (Côté et al., 2018; RCPCH, 2022). Although, children who transition to adoption are frequently removed from the biological home for varying reasons, they were excluded from the review as they do not always fall under the umbrella term of being 'looked after' after being adopted (RCN, 2021).

As there is a duty of care to support some of these children up to the age of 25 in the UK guided by the Children and Families Act (2014), this limit was applied to the inclusion criteria (Barnardos, 2021). This enabled the review to capture those individuals who might have been diagnosed later in their life with these NDDs. Additionally, this time period enabled the review to explore the earlier impacts on these children/young persons, as a result of having a NDD for earlier intervention purposes (Jedwab & Shaw, 2017).

Studies that provided a comparative prevalence between Lac and non-Lac and detailed primary data on the prevalence or incidence of NDDs for individuals < 25 years of age, supported by either/or a diagnostic code, standardised diagnostic assessment tool or survey response were included. Studies that used national estimated rates of prevalence as a comparator were excluded as it was agreed that the processes for attaining prevalence in these studies might differ from the other studies that used primary data in their research, potentially invalidating the results of the review.

The DSM V and now revised ICD 11th Revision guidelines, acknowledge that many of these NDDs now co-occur and can be dual diagnosed (APA, 2016; WHO, 2022a). Therefore, the review included studies that had prevalence rates for children who had more than one diagnosis (First et al., 2015; Ramtekkar, 2017).

Studies that did not contain defined primary prevalence data for the meta-analysis but compared prevalence and examined impacts on those Lac and non-Lac with a NDD were considered for inclusion to conduct a narrative analysis. No impacts were predefined as this may have excluded important information due to the limited number of available studies with regards to these vulnerable children and the specific associated disorders being explored.

2.3.3 Study selection

The study selection process was overseen by two additional reviewers (Hayley Hutchings (HH), Ann John (AJ)). I conducted the searches, removed all duplicate studies and performed initial screening of all studies by title and then abstract, applying the pre-defined exclusion and inclusion criteria to remove studies that did not fit the specified criteria. Myself and HH then independently screened and critically analysed the full text of the remaining papers. A third reviewer (AJ) was assigned as mediator to reach consensus should there have been any disputed articles (Waffenschmidt et al., 2019).

To ensure that new literature was not missed, intermittent hand searches were also conducted while the review was being undertaken up to November 2021 (Bashir & Conlon, 2018). One further study was added to the selection of studies (Keefe et al., 2020). A reviewer's meeting was scheduled to seek consensus and to agree if any more primary studies should be included in the review; to aid in addressing the research questions.

2.3.4 Quality and Bias assessment

The Joanna Briggs Institute (JBI) critical appraisal tools were utilised to screen and assess the quality of the literature in this review, (JBI, 2022). These tools which have been used in other reviews were applicable due to the diversity of the designs that were included in the

systematic review (JBI, 2022). Appraisal tools used in the study were designed for prevalence studies, analytical cross-sectional studies, case control and cohort studies. All tools consisted of domains that assessed and appraised the design, quality, conduct and analysis of the selected articles (Munn et al., 2014).

Adopting the same approach as in other studies, the review followed the same format scoring the studies using a point system 1-11 (Catalá-López et al, 2019). Studies were all critically analysed and evaluated as a low/medium or high risk using the predefined questions detailed in the JBI appraisal tools. If the question was evaluated as a 'Y= Yes' it would score one point, a N = No' or 'U = unclear' would score zero points. (**See appendix 2**). Those studies that were scored as ≥ 7 were rated as high quality and a low risk of bias, 4-6 moderate quality and medium risk of bias or < 4 , low quality and high risk of bias (Catalá-López et al., 2019). Myself and HH independently assessed and appraised the studies and any divergence in assessment was mediated by the third reviewer (AJ). There were no discrepancies identified.

2.3.5 Data Extraction

An extraction form based on other similar studies was adapted to collate the information related to the areas of interest (Bronsard et al., 2016; Xu & Bright, 2018). I extracted the characteristics from each study. Data collection included study name, country, total sample size, age range, type of placement, neurodevelopmental disorder specified, diagnostic system used, and any impacts on the Lac with a NDD. HH additionally screened the extraction form to verify the accuracy of the data collated. Any disputed data were discussed with the third reviewer (AJ) to reach consensus. There was none.

2.3.6 Data Synthesis & Analysis

Firstly, the review screened the studies for primary data on the prevalence rates of NDDs that were the outcomes of interest. Studies that had defined primary data and studies that had defined primary data that included subgroups were pooled together to provide two distinct subgroups (Lac & non-Lac) (see Table 2.2). Studies that detailed primary data on other NDDs of interest but did not have enough data to conduct a meta-analysis were presented in a

descriptive format (see Table 2.3). For consistency purposes, only studies where Lac represented those children detailed as being in foster care, residential care or kinship care were used for the meta-analysis (see Table 2.2). Review Manager 5.3 software was then used to conduct a meta-analysis on the included studies.

Studies that did not have defined primary data to meet eligibility for the meta-analysis but detailed prevalence on the NDDs of interest and explored impacts on the Lac with a NDD were explored as a narrative by means of thematic analysis where similarity existed.

Due to high heterogeneity between studies, risks ratio and 95% confidence intervals (CI) using the Mantel-Haenszel random-effects model were used to express and estimate the mean effect. Utilising this model enabled the review to provide a more balanced weight to smaller and larger studies and estimate a more standardised mean effect (Bashir, & Conlon, 2018). As all studies used in the meta-analysis included prevalence studies, the risk ratio was considered the more appropriate approach to calculate the effect estimates (Viera, 2008). Risks ratio (RR) results that did not cross one and had a narrow confidence interval were considered to be significant. If the risks ratio crossed one and had wider confidence intervals, they would have been considered to be inconclusive indicating no effect. Forest plots were used for representation of the studies. It was intended to use funnel plots to show publication bias, but limited data precluded this (Higgins & Green, 2011, Ioannidis & Trikalinos, 2007, Ward, 2013). Age and gender were explored during the synthesis and but could not be further analyse due to the high heterogeneity between studies.

2.4 Results

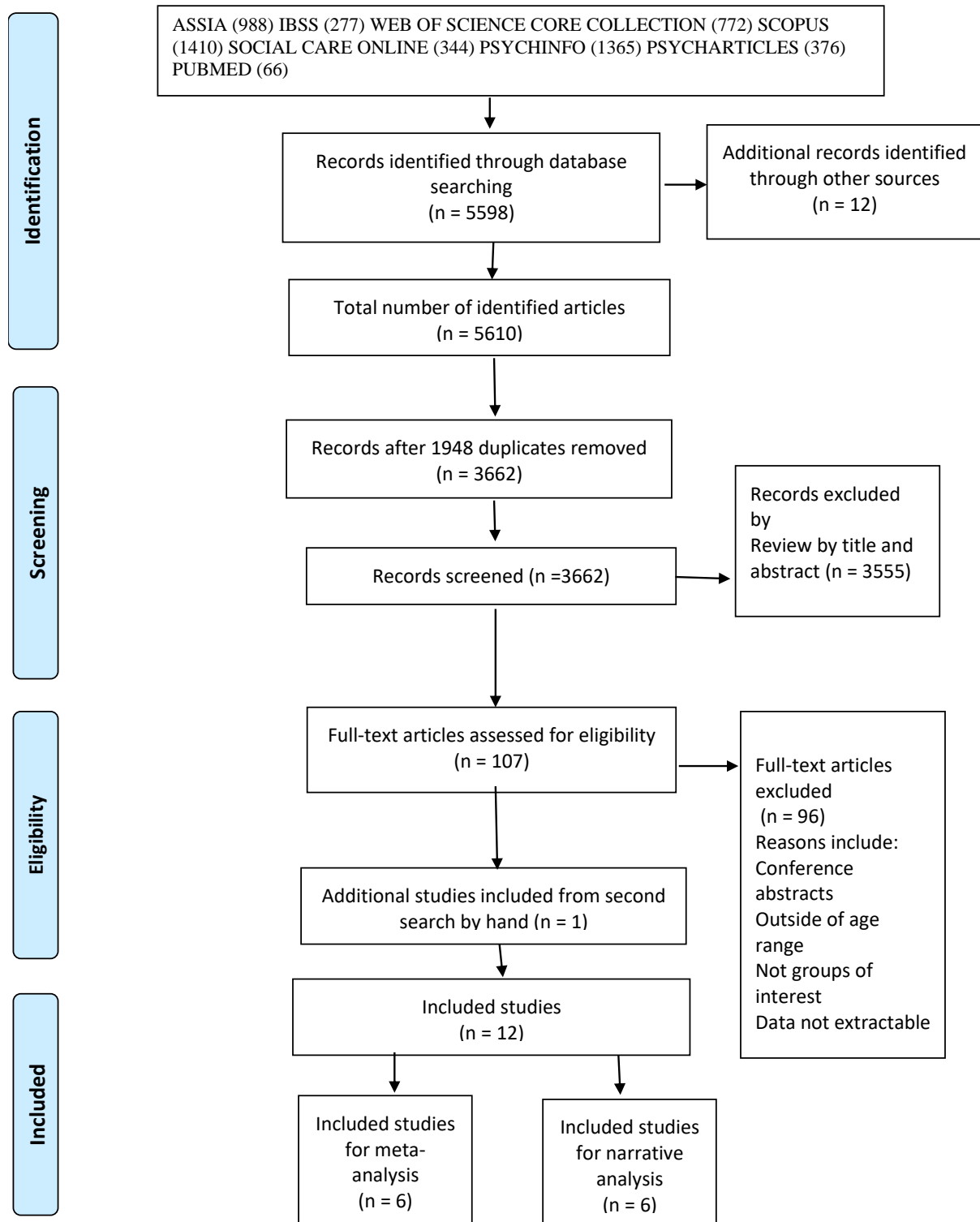
The search strategy generated 5,598 studies; an additional 12 studies derived from hand searching. One more was added after intermittent hand searching (see Figure 2.1). Following the removal of duplicates, review by title, abstract and fully assessed articles. 12 studies met eligibility for the review (Côté et al., 2018; dosReis et al., 2001; Ford et al., 2007; Egelund & Lausten, 2009; González et al., 2019; Harman et al., 2000; Keefe et al., 2020; Mandell et al., 2008; Tordön et al., 2019; Turney & Wildeman, 2016; Vanderwerker et al., 2014; Zill et al., 2014). A review meeting was scheduled to reach consensus on six studies that compared prevalence of the NDDs but did not provide defined primary data that could be used for the meta-analysis (Côté et al., 2018; Egelund & Lausten, 2009; Ford et al., 2007; Mandell et al.,

2008; Tordön et al., 2019; Zill et al., 2014). These studies were deemed appropriate for the review as they compared prevalence of the NDDs of interest but additionally explored impacts on the Lac with a NDD. The corresponding author of the Vanderwerker et al (2014) study was directly contacted to try and attain additional prevalence data on schizophrenia, bipolar, autism which had been included in the primary research but had been excluded from the results (Vanderwerker et al., 2014). However, no response was received. All twelve studies were then further examined for impacts on the Lac with a NDD.

Six studies met eligibility for a meta-analysis and the Review Manager 5.3 software was used to compared prevalence rates between Lac (those only in foster, kinship or residential care) and non-Lac (those not in foster care) (dosReis et al., 2001; Egelund & Lausten, 2009; Harman et al., 2000; Keefe et al., 2020; Turney & Wildeman, 2016; Vanderwerker et al., 2014). As only six studies met eligibility for the meta-analysis, funnel plots were not used (Higgins & Green, 2011, Ioannidis & Trikalinos, 2007, Ward, 2013).

The remaining six studies that compared prevalence of the NDDs of interest but did not meet eligibility for the meta-analysis are described as a narrative and detailed within the results (Côté et al., 2018; Ford et al., 2007; González et al., 2019; Mandell et al., 2008; Tordön et al., 2019; Zill et al., 2014).

Figure 2.1 Flowchart of study selection



All 12 eligible studies shared some similarities in terms of research design, definition of care setting, population samples, diagnostic systems and criteria. The majority of the studies were conducted in the USA (n = 8). The remainder of the studies were conducted in the United Kingdom (UK) (n = 1), Denmark (n = 1), Sweden (n = 1) and Finland (n = 1). Using the pre-defined JBI critical appraisal tools and format scoring, 12 of the studies scored <7 and were deemed to be of high quality (see **Table 2.2**). The table also details reasons for the exclusion on inclusion of studies in the meta-analysis. For more in-depth detail of characteristics see **Appendix 2**

Table 2.2 Study Characteristics of the 12 eligible studies

Study	Country	Total Sample Size	Type of care setting	Type of non-care setting	Neurodevelopmental Disorder explored	Diagnostic System	Age Range (y)	Quality Score [≥ 7 (High), 4-6 (Moderate), < 4 (Low)]	Reasons for inclusion or exclusion for meta-analysis	Impacts on Lac with a NDD
Côté et al. (2018)	Finland	54 814	Out of home care (Foster, Residential & Kinship)	Non placed in care	Bipolar	ICD 9 ICD 10	6-17	11 = High	Excluded as bipolar prevalence was grouped with psychotic disorders	Increased risk of criminal convictions
dosReis et al. (2001)	USA	15 507	Foster	SSI Other aid	ADHD	ICD 9	0-19	8 = High	Included as provides defined primary data for subgroups.	Higher usage of mental health services.
Ford et al. (2007)	UK	11 691	Foster Kinship Residential Independent Living	Disadvantaged household Non-disadvantaged household	ADHD ASD OCD	ICD 10	5-17	9 = High	Excluded as Lac population included those in independent living.	Increased risk of being placed in foster care.
Egelund & Lausten (2009)	Denmark	73 850	Foster Kinship Residential	In home care (CPS) Non-welfare	ASD, DDSS, DDMF, ADHD, TIC	ICD 10	7 -12	7 = High	Included as primary data available for subgroups.	Higher prevalence of NDDs.
González et al. (2019)	USA	2480	Foster	Peers in youth study	ADHD	DSM IV	7-15	9 = High	Excluded as prevalence data conducted	Increased risk of emotional & physical abuse; including

									over two waves.	being placed in foster care.
Harman et al. (2000)	USA	39 500	Foster	ADFC SSI	ADHD Bipolar	ICD 9	5-17	9 = High	Included as primary data available for subgroups.	Impacts were explored but none were found
Keefe et al. (2020)	USA	95 382	Foster	Non-foster	ADHD ASD	ICD 9	1-18	9 = High	Included as provides defined primary data for groups.	Impacts were explored but none were found
Mandell et al. (2008)	USA	60 641	Foster	Disabled Poverty Other	ASD	ICD 9	<21	7 = High	Excluded as prevalence data was not clearly defined between groups.	Higher prescription and usage of psychotropic drugs.
Tordön et al. (2019)	Sweden	5839	Out of home care	Not in out of home care	Eating disorders ADHD ASD	Questionnaire	18-20	8 = High	Excluded as primary data for no. of participants ranged between two values.	Sought more help from mental health services.
Turney & Wildeman (2016)	USA	92 159	Foster	Non-foster	ADHD	Health Survey	2-17	9 = High	Included as provides defined primary data for groups.	Impacts were explored but none were found
Vanderwerker et al. (2014)	USA	5394468	Foster	Non-foster	ADHD	ICD 9	0-13	9 = High	Included as provides defined primary data for groups.	Impacts were explored but none were found

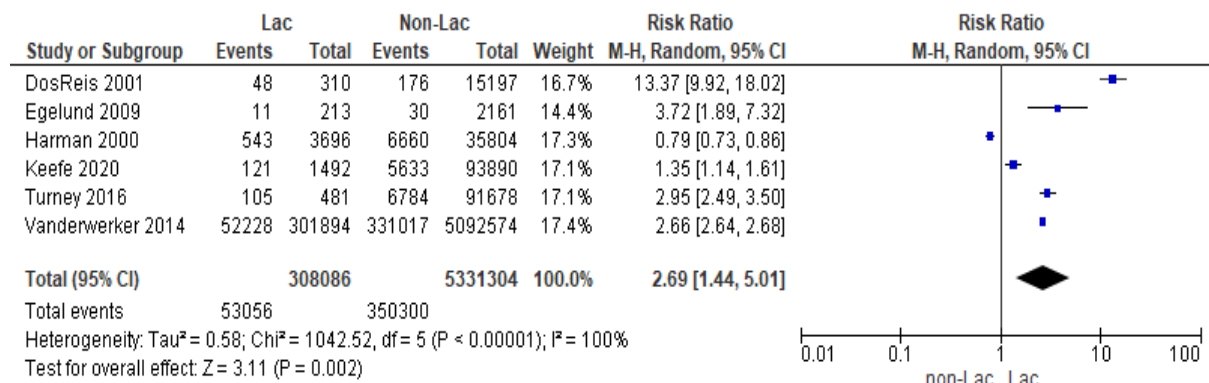
Zill et al. (2014)	USA	71411	Foster	Living with parents Living with mother only Children adopted from foster care	ADHD	National Health survey	2-17	7 = High	Excluded as non-Lac subgroup included children who had been adopted from foster care.	Impacts were explored but none were found
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Note: NDD = neurodevelopmental disorder, OCD = obsessive compulsive disorder, DDMF = specific developmental disorder of motor function, ASD = autistic disorders, ADHD = attention deficit hyperactivity disorder, TIC = tic disorder, DSM = Diagnostic and Statistical Manual of Mental Disorders, ICD = International Classification of Diseases, SSI = Supplemental Security Income, ADFC = Aid to Families with Dependent Children.

2.4.1 Meta-analysis: Prevalence of ADHD

Findings from six eligible studies show that ADHD was prevalent in 17.22 % of Lac (n= 308,086) vs 6.57 % of non-Lac (n = 5,331,304) with a RR = 2.69 [1.44, 5.01] (dosReis et al., 2001; Egelund & Lausten, 2009; Harman et al., 2000; Keefe et al., 2020; Turney & Wildeman, 2016; Vanderwerker et al., 2014). Lac was associated with having a higher prevalence of ADHD compared to their non-Lac peers (see figure 2.3).

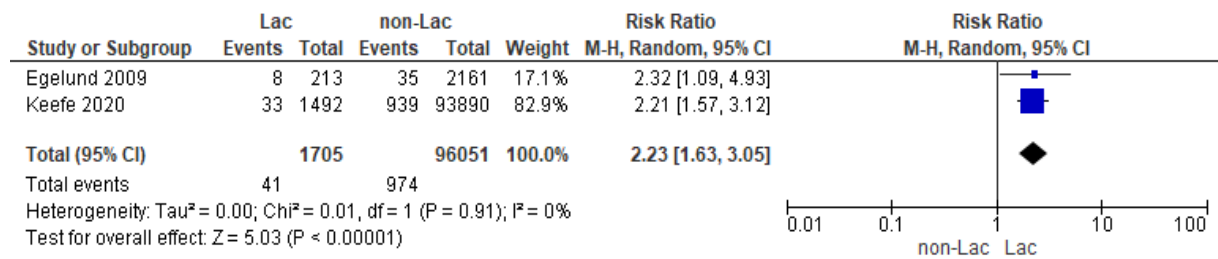
Figure 2.3 Prevalence of attention deficit hyperactivity disorder in looked after children (Lac) versus children that are not looked after (non-Lac)



2.4.2 Meta-analysis: Prevalence of ASD

Findings from two eligible studies show that ASD was prevalent in 2.4 % of Lac (n= 1,705) vs 1.01% of non-Lac (n = 96,051) with a RR = 2.23 [1.63, 3.05] Egelund & Lausten, 2009; Keefe et al., 2020). Lac was associated with having a higher prevalence of ASD compared to their non-Lac peers (see figure 2.4)

Figure 2.4 Prevalence of autistic disorders in looked after children (Lac) versus children that are not looked after (non-Lac)



Although risks ratios did not cross one in the ADHD and ASD forest plot, both had a narrow CI. It is important to interpret these figures with caution due to the small number of studies and large amount of heterogeneity within studies.

2.4.3 Prevalence of other NDDs of interest

The review could only find two eligible studies that provided comparative primary data for other NDDs of interest but due to the limited studies could not be utilised for a meta-analysis (Egelund et al. 2009; Harman et al. 2000). Specific developmental disorder of scholastic skills, Specific developmental disorder of motor function and Tic Disorder were found to be higher in the Lac population However, Bipolar disorder had a higher prevalence in the non-Lac population. See **Table 2.3** for detail.

Table 2.3 Prevalence of bipolar, specific developmental disorders of scholastic skills & tic disorders in looked after children (Lac) versus children that are not looked after (non-Lac)

Study	Neurodevelopmental disorder	Non-Lac (%)	Lac (%)
Harman et al. 2000	Bipolar disorder	1.2	1.0
Egelund et al. 2009	Specific developmental disorder of scholastic skills	0.1	0.5
	Specific developmental disorder of motor function	0.2	0.5
	Tic disorders	0.2	0.9

2.4.4 Meta-analysis: Studies that did not meet eligibility for the meta-analysis

Descriptive findings are detailed for six of the studies as they explored the NDDs of interest between Lac and non-Lac but did not have defined primary prevalence data that met the eligibility for the meta-analysis.

- Ford et al (2007) found that all children that were defined as ‘looked after’ by local authorities had a higher ADHD (Hyperkinesis) (8.7%) and ASD (Autistic-spectrum disorder) (2.6%) prevalence compared to children living in a private disadvantaged household (ADHD = 1.3%, ASD = 0.1%) and the remaining children who lived in a private household (ADHD = 1.1%, ASD = 0.3%). Obsessive-compulsive disorder (0.2%) had the same prevalence as the remaining children in a private household but lower than those children living in a private disadvantaged household (0.5%).
- Zill & Bramlett (2014) found that children adopted from foster care had the highest prevalence rate for ADHD (35.7%) compared to children in foster care (21.8%), children living with single mothers (10.7%) and children living with two biological parents (5.3%).
- Côté et al (2018) found that younger adults who had been placed as children in out of home care had greater odds of having a NDD (3.59, 1.17-11.02). However, the results

did not provide individual prevalence of the NDDs. The same was true for psychotic and bipolar disorders (3.98, 1.80-8.80).

- Tordön et al (2019) explored a Lac population which ranged between two values n = 35 -38) and the results showed that 20 participants out of the sample had either ADHD, eating disorders or ASD. Children in out of home care had a higher prevalence of ASD (Lac 5.7% vs non-Lac 1.9%) and ADHD (inattention problems) (Lac 31.4% vs non-Lac 7.1%) compared to those children without out of home care involvement. The prevalence rates were significantly higher than their non-Lac peers and compared to the national expected prevalence rate.
- Mandell et al (2008) explored ASD and even though the Lac sample included children in independent living, ASD was suggested to be highly prominent in those children in foster care, but no defined primary data were available.
- Gonzalez et al (2019) conducted their study over two waves found that ADHD was highly associated with being placed in in foster care.

2.4.5 Impacts on the Lac with a NDD

Understanding the prevalence of NDDs is important for this population however, the second objective of this systematic review was to explore impacts on Lac with a NDD. The twelve studies were examined for impacts on the Lac with a NDD. Higher mental health service usage and prescription, emotional, physical and sexual abuse, foster care involvement and criminal justice involvement are detailed as potential negative impacts on the Lac with ADHD, ASD and Bipolar. All are further discoursed in the discussion section of this chapter.

Mental health usage - DosReis et al (2001) found that Lac with mental disorders, including ADHD, depression and developmental disorders aged (6-14) had higher rates of mental health service usage compared to the comparison groups. This finding was also reflected in the Tordön et al (2019) study, where Lac with ADHD were more likely to pursue help from mental health care services compared to their non-Lac peers with ADHD.

Medication prescription – The Mandell et al (2008) study explored Medicaid, which is a federal and state program that works together with the Children’s Health Insurance Program

(CHIP), in the USA to provides health coverage to millions (Mandell et al., 2008). They found that that 20.8% of children with ASD were Lac and had the highest use of psychotropic drugs (71%) and prescribed medication. Out of this population, 18% of the children aged 0-2 years and 32% aged 3-5 had been prescribed medication.

Emotional abuse - González et al (2019) found that emotional abuse had a robust association with having an ADHD diagnosis. The study also found that boys were more likely to experience this form of abuse compared to girls.

Physical abuse - González et al (2019) identified a negative association with physical abuse and ADHD. In this study, the presence of physical abuse in Lac was (OR=2.2) compared to their non-Lac peers and in this case affected more girls than boys.

Sexual abuse - Tordön et al (2019) found that Lac had experienced more physical, penetrative sexual abuse (OR=4.3) compared to their peers. The disclosure of sexual abuse was less common in Lac and acts of persuasion, or adults' use of their social position, more common.

Foster care placement - González et al (2019) found robust associations with foster care placement and having ADHD, even after adjusting for all maltreatment. Zill et al (2014) also found that 22% of foster-care children had been diagnosed with ADHD in their childhood. Similarly, Ford et al (2007) found ADHD and ASD to be more prevalent in the foster care setting.

Criminal justice involvement - Zill & Bramlett (2014) found that 36% of Lac had received a criminal conviction between the ages (18–25yrs) compared with 21% of non-Lac. Criminal convictions in Lac with bipolar and psychotic disorders, remained substantial even after regression analysis.

2.5 Discussion

This is the first review to the researcher's knowledge that has used primary data to compare prevalence rates of these NDDs between Lac and non-Lac and offers further insight into the impacts on the Lac with a NDD. Out of the twelve eligible studies, ADHD and ASD emerged as the most studied disorders.

The review found that rates of ADHD (Lac 17.22 vs non-Lac 6.57 %) and ASD (Lac 2.4 vs non-Lac 1.01%) were significantly higher in the Lac population. Currently the worldwide estimated prevalence rates for ADHD in children <18 years is 5.29% and 0.37% in children and adults with ASD (0.37%) (Posner, 2020; WHO, 2021). Although, significantly higher, other non-comparative studies have found similar higher prevalence rates and have documented prevalence rates as high as 33.3% for ADHD and 39% for ASD in the Lac population (Green et al., 2016; Jozefiak et al., 2016).

The ADHD institute proposes that the worldwide prevalence of ADHD for children under the age of <18 years can be placed anywhere between a range of 0.1-8.1% with a mean of ~2.2% which is significantly lower than the rates of prevalence for both Lac (17.22%) and non-Lac (6.57%) found in this review in this review (ADHD Institute, 2020). The prevalence of ADHD is increasing year on year in the USA and the most recent update estimated that 9.5% of children in the USA had a diagnosis of ADHD which is closer to the overall results of this review for the non-Lac population (Zablotsky et al., 2019).

Conversely, in the Denmark study, when the in-home care population was aggregated with the non-welfare children to attain the non-Lac sample, it inflated both the ADHD and ASD prevalence in the non-LAC population. Nevertheless, the Denmark study still showed similar higher prevalence results for ADHD in Lac (Egelund et al., 2009).

Capturing routine data on the prevalence of NDDs is important to ensure specialist services are provided to support these children. Some NDDs such as ADHD appear to be routinely captured in some countries, but this is not consistent on a global level (ADHD Institute, 2020; Pawliczuk et al., 2018; Song et al., 2021). ADHD prevalence in Lac does not appear to be routinely collated in the UK (DfE, 2021; WAG, 2021). The prevalence of ASD is clearly defined and captured within the children in need census (DfE, 2021). However, ADHD falls under the very wide umbrella term of behaviour, which includes other conditions that present with behavioural difficulties. This could be attributed to the fact that the prevalence of ADHD maybe so insignificant in the UK that it does not warrant its own unique code. However, recent research suggests otherwise and documents that ADHD in 2012 was 1.06% (95% CI 1.03 to 1.09) and prevalence of ADHD doubled in the most deprived areas of England (prevalence rate ratio 2.58 (95% CI 2.36 to 2.83) which is evidence of its existence within the UK (Prasad et al. 2019).

The findings show that Lac had a higher prevalence of ASD compared to non-Lac (Lac 2.4% v 1.01%). Although, both rates are higher than worldwide estimates of ASD (WHO, 2021). In Northern Ireland it is currently estimated that 4.5% of school age children have ASD (DfH-NI, 2021). Another article that explored the prevalence of ASD in a Lac population found similar high prevalence rates in that particular, English local authority (Parsons et al., 2019). In the last documented 'Children Receiving Care and Support (CRCS) census, a total 12% of children aged 5-15 in CRCS had been diagnosed with ASD compared to 2% of all other children based on the January 2019 Pupil Level Annual Schools Census in Wales. Although, CRCS involved all children in need and children under protection, LAC made up for 41% of the population (WAG, 2019a).

This review could not find any comparative studies that detailed prevalence of the other NDDs of interest. NDDs such as dyslexia have been evidenced in some Lac literature (Woolgar, 2013) but it is extremely limited. This lack of literature on comparative studies is disadvantageous for both Lac and non-Lac as many of these NDDs can significantly impact on the child's ability to learn within the educational setting (Schelbe et al., 2021).

Reasons for the higher prevalence rates of both ADHD and ASD could be attributed to varying factors, such as increased awareness of NDDs in health and social care settings, demographic or geographical variations in the diagnostic process or improved documentation and data entry (Loomes et al., 2017; Lopez et al., 2020).

Conversely, as many children are often misdiagnosed or over-diagnosed in the general population, we must consider this same occurrence in the Lac population (Merten et al., 2017). Unravelling their complex behavioural symptomology coupled with behaviours associated with trauma and attachment as a result of ACEs, create confusion and uncertainty for many professionals and clinicians. As many mental and NDDs share similar behavioural symptomology and frequently co-exist, disorders have been known to be over-diagnosed or misdiagnosed as other conditions in childhood (Guthrie et al., 2013; Madsen et al., 2018). To add to this complexity, the diagnosis of children with NDDs such as ADHD or ASD is attained through the evaluation of historical and current behaviour provided by the parent, combined with intensive educational and psychological testing. Lac frequently move residential and educational settings and parental consent issues can contribute towards a severe lack of biological, parental involvement around childhood history (Norgate et al.,

2012; Ward, 2009). These complications would have significant impact on the diagnostic process for these children (Bitter et al., 2019; Guthrie et al., 2013; Madsen et al., 2018).

Another factor to take into consideration for possible higher prevalence rates is the hereditary or genetic origins associated with these NDDs. Many individuals in the general population have received an ADHD or ASD diagnosis much later in life after historically being misdiagnosed or diagnosed with other co-morbid conditions (Bitter et al., 2019; Leedham et al., 2020). Therefore, we must consider that there may be a genetic or hereditary influence occurring. The parents of these Lac may have fallen under the diagnostic radar and been misdiagnosed or even missed altogether as the need to treat other conditions may have overridden or masked further, more in-depth exploration of potential NDDs. Particularly, if we take into account that parents of Lac often have challenges in areas of mental health, substance misuse, domestic abuse and learning difficulties or disabilities (Augsberger et al., 2021; McAuley & Davis, 2009).

The second objective of the systematic review was to explore impacts on the Lac with a NDD. Higher mental health service usage, physical and emotional abuse, higher medication prescription, foster care involvement and criminal justice involvement were impacts on the Lac with ADHD, ASD and Bipolar and are further discussed (Côté et al., 2018; DosReis et al., 2001; González et al., 2019; Mandell et al., 2008; Tordön et al., 2019; Zill & Bramlett, 2014).

It is well noted in research that Lac have a higher prevalence of mental health problems compared to their peers and some are embedded in services which provide them with direct access to appropriate health and social care provision (Ford et al., 2007, Kääriälä & Hiilamo, 2017; Meltzer et al., 2003). This might contribute to the findings of the dosREis et al (2001) and Tordön et al (2019) studies where mental health service usage was high.

Having NDDs, coupled with additional ACEs has a significant impact on mental health needs. This is supported in a recent report led by the Joint Targeted Area Inspections (JTAs), 'Feeling heard': partner agencies working together to make a difference for children with mental ill health' (Government UK, 2020). However, they additionally found that children in the UK with ADHD and ASD experienced lengthy times to access mental health services. This included children in care, in protection and children in need amongst other vulnerable groups.

The mental health needs of Lac can be attributed to many varying complex dynamics and ACEs can play a significant factor (Scheffler et al., 2020). Additionally, many of these NDDs co-occur with debilitating anxiety and other mental disorders such as anorexia and OCD which could further contribute to their need for mental health services (Kushki et al., 2019; Wentz et al., 2019).

The higher usage of mental health services for Lac could be a contributory factor to the findings detailed in the Mandell et al (2008) study. Medication prescription and usage has been noted as high in the Lac population in several studies (Karlsson & Lundström, 2021; Raghavan et al., 2005; Willis et al., 2017). The number of children aged between 0-5 years who had been prescribed medication raises some concern. However, psychotropic medication as suggested by Mandell et al (2008) can be used for both mood-stabilizing and/or or antiepileptic properties. Many children with ASD have a high prevalence of epilepsy and take these forms of medication (Ewen et al., 2019). They further propose that the high use of psychotropic drugs may be attributed to the changing environments that foster children often experience (Norgate et al., 2012; Ward, 2009). Changes to placements and routines for Lac with ASD could exacerbate challenging behaviours and potentially lead to medicating the child to stabilise the care placement (Mandell et al., 2008).

Medication has always been a controversial area for children in cases of ASD and ADHD. Some studies have reported improved behaviours as a result of administering medications while others report negative associations and debilitating side effects (Alfageh et al., 2019; Rossignol & Frye, 2014; Popow et al., 2021). The long-term effects are still unknown and continue to be explored in literature (Alfageh et al., 2019; Rossignol & Frye, 2014; Popow et al., 2021).

Emotional abuse has a wide definition in the context of social work and is often a major contributing factor for children becoming looked after (Trickett et al., 2009). It can be attributed to a variety of factors such as maltreatment, neglect, harmful or destructive social conditioning, poor socioeconomic environment or parental mental health (Conti et al., 2021; North, 2019; Salehian & Maleki-Saghooni, 2021; Trickett et al., 2009). This could contribute to the findings presented in the González et al., (2019) study. where emotional abuse had robust association with having an ADHD diagnosis.). It is well documented in research that children with ADHD are at higher risk of experiencing maltreatment compared to those individuals with no ADHD diagnosis (Gokten et al., 2016; Stern et al., 2018). González et

al (2019) found that boys were more likely to experience this form of abuse compared to girls. This is reflected in another study which found similar findings and further observed an association between maternal hyperactivity/impulsivity and male gender of the child which further increased the risk of emotional abuse (Gul & Gurkan, 2018). One could propose that the abuse could be further exacerbated by the associated externalised behaviours associated with boys and an ADHD diagnosis and place these children at more risk, particularly if unsupported (Ghanizadeh & Jafari, 2010; Mowlem et al, 2019; Palermo, 2003).

González et al (2019) also identified a negative association with physical abuse and ADHD and found that the prevalence of this abuse was much higher in Lac compared to their non-Lac peers and affected more girls. Physical abuse, as emotional abuse is also often associated with the child who has ADHD (Fuller-Thomson et al., 2014; Szymanski et al., 2011). This is important to note and further explore as girls with ADHD can be vulnerable to intimate partner violence and physical maltreatment suggesting that they might be at more risk of experiencing physical abuse (Craig et al., 2020; Hinshaw et al., 2021). Physical and emotional abuse are noted as primary reasons for referral into social services and Lac, with a disability, experience more physical abuse than their peers (Stalker & McArthur, 2012). This could place the 'looked after' girl with ADHD at further risk if we factor in the addition of ACEs and their often-vulnerable environment (Coorg & Tournay, 2013; Palermo, 2003).

Sexual abuse is another form of detrimental abuse that many Lac experience, particularly those Lac who have been placed in residential care (Euser et la., 2013). The Tordön et al (2019) study found that Lac had experienced more sexual abuse compared to their peers. Although, the study explored other mental disorders, the results did show a higher prevalence of ADHD, eating disorders and ASD compared to their peers and national prevalence rates (Tordon et al., 2019). They found that disclosure of sexual abuse was less common in Lac and acts of persuasion, or adults' use of their social position, was more common. The higher non-disclosure of abuse by Lac was not an anticipated result, as they have closely monitored support systems and the non-disclosure could have been contributed to factors such as the relationship to the perpetrator; age, violence, coercion, or even demographic variables such as gender and ethnicity (Allnock, 2010). Davies & Jones (2013) explored the social position and use of coercive position in sexual abuse cases and found that acquaintances and relatives were the highest assailant relationship in each case. Research ascertains that this is not an unexpected finding as many children who have been abused and neglected can form unhealthy relationships and develop an attachment to those that are close to them in a social

position. Sexuality and sexual understanding can be very confusing for the child with ASD and ADHD, particularly those that are perceived as higher functioning (Pecora et al., 2016; Sevlever et al., 2013; Wymbs & Gidycz, 2021). They struggle to understand body language, intentions and emotions; that can place them in very vulnerable situations, unable to understand the intentions of an abuser (Kildahl et al., 2020; Sevlever et al., 2013). Therefore, for the child with a NDD and impaired social and cognitive skills; the risk of sexual abuse could potentially be even higher.

Conversely, González et al. (2019) found no association with sexual abuse and ADHD. Although it is important to note that self-report bias could have influenced the results as many children or young adults might not want to divulge that they have been sexually abused, especially as sexual abuse can often be perpetrated by a close family member (Allnock, 2010; Paine & Hansen, 2002; Sorensen & Snow, 1991).

Only one study in this review found robust associations with foster care placement and having ADHD, (González et al., 2019). However, Zill et al (2014) also found that 22% of foster-care children had been diagnosed with ADHD in their childhood. Interestingly in the same study it was children who had been adopted from foster care that had the highest prevalence of ADHD (36%) which requires further exploration as several studies have found similar rates in adopted children (Keyes et al., 2008; Lindblad et al., 2010; Tully et al., 2008).

Similar findings from the Ford et al (2007) study also found ADHD and ASD to be more prevalent in this care setting and suggested that the higher prevalence rates may be more attributed to the inadequate support and services available to families who have children with ADHD and ASD which is now well documented in research (Crane et al., 2016; Sayal et al., 2015). Additional literature supports these findings and ascertain that some parents voluntarily place their children with ASD in foster care with no history of maltreatment, due to a lack of available and accessible specialist support or treatments (Cidav et al., 2018). Many children with ASD struggle with overwhelming sensory deficits and debilitating anxiety which often result in emotional and physical challenging behaviours (Herrington et al., 2016). Therefore, it could be suggested that many parents would find it difficult to safeguard their children and cope with the behaviours which are often associated with ASD. ASD can also frequently be associated with many other co-existing conditions such as OCD, eating disorders and anxiety, creating an even more complex situation and environment for the child and wider family. However, the González et al (2019) study

detailed in the review proposed that children with disorders such as ADHD or those that had ADHD symptomology might be more vulnerable to experiencing maltreatment, which conflicts with Cidav's proposed no experience of maltreatment (Cidav et al., 2018).

Nevertheless, one could suggest that this could be attributed to the fact that ADHD is a NDD that is often (not always) associated with more externalising and physical behaviours than ASD, possibly increasing the risk of abuse.

Relevant, specialised support services are still scarce for many families pre/post diagnosis (Crane et al., 2016; Heslop et al., 2019; Sayal et al., 2015). From an economic and wellbeing perspective, specialist, holistic, early service provision is needed to better support these children. The average length of stay for Lac with ASD is suggested to be 1.6 times longer than Lac without ASD and they are also less likely to be placed in a family setting (31% versus 53%) (Bilaver & Havlicek, 2013). More importantly, the kinship setting might provide a more stable placement setting as many children with ASD react positively to familiar and recognisable surroundings; attributed to sharing familiarity with their biological kin (Rock et al., 2015).

The final study found that a higher prevalence of criminal convictions in the Lac population compared to their non-Lac peers. Additionally, the estimated criminal convictions in Lac with bipolar disorders and psychotic disorders, remained substantial even after regression analysis (Cote et al., 2018). Bipolar disorder has been associated with criminal involvement in several studies however, research is still limited in respect of the Lac with this disorder (Fovet et al., 2015; Prince & Wald, 2018). Behavioural symptomology associated with bipolar disorders can be complex, very difficult to diagnose and can have varying subtypes such as Bipolar 1 and 11, which has not been detailed within this study (Fovet et al., 2015; Gitlin & Malhi, 2020). Nevertheless, these disorders are often diagnosed later in adulthood which could have attributed to this finding (Harwick et al., 2017). Research is still limited in Lac with a bipolar disorder and whether the condition has any impact on the association with criminal involvement (Morris et al., 2020).

2.6 Limitations of the review

Some limitations of this review were high heterogeneity between studies; subgroup analysis, and some study characteristics which may have influenced the results. The Lac and non-Lac

groups detailed in this review, although detailed a priori in the protocol, could have been reunified with their biological parent/s. However, reunification is not always sustained as a result of varying factors such as poor parental physical and mental health and continuous substance misuse/abuse (Carlson et al., 2020; Fernandez, et al., 2019). Nevertheless, Lac can transition into different care settings and the children in these articles may have previously entered the care setting prior to or after the study collated the data or the data did not disclose that the child had ever been in a care setting. Many children move in and out of the care system at different points in their lifetime which could have impacted on the results attained.

Only publications in the English language were searched. Language bias can often occur as a result of using this approach as the studies identified might not have been a complete, accurate representation of the evidence (Rasmussen, & Montgomery, 2018). The I_2 test was not scrutinised in the overall results as research proposes that this test can have low statistical power when there are a small number of studies and the confidence intervals (CI) large, which was the case for this review. More importance has been placed on the 95% CI (Ioannidis et al., 2007).

A few of the studies were conducted across several European countries, however, eight of the studies reviewed were conducted in the USA. As detailed within this thesis, each country has a different approach and process associated with a Lac which could have had an impact on the findings (Heady et al., 2022)

The high prevalence of ADHD found in this review could have been attributed to the majority of studies ($n=5/6$) having been conducted in the USA as they have an overall higher prevalence of ADHD in the general population which might have influenced the results (Zablotsky et al., 2019). However, the same higher prevalence in Lac compared to non-Lac does not differ.

There are also suggested limitations to attaining prevalence rates on NDDs based on either/or a diagnostic code, standardised diagnostic assessment tool or survey response. Varying factors such as self-reporting bias, coding of disorders applied without clinician interviews and diagnostic codes would have changed over time for some of these disorders (Merten et al., 2017). However, the review followed other studies of similar methodology and include in the collated characteristics the description of the tools, codes and diagnostic manual used for transparency purposes (Bronsard et al., 2016).

2.7 Limitations to the evidence

The findings from the Tordön et al (2019) was based on a small sample and was self-reported which could have resulted in self-reporting bias.

Although, mental health service usage was high in Lac, the reasons for accessing these services could not be determined and therefore could be contributed to a multitude of complex factors associated with this vulnerable population.

An additional limitation is that the study that found a high prescription and usage of psychotropic medication could not define if the drugs had been used for mood-stabilizing and/or or antiepileptic properties which could have contributed to the results of this study.

2.8 Key findings

- Lac had a higher prevalence rate of ADHD compared to the non-Lac population RR = 2.69 [1.44, 5.01].
- Lac had a higher prevalence rate of ASD compared to the non-Lac population RR = 2.23 [1.63, 3.05].
- The findings suggest that there is a scarcity of literature that explores the prevalence of the other NDDs of interest.
- Lac with a NDD are suggested to be at more risk of (a) being placed in a care setting (b) criminal involvement (c) being prescribed and using psychotropic drugs (d) using mental health services (e) of emotional abuse and (f) physical abuse.

2.9 Conclusion

Due to the limited number of research studies comparing Lac versus non-Lac in this context, the findings should be interpreted with caution as there are a multitude of contributory factors that could have attributed to these higher prevalence rates. It is important to acknowledge that the findings did not ascertain whether it was the actual NDD, lack of support, the complex dynamics surrounding the Lac, or a combination of both, that might have contributed to the increased adverse impacts for these children. Nevertheless, the results of this review raise

some very important questions and propose that the prevalence of ADHD and ASD is higher compared to their peers which is line with new emerging research (Parsons et al., 2019; Willis et al., 2017). Equally, this review proposes that they may be more vulnerable and more exposed to risks. The findings from this chapter will be considered and further examined in in the final chapter and related to the other findings from other chapters in this thesis. Implications will be further discussed, and recommendations proposed for future research, policy and practice.

Chapter 3: A narrative review on the risks for the Lac with a NDD

3.1 Introduction

The findings from the systematic review highlighted some detrimental and adverse impacts on the Lac who has a NDD. As already detailed within this thesis, Lac without a NDD are already more at risk of experiencing ACE's and detrimental health and social outcomes associated with mental health, mental disorders, disability, suicide, criminal system involvement, teenage parenthood, substance misuse and poor educational attainment (Ford et al., 2007, Hill et al., 2017; Kääriälä & Hiilamo, 2017; Lightfoot et al., 2011; Meltzer et al., 2003, Teyhan et al., 2018). In relation to the second objective of this thesis, this chapter further explores if any other impacts may affect the Lac with a NDD. Five studies that did not provide comparative data between Lac and non-Lac with a NDD were excluded from the systematic review. However, these studies highlighted some adverse impacts on the Lac with a NDD. This chapter examines these five studies and relates the findings to wider literature.

3.3 Methods

Five excluded articles from the systematic review were examined in depth and the findings were related to wider literature (Bilaver & Havlicek, 2013; Greger et al., 2015; Meltzer et al., 2003; Thompson & Hasin, 2012; Yampolskaya & Chuang, 2012). Quality and bias assessment using the (JBI) critical appraisal tools were conducted on the five studies and deemed applicable for this narrative review (see **Table 3.1**) (Rother, 2007). A data extraction form similar to the format used to collate the study characteristics for the systematic review and meta – analysis was adapted and utilised.

Databases such as google scholar using key words such as 'mental', 'developmental', 'disorder', 'looked after child' 'outcomes' were used to identify wider literature. Using a similar approach to the systematic review, synonyms were also used to expand the searches, as a result of the extensive array of terminology that is often associated with both Lac and the NDDs that were being explored.

No strict restrictions were placed on the selection of publications as is the normal process for a narrative review (Rother, 2007). However, study selection was based on studies that identified risks for the Lac with a NDD. A descriptive approach was used to analyse the data and discuss findings.

3.4 Results & Discussion

All 5 studies shared some similarities in terms of research design, definition of care setting, population samples, diagnostic systems and criteria. Studies were conducted in the USA (n = 3), UK (n = 1), Norway (n = 1). Using the pre-defined JBI critical appraisal tools and format scoring, all 5 of the studies were deemed to be of high quality (see **Table 3.1**).

Table 3:1 Study characteristics for narrative review

Study	Country	Total Sample Size	Type of care setting	Type of non-care setting	Neurodevelopmental Disorder explored	Diagnostic System	Age Range (y)	Quality Score	Findings
Bilaver & Havlicek (2013)	USA	9853	Out of home care	N/A	ASD	ICD 9	3-18	9 = High	2.4% of the children entering foster care had a diagnosis of ASD, twice the national average in that county. Additionally, only 31% of children with ASD in our study population initially entered a kin home compared with 53% of children without ASD and the median length of stay for children with ASD is 1.6 times longer than children without ASD.
Greger et al. (2015)	Norway	335	Residential	N/A	AS, ADHD & RAD	DSM 1V	12-23	8 = High	There was a higher prevalence of Asperger's syndrome (AS), conduct disorder, major depressive disorder, dysthymia, general anxiety disorder and having attempted suicide in children who had been more exposed to maltreatment. Poly-victimization was associated with increased risk of AS, MDD, GAD and CD and attempted suicide. Children with AS were associated with higher odds of having current suicidal thoughts and suicidal attempts. Exposure to family

									violence was associated with higher odds of having ADHD. Victims of family violence had significantly increased odds with having Victims of sexual abuse and rape had significantly increased odds with having ADHD
Meltzer et al. (2003)	UK	1039	Foster Kinship Residential Independent Living	N/A	OCD, ADHD, ASD, TIC & ED	ICD 10	5-17	8 = High	The study suggests that children in residential care and those that have been placed in their placement for at least five years, have increased odds of having autism, tic disorders and eating disorders compared to any other looked after care placement. Children with hyperkinetic disorders were particularly likely to suffer from bed wetting (29% compared with 10%), eye/sight problems (25% compared with 14%) speech/language problems (22% compared with 12%) and difficulty with coordination (17% compared with 10%). ⁷ Medication use was higher for those children with ADHD and autism. Children with hyperkinetic disorders were more likely than children with other types of disorder to have ever been life-threateningly ill (16% compared with between 8% and 10% of the other groups). However, Children with an

									emotional or less common disorder were more likely than those with a conduct or hyperkinetic disorder to have visited a hospital or clinic for treatment or tests. Children with hyperkinesis had the highest rates of educational difficulties; 46% had severe problems with spelling, 45% with maths, and 39% with reading. 42% of all children that had a mental disorder had a SEN statement and 5 out of 10 children with a hyperkinetic disorder had a SEN statement.
Thompson & Hasin (2012)	USA	423	Foster care	N/A	BP & ADHD	Approved Psychosocial assessment	18-21	7= High	BP and ADHD were present in the study. A history of foster care was associated with increased risk of psychiatric disorders and treatment among homeless young adults. Additionally, homeless young adults who had not been in foster care had high rates of disorders, therefore should be screened for psychiatric disorders and treatment.
Yampolskaya & Chuang (2012)	USA	5720	Out of home care	N/A	BP & ADHD	ICD 9	7 -17	8 = High	Children diagnosed with bipolar disorder had 85% greater odds of being placed with a juvenile justice facility compared to children with no identified mental health disorder. Children diagnosed with attention-deficit disorder were almost twice more likely

to be placed in a juvenile justice facility. Conduct disorder was the most prevalent (22%) but attention deficit disorder followed with (8%).

Note: ASD = autistic disorders, AS = Asperger's syndrome, ADHD = attention deficit hyperactivity disorder, RAD = reactive attachment disorder, OCD = obsessive compulsive disorder, TIC = tic disorder, ED = eating disorders, BP = bipolar, DSM = Diagnostic and Statistical Manual of Mental Disorders, ICD = International Classification of Diseases

The results of the narrative review identified similar risks like that found in the narrative section of the systematic review but also found additional risks associated with the Lac with a NDD. Factors such as care placement, physical abuse, sexual abuse, criminal involvement, homelessness, suicide, learning difficulties and physical health are further discussed in more detail. Although, this is only a brief scoping of the articles and cannot be generalised, it does raise further questions for future research to explore in relation to the Lac with a NDD. All of these are detailed in the key findings.

3.4.1 Care Placement

Achieving a stable care placement setting for the Lac is considered to be one of the most important aspects of social care with reunification with the biological parent at the heart of each decision, where possible (Rock et al., 2015). Two studies found a negative association with Lac and NDDs in relation to care placement, settings and stability (Bilaver & Havlicek, 2013; Meltzer et al., 2003).

Both studies found that Lac with ADHD or ASD can experience longer placements, are more likely to be placed in a residential care home and are less likely to be placed in a familiar, kinship care setting compared to those with no disorder (Bilaver et al., 2013; Meltzer et al., 2003). Bilaver & Havlicek (2013) found that the average length of stay for children with ASD was 1.6 times longer than children without ASD. These results are reflected in the Meltzer et al (2003) study which found that children in residential care and those who had a placement for at least five years had increased odds of having autism, tic disorders and eating disorders compared to any other looked after care placement (Meltzer et al., 2003).

Meltzer et al. (2003) found that children with pervasive development disorders, the majority being autism, were more likely to be placed in residential care compared to other placements (11% vs 2%). Furthermore, the study found that children with ASD and ADHD (hyperkinetic disorders) were more likely to be placed in specialist residential care than in general care, ASD (17% vs 3%) and ADHD (12% vs 1%).

This could be attributed to the challenges of the disorders, as many children with ADHD and ASD often react negatively, either physically or emotionally to changes in their routines or environment (Jang et al., 2013). Placing them in a short-term foster care setting with strangers in a new environment could potentially exacerbate the challenging or emotional

behaviours (Fein et al., 2005; Vasquez & Stensland, 2016). Creating a long term, familiar, consistent environment such as the residential care home with specialist services could be suggested to be a protective factor for these children as it enables them to feel safe in a social world that they do not understand (Fein et al., 2005; Vasquez & Stensland, 2016).

This is reflected in another study where children with ASD were suggested to be less likely to be placed in a family setting, more likely to run from the care setting and also more likely to receive hospitalisation (Bilaver & Havlicek, 2013). In this study, only 31% of children with ASD entered a kinship home compared with 53% of children who did not have ASD. The less likelihood of being placed in a kinship care setting could be suggested to be detrimental to the child as ironically, this type of care setting could actually be a protective factor in this scenario; many children with ASD will automatically feel and share familiarity with their kin. Rock et al. (2015) support this and propose that kinship care is a protective factor for many Lac. The review proposes that more research is needed to explore whether placing Lac with ASD or ADHD in a kinship care setting may be more of a protective factor than placing them in a residential care home, away from family and social networks. From a cost perspective, kinship carers would require specialist ASD training and relevant, consistent support to sustain the family kinship care setting. Conversely, kinship placement could prove to be more cost-effective long term as residential care settings come with a very high cost to the economy (Buescher et al., 2014; Mandell, 2017).

Nevertheless, complexities in care placement settings and stability can often be difficult to attain and sustain for the Lac as a result of varying factors such as the older age of placements, removal from siblings, externalising behaviours and having multiple social workers (Rock et al., 2015).

3.4.2 Physical abuse

Physical abuse is consistently documented in research as being a significant, associated risk factor for Lac and primary reason for referral into services as already mentioned in the review (Euser et al., 2014; Font et al., 2018). One study found a negative association with physical abuse and Lac, as a result of having a NDD (Greger et al., 2015). The study found that exposure to family violence showed the strongest association with having an ADHD disorder.

Additionally, being a victim of family violence showed the strongest association with having ASD.

ADHD and ASD can sometimes be very challenging disorders for both the child and parent, particularly leading up to the transition between childhood and adulthood (Mrug et al., 2012; Stewart et al., 2020). A lack of support, awareness or specialised parenting could equate to a child and parent in distress; particularly if a parental mental health disorder is already present. This could significantly impact the parental ability to support or nurture these children and could quickly escalate into physical abuse (Hall-Lande et al., 2015). From a safeguarding perspective, specialised support should be made an integral component of the support plan for these families. Factors such as extreme stressful environments, physical and emotional aggression, limited support, social isolation and stigma are contributory and in some cases; result in the death of the child (Palermo, 2003).

This is supported in further studies where it was found that ADHD was also associated with a higher risk of physical abuse and neglect. In fact, one in five children with ASD in a community had experienced physical abuse (Gokten et al., 2016; Mandell et al., 2005; McMillen, 2005). There is already broad research that acknowledges that Lac with disabilities can experience more physical abuse than their peers. However, these studies suggest that Lac who have been diagnosed with NDDs such as ASD and ADHD may be even more vulnerable and more likely to experience physical abuse compared to their peers, including those peers with other disabilities.

From a support perspective, proactive service provision is needed to provide both the parent and child with coping strategies and interventions that will deflect the aggression; with an aim to reduce the amount of possible physical conflict that could occur. Techniques that address the social, psychological and environmental influences, such as reflective practice, cognitive behavioural therapy and sensory intelligence awareness could aid in reducing physical abuse (Bennett-Levy et al., 2009; Falkner, 2020).

3.4.3 Sexual abuse

Sexual abuse is an adverse experience often associated with being a Lac (Dinkler et al., 2017; Euser et al., 2013; Hallett et al., 2019). One study explored this area and found that victims of sexual abuse and rape had significantly increased odds of having an ADHD diagnosis

(Greger et al., 2015). This article explored vulnerable adolescents from residential care units. The results are important as there are very few and limited studies that examine this gap in research. Several studies have suggested that the prevalence of NDDs is high in residential units (Meltzer et al., 2003; Ozawa et al., 2018).

There are limited studies in Lac literature that support the Greger et al (2015) study. However, several articles which have explored ADHD in the general population support this finding. ADHD has been associated with a higher risk of sexual abuse not just for boys but also for girls. In one sample of children who had ADHD; 48% of the boys and 47% of the girls had reported a history of sexual abuse (Sonnby et al., 2011; Weinstein et al., 2000). Furthermore, another study found that adults who had been diagnosed with ADHD were at a higher risk of experiencing sexual and physical abuse in their childhood (Fuller-Thompson et al., 2016; Rucklidge et al., 2006).

Additionally, if we explore ASD, children with ASD have been associated with a threefold increased risk of coercive sexual victimization; this included children with ADHD (Ohlsson et al., 2018). In another study, one in six children with ASD in a community setting had also experienced sexual abuse (Mandell et al., 2005). Children or adolescents with ASD and ADHD are suggested to be at higher risk of sexual abuse and victimisation as a result of their impairments or challenges in reading body language or interpreting sexual behaviours or advances (Edelson, 2010; Sevlever et al., 2013; Fuller-Thomson et al., 2016).

Research is still in its infancy regarding understanding sexual relationships and abuse and the impacts they may have on the child with ASD and ADHD (Dinkler et al., 2017; Edelson, 2010). It is even more limited in research associated with Lac (Langevin et al., 2021). The need for more research is even greater if we consider that Lac are more likely to have teenage pregnancies, multiple sexual partners and be at more risk of being sexually exploited and trafficked (Reid, 2018; Shuker & Pearce, 2019). A recent report found that up to 50% of the women who had been involved in sex work had spent some time in the care system as children (Oakley et al, 2018). More research is needed in this area and a specialised therapeutic program designed to address the needs of these vulnerable children to safeguard them from potential future sexual abuse, unhealthy relationships and sexual exploitation.

3.4.4 Criminal Involvement

One study found that Lac had higher rates of criminal convictions compared to their peers and higher rates of recidivism if they had disorders such as Bipolar or ADHD (Yampolskaya & Chuang, 2012). Although conduct disorder (an associated co-morbid condition with ADHD) was the strongest predictor of juvenile justice involvement, children who had been diagnosed with ADHD (which had the highest prevalence) were almost twice as likely to be placed in a juvenile justice facility. Furthermore, children who had been placed in a care setting and diagnosed with bipolar disorder had 85% greater odds of being placed with a juvenile justice facility compared to those with no mental disorder (Yampolskaya & Chuang, 2012). Several other studies support these results proposing that ADHD and NDDs are prominent in youth offending systems and the criminal system but limited are studies that have explored if these children came from a looked after care setting (Beaudry et al., 2021; Billstedt et al., 2017; Chae et al., 2001; Rösler et al., 2004). The ‘In Care, Out of Trouble’ review chaired by Lord Laming found that there was an urgent need to earlier identify and better understand how to meet the needs of these children with NDDs to prevent them going into care/prison (Prison Reform Trust, 2016). A report conducted by the HM Inspectorate of Prisons found that in 2015-16, approximately 39% of those children in secure training centres and 37% of those in young offender’s institutions had been in care (Oakley et al., 2018; Simmonds, 2016). In 2015, the Youth Justice Board found that recidivism rates were approximately twice as high in Lac compared to their non-Lac peers (Youth Justice Board, 2015).

It is important to note that many young adults do not attain their NDD diagnosis until adulthood (Cubbin et al., 2020; Fusar-Poli et al., 2020). Many of these disorders are often misdiagnosed or not diagnosed until much later in their lives. This has significant implications for the health and social wellbeing of these individuals as early identification and support is integral to improving their future overall wellbeing (Hutchon et al., 2019; Manolova, 2017). Unmanaged or unsupported ADHD or ASD can result in poor outcomes in drug use/addictive behaviour, antisocial behaviour, services use and occupation (Shaw et al., 2012). More importantly, this has significant safeguarding implications for the young adult who has been placed in a juvenile facility (McCarthy et al., 2019, Mogavero, 2019; Young et al., 2018). Many individuals with NDDs can self-harm and are frequently misunderstood in the youth justice system due to their cognitive impairments; their

behaviours can often be misinterpreted by their peers placing them in yet more vulnerable situations (McCarthy et al., 2019, Mogavero, 2019; Young et al., 2018).

With Lac already being overrepresented in the youth justice system, these findings suggest that more research is needed to understand the impact on Lac with a NDD in relation to the criminal justice system (Government UK, 2021a).

3.4.5 Homelessness

One study explored homeless adults (aged 18-21 years) to see if there was an association between having a psychiatric disorder, accessing psychiatric services, psychiatric hospitalisation, medication and having been in the foster care system. The study found that those individuals who had a history of foster care were 70% more likely to report having a psychiatric disorder compared to their peers who had not been placed in a care setting. They were twice as likely to have been involved in mental health counselling; been prescribed medication and to have been hospitalised as a result of their disorder (Thompson & Hasin, 2012). Although, the study had a small sample and other disorders were also explored, ADHD and Bipolar prevalence was higher in those individuals that had been in the care setting, compared to those who had not been in foster care. This is also reflected in other research that found that children with ADHD were much more likely to end up homeless than those children who did not have ADHD (Murillo et al., 2016). The same poor outcome has been associated with having psychiatric disorders such as bipolar in the general population (Iwundu et al., 2020).

Research proposes that monitoring children who have some of these NDDs should be an integral part of the service to ensure that these young adults access the relevant services to meet their psychiatric needs (Murillo et al., 2016). However, in the study by Thompson & Hasin (2012), being in the foster care system was suggested to be a protective factor here as the children had been identified and provided with therapeutic and medicinal support. However, one could argue that in this study; having therapy and access to services has had no effect on becoming homeless.

If we accept reports that 25% of homeless young adults had been in a care setting in their childhood, it suggests that there is an urgent need to further explore the outcomes that are associated with Lac who have NDDs (Government UK, 2021a; National Audit Office, 2015).

Children who are already at risk may be at further risk if they have NDDs such as ADHD or bipolar. No articles to our knowledge in the UK have explored any associations with having been in foster care, homelessness and having a NDD.

3.4.6 Suicidal Ideation

The Greger et al (2015) study also explored the topic of suicidal ideation and behaviour in relation to Lac and ASD. They found that when ASD and attempted suicide co-occurred in the child, the prevalence was much higher in maltreated children who resided in a residential unit compared to their non-maltreated peers (Greger et al., 2015). Suicidal ideation and suicide attempts are suggested to be significantly higher in children who have ASD in the general population (Chen et al., 2017; Hedley & Uljarević, 2018).

Equally, a recent study found that children who were in a looked after setting had a higher risk of suicidal behaviours (Katz et al., 2020). Another study found that children in care were three times more likely to attempt suicide compared to their peers not in a care setting (Evans et al., 2017). There could be a multitude of reasons that contribute to this very poor outcome such as low socioeconomic status (SES), traumatic ACEs, substance misuse, poor mental or physical health or a lack of social networks and support (Koda et al., 2022; Rodway et al., 2016). Nevertheless, individuals with ASD are proposed to be up to nine times more likely to die prematurely, with suicide as the main cause (Hirvikoski et al., 2016). If we further explore other NDDs of interest in this thesis, one study found that 35.2% of adolescents with foetal alcohol syndrome disorder (FASD) reported suicide ideation and attempts compared to 17.2% of the general population (O'Connor et al., 2019). ADHD has also been associated with a high risk of suicidal behaviours (Garas & Balazs, 2020; Shen et al., 2021). As discussed, previously, if we include the traumatic ACEs associated with these children, they could be placed at further risk of this outcome as suggested by Chronis-Tuscano (2022).

3.4.7 Learning difficulties

Poor educational attainment and special educational needs are consistently noted as being significantly higher in the Lac population (Oakley et al., 2018; O'Higgins et al., 2015). One study found that ADHD impacted on the learning ability of Lac in an educational setting.

Meltzer et al (2003) explored the mental health of Lac in England. The study found that five out of ten Lac who had ADHD had a statement of special educational need (SEN).

Furthermore, 35% of those children who had a mental disorder were three or more years behind in scholastic ability; ADHD and co-morbidity conduct disorders contributed to most of this result (Meltzer et al., 2003).

Lac with a mental disorder were twice as likely to have difficulties in the three key areas of learning: reading, maths and spelling. However, ADHD had the highest rates of marked difficulty, 46% had severe problems with spelling, 45% with maths, and 39% with reading. Although, ADHD is not classified as a learning disorder; it is often associated with challenging learning difficulties in areas of poor concentration levels, hyperactivity in the classroom and inability to take instruction (Adlof, 2020). It is also important to note that NDDs such as dyslexia, dyspraxia and dyscalculia which frequently co-occur with an ADHD diagnosis, affect coordination and memory significantly impacting on a child's ability to write, spell, read and complete mathematical problems (Adlof, 2020; Fleming et al., 2020; Roongpraiwan et al., 2002). If ADHD is higher in the Lac population as suggested by the results of the meta-analysis in the previous chapter; this area of research requires more exploration and might contribute to better understanding of the educational difficulties that some of these vulnerable children might be experiencing in the educational setting.

3.4.8 Physical health

Physical health has often been suggested to be poor in Lac, attributed as a result of their adverse childhood experiences, abuse and neglect (Carr et al., 2020; Hill & Thompson, 2003; Turney & Wildeman, 2016). Conversely, several studies have found conflicting results (Ferrara et al., 2013; Maclean et al., 2016; Sebba et al., 2015). Ferrara et al (2013) found that psychiatric disorders were high but no difference in physical health was found between those children who had been institutionalised and their non-Lac peers.

The Meltzer et al (2003) study found that Lac with ADHD (documented as hyperkinetic disorders) were more likely to suffer from bed wetting (29% compared with 10%), eye/sight problems (25% compared with 14%) speech/language problems (22% compared with 12%) and difficulty with coordination (17% compared with 10% compared to their peers with no disorder (Meltzer et al., 2003). Additionally, they were more likely than children with other

types of disorder to have ever been life-threateningly ill (16% compared with between 8% and 10% of the other groups).

Bed wetting, speech and language difficulties, coordination and vision problems can be associated with a multiplicity of factors such as stress, trauma, changes, developmental delays and emotional anxiety (Bounds et al., 2021; López-Martínez et al., 2018; Touchette et al., 2005). It is important to note that these physical problems may also arise from other multi-factorial origins. We must consider that bed wetting (enuresis) could be a physiological response, attributed to an imbalance in the autonomic nervous system as suggested by research (Abd-Elmoneim et al., 2020; Jameson et al., 2016; Touchette et al., 2015). It is vital that an interdisciplinary approach is used to help aid those front-line professionals who first encounter these vulnerable children as they might require different approaches to therapeutic intervention. There is research that suggests that children with ADHD in the general population experience more physical health problems than their peers who do not have ADHD (Pan & Bölte, 2020; Park et al., 2020). However, no other study has explored the impacts on the physical health of Lac who have ADHD.

3.5 Key findings

- Lac with ASD and ADHD are at higher risk of being placed in long term care settings such as residential care.
- Lac with ASD and ADHD are at higher risk of experiencing physical abuse, particularly within the home.
- Lac with ADHD are at higher risk of experiencing sexual abuse.
- Lac with bipolar and ADHD are at higher risk of criminal involvement.
- Lac with bipolar and ADHD may be at higher risk of becoming homeless.
- Lac with ASD are at higher risk of experiencing suicidal ideation.
- Lac with ADHD experience greater learning difficulties in areas of learning; reading, maths and spelling.
- Lac with ADHD experience greater physical health difficulties in areas of bed wetting, eye/sight problems, speech/language problems and coordination.

3.6 Conclusion

The findings in this chapter cannot be generalised due to the limited studies examined in this brief narrative review. Furthermore, as already detailed within the conclusion of the systematic review, it cannot be determined whether it was the actual NDD, lack of support, complex dynamics surrounding the Lac, or a combination of both, that might have contributed to these increased adverse impacts on the Lac. Disentangling the complexities would be very difficult to achieve for a multitude of professionals that support these children. Nevertheless, it does highlight that the co-occurrence of some of these impacts are high in this population and that there are some significant gaps in literature which require further exploration. Lac with a NDD, with their associated biological, psychological and social challenges may be at higher risk of experiencing ACE's and detrimental health and social outcomes compared to their peers who do not have a NDD. The next chapter of this thesis further explores some of these aspects using a small q qualitative approach.

Chapter 4: A qualitative study on social worker perspectives of NDDs and services

4.1 Introduction & aims

The findings from the thesis so far have shown that NDDs, in particular ADHD and ASD, are suggested to be higher in the Lac population compared to their non-Lac peers. Furthermore, it suggests that Lac with a NDD may be at more risk of experiencing adverse impacts compared to their Lac peers who do not have a NDD. This included topics around the care setting, the longer placements and type of placements, the higher mental health usage and prescription, abuse, criminal involvement, learning difficulties and physical health. Therefore, this next chapter takes a small q qualitative approach to further explore some of these aspects but from the perspectives and opinions of the social worker professional who has a unique insight into the lives of these children. It explores social worker professionals' perspectives and opinions on the subject area of NDDs and the challenges and barriers that Lac with a NDD might encounter or experience in broad areas of family, services and outcomes. These professionals play an integral part in the safeguarding and protection of these children, yet there is a dearth of literature that involves the opinions of this group in relation the Lac. No literature to date, to my knowledge has explored their perceptions and opinions on anything related to the Lac with a NDD.

The social worker who is responsible for the care and safety of the Lac, is recognised as being one of the most stressful roles held within the social care sector (Finch, 2020). They are often the first point of contact for these vulnerable children, having to quickly navigate processes and systems to best help and protect the child. For this very reason, social workers' have to adapt and undertake an array of multi-faceted responsibilities when supporting Lac in areas of trauma, sexual exploitation, sexual health, domestic violence, substance misuse, criminal activities, truancy and mental health. Their knowledge base has to span a multitude of inter-disciplinary roles ranging from counsellor, therapist, case manager, educator, facilitator, mediator to advocate (Asquith et al, 2005; Finch, 2020).

NDDs such as ASD, ADHD and dyslexia are relatively well recognised within the health and social care sector. However, many front-line professionals still struggle to understand the sometimes, subtle behavioural symptomology of NDDs and the biological, psychological and social impacts that are often associated with some of these

disorders (Crane et al., 2019; Lord et al., 2022; Schelbe et al., 2021; Sciutto, 2015). Third party providers in the form of charities and community groups, have raised much awareness and provided much needed support over the years (Crane et al., 2019). However, with the increase in prevalence of NDDs, demands on services have placed these third-party providers under immense pressures leaving many families in crisis (Crane et al., 2019). New policies such as the Integrated Autism Service in Wales have contributed to increased awareness and knowledge for NDDs such as ASD, however there is still limited specialist service provision for these children with additional complexities, particularly in Wales (Autism Wales, 2022; Holtom & Lloyd-Jones, 2019).

The social worker professional is often the front-line professional who has to continuously address an exhaustive myriad of challenges and adapt a holistic approach to bridge services between health and social sectors; to meet the needs of these children. As the social worker is primarily responsible for navigating care and support for these children it was important to also explore this area from their perspective.

This chapter explores the perspectives of social workers who have a unique insight into the challenges and barriers associated with the Lac who has a NDD and further explores if any of the adverse impacts found in the thesis findings so far reflect their experiences or encounters when working alongside these children. The study aimed to explore several overarching topics:

- The professional understanding and perceptions of NDDs in the Lac population.
- The service provision available to meet the needs of the child, carer/parent and social worker.
- The impact on the health and social wellbeing of Lac with a NDD.
- The wider factors that Lac with a NDD might encounter or experience.

4.2 Theoretical underpinnings & ethical considerations

Epistemology or the theory of knowledge as it is often referred to, is an important part of any research paradigm in either qualitative or quantitative research. It forms a foundation for how

we conduct research derived from our assumptions and beliefs (Clarke & Braun, 2013; Hothersall, 2016).) Clarke & Braun, 2013 suggest that every piece of qualitative research is underpinned by epistemological assumptions which are important to address and understand whether the knowledge that we aim to seek is discovered or created by the research or researcher. It examines whether it is a ‘true’ finding or not, in relation to the methods used, validity and the distinction between justified belief and opinion (Clarke & Braun, 2013). They suggest there are several schools of schools of epistemology assumptions – positivism, constructivism or contextualism. All assumptions have their strengths and weaknesses and have been discoursed within literature for many years (Hothersall, 2016; Ryan, 2006).

The positivist belief is that knowledge is generalisable, objective, observable and results can only be attained by using scientific methodology which is normally associated with the more ‘quantitative’ methodology. They posit that there is only one reality and that it can be measured in some way (Hothersall, 2016; Ryan, 2006). However, there is an additional epistemological assumption which either rejects or modifies the positivist beliefs and that is post-positivism (Clark, 1998; Reimer,1996). The post-positivist belief is that knowledge cannot always be observed and often favours objectivity over subjectivity, but in which results can be attained by a varied quantitative/qualitative/ mixed method methodology. This mix of methodologies and using different methods to attain ‘knowledge’ is what underpins this study and relates to the pragmatism approach used for this thesis (Henderson, 2011; Hothersall, 2016; Panhwar et al., 2017; Ryan, 2006).

The study explores the perceptions and opinions of social work professionals from a more external perspective. Therefore, this study leans more to post-positivism as the real truth or in-depth knowledge can only be attained from the Lac themselves which is not the case here. As already detailed in this thesis, this is a small q qualitative study in which I have used a more subjective qualitative approach and not quantitative (Clarke & Braun, 2013). The post-positivist approach aims to seek the truth but acknowledges that this can be flawed with limitations, as it can be influenced by the researchers’ beliefs, opinions and existing theory and concept (Clarke & Braun, 2013; Ryan, 2006). These influences themselves can cause limitations which will be further discussed.

This study seeks to gain knowledge and understanding from an ‘external’ viewpoint and perspective which might contribute to further understanding the diverse dynamics that apply

for to the Lac with a NDD and become a springboard for future research (Henderson, 2011; Ryan, 2006).

The choice and content of the methods used to collect data derive from the thesis findings and existing theory in wider literature which further supports the post-positivism stance (Clarke & Braun, 2013). Qualitative data collection can vary in methods from observations, surveys, focus groups to varying structures in interviews (Clarke & Braun, 2013; DeMarrais & Lapan, 2003). Although, post-positivism is debated as being more associated with quantitative methods, this study used a qualitative method to collate the data which is also suggested to fall within the qualitative paradigm, although there is some still discourse in this area (Clarke & Braun, 2013, Ryan, 2006; Wiltshire & Ronkainen, 2021). As I wanted to personally engage and interact with social worker professionals, I chose the interactive interview as a data collection method. Focus groups were considered but this was not feasible due to the nature of the participants demanding roles and complexities in attaining a group of them all at one time.

May (1997) outlines three types of interview techniques that can be utilised, the structured, semi-structured or unstructured and all have their strengths and challenges. Interviews that are too structured can restrict the flow of the conversation between researcher and participant and are normally used for more confirmatory studies (Chenail, 2011). Whereas the unstructured interview has questions that are not pre-determined which enables a more bi-directional process to occur and enable individuals to answer more freely without restriction (May, 1997). Semi-structured interviews provide a little more structure to the process, particularly if time is limited and can include a pre-determined broad topic framework but one that can allow the researcher and participants to examine different facets of the themes/topics being explored (Pope et al. 2000; Pope et al., 2002). Like unstructured interviews, this enables the researcher to probe further with additional questions, gain a better rapport and alleviate anxiety for the participants (Barbour, 2013). However, the social interaction between the participant and researcher itself can sometimes negate the data if bias and reflection on values and beliefs are not addressed while conducting this method (May 1997; Fitzpatrick & Boulton, 1994; Goodwin et al, 2020). This data collection method was selected due to the pre-determined broad topic framework and time restrictions anticipated with the busy schedules of social worker professionals. However, there are exhaustive challenges and biases to consider when conducting interviews in concepts such as the power

structures, social position, trust, value, meaning, interpretation, reality, commitment to the process, hidden agendas and so much more (Barbour & Schostak, 2005).

Quantitative research is often portrayed as being more scientifically rigorous as a result of statistical methods, validity, generalisability and reproducibility used but rigour is often seen as being lacking in qualitative research (Mackieson et al. 2019). For qualitative research validity and generalisability does not apply but rigour can be demonstrated through various other avenues such as reflexivity, credibility and transparency (Shufutinsky, 2020). May & Pope (1995) further proposes that no research can capture the exact truth as it is a selective process to each individual and each method has its strengths and challenges. They propose that strategies for both quantitative and qualitative research follow the same process, 'systematic and self-conscious research design, data collection, interpretation, and communication.' (May & Pope, 1995, pg110). They further propose that the assumptions and methods utilised can often support the rigour of a study. Providing detail of the why, how and what in the design, the strategies and why particular methods were used and detailing how you applied them can contribute to the rigorousness of a study.

Reflexivity aids in addressing some of these challenges and biases however it would be impossible for me to say that I had addressed all of these during this process as the concepts themselves can have a magnitude of meanings or interpretations which is unique to the individual (Haynes, 2012; Mays & Pope, 1995). Reflexivity is an ongoing process when conducting qualitative work, having an awareness of how you conduct the process and the reasons why, questioning your knowledge, methods, analysis and findings ensuring biases do not creep in (Barbour & Schostak, 2005; Shufutinsky, 2020). Attia & Edge (2016) suggest there are two types of reflexivity, prospective and retrospective. These two types differ as prospective refers to how the researcher bias and opinions impact on the study and retrospective refers to the impacts on the researcher themselves (Attia & Edge, 2016). Haynes (2012) further proposes that there are many different levels of reflexivity theoretical, methodological, cultural, emotional and subjective and so many more. As the post-positivism assumption can be influenced by the researchers' beliefs, opinions and existing theory and concept as already mentioned, reflexivity was an important dynamic in this study.

Prospective, retrospective, emotional and subjective reflexivity played an integral part with my pre-existing understanding of NDDs on both a personal and theoretical level which made me very conscious to use reflexivity such as open discussions with my colleagues, supervisor

and I also internally reflected throughout the research process so as not to impose my ideology or thoughts (Haynes, 2012; Shufutinsky, 2020). It made me constantly question my aims of the research and own self biases based on my own personal experiences, feeling and emotions and how that might influence the findings. Other literature further suggest that no knowledge can be attained without having some sort of implicit or explicit value assumptions which will always create bias in any research (Goodwin et al., 2020; Mackieson et al, 2019). DeMarrais & Lapan, (2003) further suggest that biases can bring a new dimension to the study, bringing one's own perspectives can contribute to the research as long as you have a self-awareness of them.

As this was a small q study, the data collection tool was a topic questionnaire which was formulated based on some of the results of the thesis so far and existing theory from wider literature. Questionnaires can make way for further topics or codes to be explored and interpreted as a bi-directional discourse between researcher and participant (DeMarrais & Lapan, 2003). This provided the data collection with a framework of broad topics to explore but also enabled further probing questions that could be used to take both a deductive and inductive approach to the analysis to highlight any other additional codes (Bingham & Witkowsky, 2022; DeMarrais & Lapan, 2003). Using this approach aided in organising the data so that I could remain aligned with the research questions.

The design of the questionnaire is important in qualitative work as it can be key to building rapport and trust with the participant to explore the topic areas of interest. They need to follow a logical flow and should be structured with no jargon to enable the participant to answer the interview question as freely as possible (Braun & Clarke, 2021). The length of the questionnaire (number of questions) is also important to consider for time constraints not just for the researcher but for the participant. You need time to build up the rapport and trust and equally have time to ask all interview questions. It was intended to conduct a pilot interview with a retired social worker to check the quality and rigour of the interview schedule. **See appendix 6.** However, this did not occur as a result of her/his illness. However, two of my supervisors reviewed the questions to ensure they were of quality to address the research questions.

This tool provides the study with textual data that can be either transcribed as full or clean verbatim or to initiate analysis. Transcribing the data yourself can help you to familiarise yourself while developing some initial thoughts of what the data is trying to tell you (Braun

& Clarke, 2021). There are many methods to analyse qualitative data and Braun & Clarke (2021) provide an exhaustive list. However, as this was a small q study, the flexibility of a thematic analysis seemed the most appropriate choice. With every method come strengths and weaknesses and thematic analysis is not devoid of them. It is recognised as the most useful beginners' method for those researchers new to qualitative work and allows the researcher to take either a deductive or inductive approach. It does not make claims but can enable an interpretation or construct of themes that can be supported by the data (Braun & Clarke, 2021). This has been further developed into three forms of thematic analysis (TA), reflexive TA, coding reliability TA and codebook TA. As this a small q qualitative study which takes a more post-positivism approach the coding reliability TA as suggested by Braun & Clarke (2021) better captures approaches used within a small q framework. Therefore, this TA approach was used in the study.

Coding reliability TA is a process that is underpinned by the development of a code book or/and a coding frame which is used to code for instances of themes. The broad themes/topics can already exist prior to coding. Although this approach has its limitations and has been suggested to be an approach that can blur the process of how codes are defined and result in underdeveloped themes. Particularly when it is compared to reflexive TA and the other coding processes associated with a Big Q. Nevertheless, it is an approach that is used and is acknowledged as having some logic to it as long as it not defined as a Big Q (Braun & Clarke, 2021).

Coding is a multi-level process whereby textual data are examined, highlighted or selected to generate code labels which are then constructed into themes. Braun & Clarke (2021) suggest there are two processes to identifying themes, process A or B. As this is a small q qualitative study and some of the broad topic categories of interest were pre-defined this study leans more to process A; theme identification and themes as input. Byrne (2022) suggests that latent coding which explores beneath the surface of the data to capture or interpret underlying ideas or patterns can sometimes overlap with semantic coding and produce meaningful information (Byrne, 2022). This study leans more to semantic coding as it takes a more descriptive approach where one only looks at the meaning associated with the surface of the data (Braun & Clarke, 2021).

Ethical considerations

Ethical considerations should always be underpinned by good strong ethical principles and practice, regardless of whether the research is qualitative or quantitative (Goodwin et al., 2020). Ethical considerations should always focus on the rights of the participants, the credibility of the knowledge and the academic integrity of a study (Goodwin et al., 2020). Ethical principles are how the study is guided by the law or governed by frameworks while ethical practice is how the study is guided by the researcher's moral and beliefs.

Many countries have varying legislation and regulatory frameworks, this study adheres to the ethical guidelines outlined by the British Sociological Association and Social Research Association (British Sociological Association (BSA), 2017; Social Research Association (SRA), 2021). Ethical principles are integral to what is deemed as Human subjects

Ethical issues were considered pre-commencement of the study and throughout. Guidelines were adhered to throughout the study and outlined in relation to any harm to the participant, consent, confidentiality and anonymity. An ethical approval form was submitted to the Swansea University Medical School's ethics committee before the research commenced. **See appendix 5.** This included a recruitment email, participant information sheet, consent form and an interview schedule which detailed ethical consideration, all of which were subsequently approved. The methods section of this study outlines these issues in more depth.

4.3 Methods

A small q approach consisting of semi-structured interviews with social worker professionals was used to undertake this small q qualitative work and explore the research areas detailed.

4.3.1 Sample & Recruitment

A purposeful (non-probability) sampling approach was used as it is suggested that this technique uses smaller samples to explore perceptions which fits the aims of this study. Furthermore, it does not require a complex sampling frame or calculation to determine sample size (Guest et al, 2017). It is the researcher that decides on the number of participants to be interviewed which takes into consideration factors such as time restraints; for both the

researcher and role of the participant; allocation of resources, quality of data and time for analysis. However, it is acknowledged that this technique can be subjective and does not represent the views of the wider population. Due to the nature of the social worker role and unforeseen impact on social services, the number of participants interviewed were based on these important factors.

Participants were recruited by means of an email, which outlined the aims and objectives of the study. This was sent to all heads of children's services to gain initial interest prior to submitting for ethics approval. Three local authorities agreed in principle, however due to the coronavirus situation and allocated resources, only two local authorities were able to take part in the study.

Both heads of children's services were sent an email inviting social workers and social worker professionals to participate on a voluntary basis. No exclusion criteria such as age or sex were applied. A recruitment letter was emailed to prospective participants with the inclusion criteria detailed. The participant was required to have a minimum of five years' experience working with both young children and adolescents in the looked after care setting. Interviewing social workers with a long-term, wealth of experience and knowledge would enable the study to capture a more information rich dataset that could address the research questions. Participant information sheets and consent forms were sent to the interested participants, enabling them more time to make their final decision on whether to be part of the study (See **Appendix 3 & 4**). An interview date and time was then scheduled at their convenience.

4.3.2 Ethical approval

Ethical approval was granted by the Swansea University Medical School Research Ethics and Governance Committee prior to conducting the interviews (see **Appendix 6**). However, due to the unforeseen coronavirus pandemic, the approval had to be amended as all interviews that were initially planned face to face had to be conducted over Microsoft Teams. As already detailed within this thesis, ethical considerations place significant focus on the protection of participant rights, the credibility of the knowledge and the academic integrity of a study

(Goodwin et al., 2020). The next three sections go into some detail regarding how ethical considerations were considered throughout this study.

4.3.3 Protection of Human Subjects

Initially, the interviews were going to be held face to face and therefore physical, psychological, social, economic or legal risks for myself as a researcher were considered. Adherence to the ‘Lone Working Policy Arrangements’, particularly the ‘lone worker working off site’ section created by Swansea University to address any potential physical safety issues would have occurred. Contact and raised awareness of all scheduled interviews, dates and times would have been adhered to. However, as the interviews were conducted over teams this was not applicable.

The study did not anticipate any physical, psychological, social, economic or legal risks for the participant (BSA, 2017; SRA, 2021). Participants were provided with an information sheet that detailed policies and procedures for participants rights, safety, disability needs, data protection privacy notice and confidentiality.

Data protection and confidentiality were guided by and adhered to all seven data protection principles outlined in University’s ‘Data Protection Policy’ document, in accordance with the General Data Protection Regulation (GDPR) and the new Data Protection Act 2018 (DPA 2018).

All data were anonymised to protect the identity of the LAs, participants, and population of interest. Due to the nature of the interviews to reduce the risk of case discussion, no personal names of the children were included in the interview, only referred to as he/she.

Additionally, the allocated interview meeting was held in a safe and secure place where case discussion could not be overheard. In the event of the participant becoming upset during the interview he/she was advised that they could take a break, resume the interview, reschedule or cancel the interview.

No electronic records that linked the collated data to the personal information of the participant was retained and all electronic data were stored on the researchers’ computer and password protected. In the event of an unforeseen data breach, both the participant and

'Information Commissioner's Office' would be informed with 72 hours and the appropriate action followed.

If the participant had any concerns about anonymity, the participant was reassured that the data would remain anonymised. However, it was stated that the unidentifiable data would become available to other academic avenues in the form of publication or presentation at conferences. A copy of the findings could be made available to the participant at his/her request.

There were no anticipated doubts about participants' abilities to provide informed consent due to the nature of the participant job role. The consent form was sent out to the participant pre-interview but to ensure that they were still happy to participate, consent was additionally verbally recorded from the outset of the interview during the briefing statement. The participant was advised that he/she could withdraw from the study at any point, with no explanation needed and all data would immediately be deleted, and an e-mail sent to the participant confirming the deletion of the hard copies and electronic files. Additionally, he/she was provided with all relevant contacts and procedures should he/she not be happy with the interview process.

4.3.4 Data Collection

Interviews were arranged through several email communications and then scheduled around the social worker professional's availability and time. Interviews had to be conducted via Microsoft Teams which caused some disruption to the interviews on occasions in relation to poor internet connections. In addition to this, some of the interviews had to be paused as the social worker had to take a call, in relation to a Lac. All interviews were recorded using two digital voice recorders to prevent missing data due to technical issues. The interview began with a short introduction explaining the aims and objectives of the study, including how the interview would be conducted and guided. I anticipated that the interview would last approximately 60 minutes. However, the participant was asked prior to the interview if they would be happy to continue should it take longer than 60 minutes. The consent form was read out and the participant confirmed that they were still happy to proceed.

Interviews were conducted using a semi-structured topic guide (see **Appendix 6**) which used open questions that were developed from existing literature and the findings from the systematic review. Ten interviews were conducted that lasted approximately 13 hours, 19 minutes and 58 seconds.

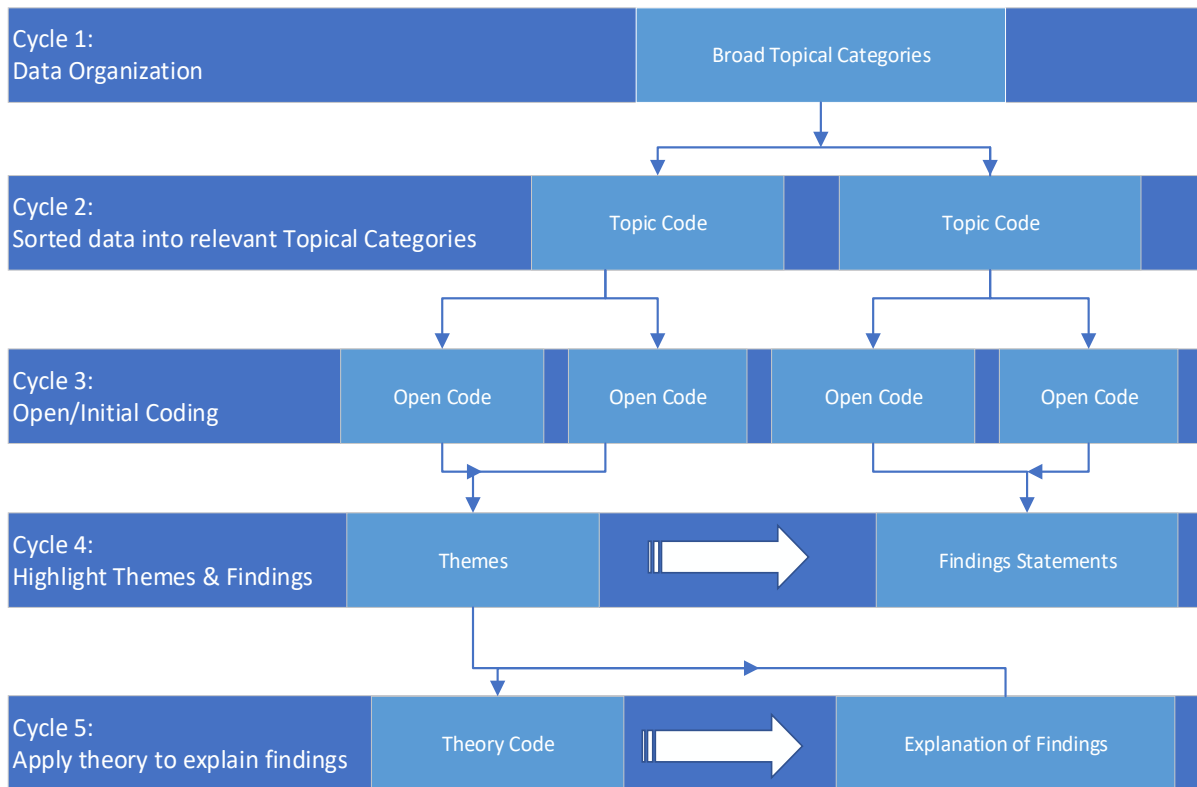
As time was becoming limited and I was very fortunate to have extra funding support from the Economic and Social Research Council, they agreed to pay for a third-party transcription service which the University regularly use. Therefore, this third party transcribed the data verbatim. To assess the quality, I read over the transcripts several times and intermittently checked that the recordings matched what was transcribed in the transcripts full verbatim.

4.3.5 Data Analysis

A thematic analysis using NVivo software was undertaken to analyse, code and identify themes that contributed to the aims of the study (Mackieson et al., 2019). As validity and reliability in qualitative research is often perceived as subjective and prone to bias, each transcribed interview was read several times over a period of six months for reflexive purposes and to ensure no themes had been missed (Mackieson et al., 2019; Toews et al., 2016).

The study followed a pragmatic approach that used both deductive and inductive analysis which is detailed below in an adapted framework see **figure 2.2** (Bingham & Witkowsky, 2022). This enabled me not to just explore the pre-defined broad topic areas and codes but enabled me to further explore additional topic areas and codes that might contribute to additional themes.

Figure 2.2 Coding Framework for Analysis (Adapted from Bingham & Witkowsky, 2022)



Firstly, I familiarised myself with the data and read through the transcripts. I then applied broad topic categories which included anything related to neurodevelopmental disorders, family, the child (Lac), outcomes and service provision and related to the research questions in NVivo. From these broad areas a deductive approach to coding was taken applying some of the theory to the interview data creating topic codes. These codes captured related or representative words or quotes related to the research questions. I then read through the topic codes and assigned open codes. After this, I then re-read the transcripts using an inductive approach to further explore if any of the data highlighted any other additional topic codes and followed the same process for assigning open codes.

From there I began analysing the open codes and condensing those that had similarity and categorised them into overall primary themes. As the amount of transcription was substantial this allowed me to further analyse the codes in the primary themes which subsequently resulted in some sub themes (Vaismoradi et al., 2016). Sub-themes in this study equate to a subdivision of the overall primary theme. They fall under the umbrella of the primary theme and are categorised into specific aspects of the primary theme. After this I consistently and

sporadically used text search queries on primary words derived from the primary and sub-themes to see if I had missed any other quotes that might contribute to the themes (Bingham & Witkowsky, 2022; Hilal & Alabri, 2013).

As only two LA's were interviewed, no demographics or participant identifiers are detailed due to the nature of the social worker role and population of interest for anonymity reasons. Although, the terms he/she were used, the detail in some of the cases discussed might have revealed the identification of the Lac or family and the social worker, particularly as only two LA boards were involved in the study. Several quotes and extracts were redacted to protect the identity and anonymity of the participants

It has also been reviewed and published by the Adoption and Fostering journal.

4.4 Results

Ten interviews were conducted with nine social workers with extensive experience (over 5 years) and one other social worker professional who formed part of the social services multi-disciplinary team and works closely with these children. All were recruited from two Welsh local authority (LA) boards. Attention deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), dyslexia and dyspraxia were the most discussed NDDs. Seven primary themes and sub themes are highlighted in areas of (1) perceptions of NDDs, (2) perceptions of diagnosis, (3) access to service provision, (4) impact on care settings, (5) impacts on health and social wellbeing, (6) parental capacity, mental and social wellbeing and (7) social worker challenges, needs and recommendations.

4.4.1 Perceptions of NDDs

This part of the study set out to explore the external perceptions, understanding and knowledge of NDDs from a social worker professional perspective as they are often the first point of contact when the child enters the care setting. They have to safeguard and protect these children and navigate services to meet their individual needs.

The initial aim was to investigate the perceptions of NDDs and explore if they even, existed in the Lac population based on the social workers experiences working with these children.

As already detailed within this thesis, NDDs can cross a wide spectrum. Therefore, this enabled the study to narrow the focus on what specific NDDs might affect this population.

4.4.1.1 Perceived prevalence

There was a general consensus in the participants responses that acknowledged that NDDs were increasing and becoming more prevalent in this population. ADHD was perceived to be a prominent disorder, followed by ASD, dyslexia, and dyspraxia. However, this is only based on the perceptions of ten social worker professionals.

“I’d say a lot of the children, a high percentage of the children that we’ve got looked after in our team probably have got a label of some sort, okay, be that dyslexia or dyspraxia, or waiting for autism diagnosis, I would say probably quite a lot of them”

“Oh, the boys seem to be diagnosed with ADHD. That’s an interesting thing that I’ve noticed. A pattern I’ve noticed myself in working, you know, with, you know, in my role as a support worker and as a social worker”

“...Unfortunately. Autism is what I hear all the time...”

“Diagnosis of dyspraxia and dyslexia, and ADHD, they’ve been the more common ones”

Conversely, one other participant did not think that NDDs were high in this population and suggested that there was a cultural and societal influence on the presence of ADHD in this population.

“it’s the rage at the moment ADHD is I think. It’s very popular...”

4.4.1.2 Professional knowledge of NDDs

Having an in-depth knowledge of how the child with a NDD presents in behaviours is essential to providing the correct provision and support that is individualistic to each child. Many of the participants acknowledged that they had a limited understanding of NDDs and

unpicking what was causing the underlying behaviours was confusing, difficult and frustrating for the participants which is congruent with some literature (Chasnoff et al., 2015; Gilbert et al, 2021). Deciphering what behaviours were caused by trauma, attachment or an NDD was a significant issue for many of these participants as a result of the similar behavioural symptomatology.

'...because often children can be diagnosed with ADHD and actually it's more about their attachment disorder. And again, with autism it can be very, very close and similar traits''

'if I was making a layperson's diagnosis, I would say they would have autism, but we also know and are more aware that attachment difficulties can mirror autism. So, we're cautious now in making any lay – giving those labels then without that, we know that attachment difficulties and things like ADHD and autism can mirror each other''

'...what we struggle with is that we have loads of – you probably have people saying this, we have loads of people saying, oh it's ADHD, there's something wrong with him, he's got bipolar, but how do you separate that from the trauma they've experienced and recovering from that''

'I know it's hard to define trauma from ADHD, but maybe sometimes the trauma is actually causing the ADHD, do you know''

'that I think nine times out of the ten there's other factors that are contributing to the behaviours that are being seen. And I certainly am sceptical when it comes to then, you know, somebody saying, I think it's ADHD. I think it's autism. Not to say that I'm dismissive of it, because I'm not, but I would want to know more about why they've drawn that conclusion really''

Limited training in the behavioural symptomology associated with both trauma, attachment and NDDs was also suggested to contribute further to the confusion.

'I'd say definitely any training would help our knowledge... because sometimes we can't even identify it ourselves, we're not experts''

“So, we get sent autism training sometimes, but it’s normally only about half a day it is, it’s just to understand and it’s not very in depth, it’s standard stuff, you know?”

“Because it’s, you know, one group of people the trend is of a diagnosis and the other people because they might have been on attachment training and heard people say well it’s really, really close and they’re like, “Right, it’s definitely attachment,” because they’re a looked after child. And I think we need to always have an open mind because I think there’s a big danger just because you’re a looked after child that you can’t possibly have any kind of ADHD or anything like that because it’s always going to be attachment because of your background”

“...training, so there’s been – you know, there’s courses on ASD, you know, we can have joint training with the schools, we could have time out to research on the internet if we wanted to...”

Social workers have to attain a wide breadth of knowledge and understanding of a multitude of varying needs. Therefore, this finding could be suggested to be a result of a frequent lack of resource and time for in-depth training; which would inevitably prohibit a deeper understanding of NDDs and their associated complexities.

4.4.2 Perceptions of diagnosis

Diagnosis is associated with the identification of a condition to enable the provision of timely, specialised treatment and interventional support that will improve future life chances. Conversely, it can have the opposite effect if incorrectly diagnosed or missed altogether (Langenfeld et al., 2021; Pinto, 2019). As already detailed within this thesis. many professionals find NDDs very complex and misdiagnosis, overdiagnosis can occur which can result in incorrect specialist provision and be detrimental to the child (Giuliano & Geyer, 2017; Marangon et al., 2015; Merten et al., 2017). , Exploring the social worker perceptions in this area might contribute to a wider understanding of NDDs in this population and whether social workers perceive diagnoses as something that helps the Lac with NDD. This provoked an array of conflicting thoughts and opinions, that included misdiagnosis and overdiagnosis, benefits and disadvantages of diagnostic labelling.

4.4.2.1 Misdiagnosis and overdiagnosis

Several participants expressed concerns with misdiagnosis and overdiagnosis of NDDs which planted a seed of doubt in perceptions of clinician's final diagnostic assessments.

“where children have come into foster care with an ADHD diagnosis and once they've come into foster care and settled down, they've been reassessed by paediatricians. And I can actually think of quite a few examples thinking about it, where that's happened, where they've come in with oppositional defiance disorder, ADHD, they've actually been put on medication at a very young age, they come in, they settle and that diagnosis has been taken away so that label has then been removed”

“it's easier to label the child and to try and medicate the child, whether that's consciously done or not. And so, yeah, I think we do as a team – sort of there is a concern about the kind of over-diagnosis of ADHD type symptoms”

“Or they're more ASD aware, so they're picking up on traits sooner, or it could be that they are seeing everything through that lens and there might be some misdiagnosis, and it might just be the little child's personality traits or something”

“With us, we assume the paediatrician is – well, they are experts, and if they say that a child's got ADHD, well, there we go”

Conversely, several participants expressed their concerns that some disorders such as autism, dyslexia and dyspraxia were being missed. This is reflected in literature which propose that many children with fewer behavioural problems are frequently missed (Hull & Mandy, 2017).

“a lot of children that I know that have been placed for adoption have gone on to be – to have been diagnosed with autism, post adoption...”

“And I think to be honest, dyslexia is missed quite a bit 'cos it's put down to, well, they haven't had a lot of schooling, they haven't had this, they haven't had that. So, it gets – that gets missed as well...one little girl of mine, she was missed for ages and ages and we always

used to say about dyspraxia and during annual like health reviews we'd mention it and mention it. No, they're just clumsy...''

''With the dyspraxia and the dyslexia that tends to be after they've become looked after, because I think foster carers are more tuned into looking for it. So, you've suddenly got a group of professionals, foster carers, PEPs in schools, a team of people around that there's a microscope on the child that may not have been there at home''

One participant viewed the ASD diagnostic assessment as a more thorough and comprehensive diagnostic process compared to the ADHD diagnostic process as a result of the lengthy and rigorous process it takes to attain an ASD diagnosis.

''With ADHD I would say yes, because a lot of the time they go off parental account. With the autism it's so difficult to get a diagnosis I would say probably by the time they get to that stage the chances are it's not a misdiagnosis''

4.4.2.2 Benefits and disadvantages of diagnostic labelling

From a sociological perspective, diagnosis is often associated with labelling and categorising a child. Any additional label has always been a controversial area in research (Mannay et al., 2017). For the Lac who has already often acquired a wide array of labels, this was an important area to explore and raised mixed responses.

Several participants viewed a diagnostic label as a protective factor for the child's future wellbeing. Particularly from an educational perspective, as they perceived the diagnosis and label as a pathway to accessing better educational provision.

''It might lean more towards the positive side because carers and stuff know that there's that support already in place for them. So I think sometimes without it, you know, there's that struggle and there's that struggle for school. And if schools aren't on board, they get expelled, they do this, they do that, and in my experience then the placement breaks down''

''I've got a child that's got dyspraxia and dyslexia and once that had been diagnosed it was a relief to have the label...I think labelling as such, and getting a diagnosis, whichever way you

want to look at it does help because children then get services they don't – it's a key to getting services that they wouldn't get otherwise''

''I think that if you have a broken leg you need to have it in plaster. So based on that, if – and there are children and there are going to be children who it may start as a young child and it may deteriorate as they go on and yes, in some cases, a diagnosis may well make the difference to helping them plod their way through life''

''well ADHD I suppose they get medication around sleep and behavioural management and that makes things easier for people caring for them''

''I'd say probably generally has a more positive impact''

''He has a learning difficulty and having that label certainly helps him in the situation that he's in, in school. He's now loving school. School is not stressful or hasn't been causing him anxiety. He's not bringing any of that home to his foster carers, who are then struggling with holding the placement together...So, therefore a label can definitely help''

Conversely, although some viewed the diagnosis as a positive factor, one participant expressed concerns on the impact of self-fulfilling prophecy and that a label might hinder the child's self-belief in attaining better outcomes.

''I have had a case as I said that's helped them with their school, having that diagnosis has helped them concentrate in school and with themselves. But on the flipside of that then if you talk to that young boy he would say if he's not doing anything, he will use the excuse I've got ADHD so do you know what I mean? So even though it has increased his concentration and his parents have seen an improvement and stuff he is totally convinced himself that he's got this label now and he uses it positively in some aspects, but he uses it as an excuse in other aspects''

Some participants viewed diagnostic labelling the child as unproductive. They conveyed deep concerns that attaining a diagnostic label of a NDD might deflect from exploring other underlying difficulties or trauma that the child might need support with. Providing appropriate and relevant support was viewed as a more effective future care plan for the child.

“Just because of what I said really that there could be their needs being unmet because the care plan, if you want to call it that, or the way that professionals support that child or young person will all be based around that diagnosis. And the focus may not be perhaps on other factors that that child or young person might need support with”

“I’m not sure how helpful a label is, it’s more about the support that we’ve got around them than giving them a label, it’s more about how the adults around them respond and support”

“He goes like that when he’s excited, but it’s the slightest thing isn’t it, and I suppose loads of people have autistic traits as well don’t they, but then with that carers I really would like a specialist to be able to just discuss things through with her and reassure her that yeah he might have autistic traits but that doesn’t mean he needs to go down this line of having a label and stuff. Do you know, and on the waiting list and stuff, you can support him in the home to overcome some of these things, do you know what I mean it doesn’t need that label. Yeah, exactly, but what support is out there even when you get the label isn’t it?”

“Quick fix because it sometimes feels more comfortable for those who are working with that child or young person to be able to say, right, that’s what it is and so therefore this is what we’re going to do to help...And then it makes me feel, you know, I suppose a little bit anxious and more so, sad for that child or young person that potentially the direction, or the trajectory, of therefore the support that they’re going to receive is all going to be based around that diagnosis and people could miss other factors that perhaps that child or young person needs support with. To support them not just now but into their adulthood as well. And that really worries me for that child or young person really, that they’re getting an unmet need”

4.4.2.3 Medication prescription and usage

One of the findings from the systematic review was that Lac with ASD had a higher usage of psychotropic medication and higher prescription compared to their peers. Medication usage in the Lac population has been suggested to be higher compared to their peers (Raghavan et al., 2005; Mandell et al., 2008). It was an important area to explore as for many children diagnosed with a NDD, medication is often a pathway used to reduce challenging behaviours or to assist in areas of sleep, concentration and regulation of emotional responses. It can work effectively for many children with a NDD however it has been suggested to have the opposite

effect on others (Alfageh et al., 2019; Cortese et al., 2018; Rossignol & Frye, 2014; Rubin et al., 2015; Popow et al., 2021; Toomey et al., 2012). There were a lot of mixed opinions and perspectives on the subject of medication. ADHD was the predominant disorder discussed when conversing around the subject of medicating children and adolescents.

Participants acknowledged the challenges that are often placed on parents/foster carers who are responsible for children with ADHD. However, having a stable, safe and caring environment was suggested to be the most effective approach for the child, with positive outcomes.

“I know for foster carers it can be very difficult, and for parents, and medication is the first go to for that. ...medication and labels are an easy way of dealing with it. I think that’s a common factor”

“So, he’s been diagnosed with global developmental delay as well, ADHD, so it comes with a pile of things doesn’t it? But he’s finally off the medication and doing well so what does that say isn’t it?”

“Well one of the children that I’ve spoken to you about before that came in with an ADHD diagnosis, they managed to get her medication about three, so she came about three and she was already on ADHD medication, she isn’t now”

Some participants found that medication had helped with the educational settings and had a positive impact on the child, although only to be used as a last resort.

“As it goes, well they’re increasing her medication and she’s quite stable now”

“Anyway, and he takes the medication and he’s been diagnosed with ADHD. And the impact on his learning has been massive and his ability to focus and all those kinds of things. So I’m a little bit split really...we always if there are children who are medicated we will always question and challenge”

“...I don't think it's the be-all and end-all. I think its part of helping”

“They were saying his medication needed reviewing because maybe he needs more as he’s growing up, maybe. Anyway, this went on for years and now he went to live with his gran. And we have supported that, so we’ve supported her to keep the child. They had to stop his schooling at one point because his behaviour was so bad. He was only in – the school actually went to him and he went in one day a week. Now he’s in every day, and they want to increase that to two o’clock now every day, and she told me last week that she’s almost stopped all of his medication”

Conversely, some expressed concerns with the use of over medication in children with NDDs, particularly ADHD. They had often found that the prescribed drugs had in fact exacerbated the behaviours, not reduced them.

“Say about fifty-fifty really. I’m thinking about my team now, and you know, whose kids are medicated or not. Yeah, fifty-fifty”

“...with ADHD...medication and labels are an easy way of dealing with it. I think that’s a common factor”

“...that’s been our struggle with so many cases at the moment, that then doctors put them on ADHD medication, like I’ve had a case recently who he was trialled on ADHD medication, and it actually made his behaviours ten times worse and he was irritated...I feel like you need to try – exhaust all options and medication should be the last option”

4.4.3 Access to service provision

Early identification and intervention are key to improving the emotional and psychological and social wellbeing of children with a NDD and a diagnosis is usually associated with a direct means to accessing specialist service provision (Hutchon et al., 2019; Manolova, 2017). However, studies on the general population propose that this is not reflective of lived reality (Crane et al., 2018; Legg & Tickle, 2019; Sayal et al., 2018). Services were a broad aim of the study and the role of the social worker has to navigating care and support for these children between health and social care services. Therefore, the study explored the

experiences of social workers when working with these children and what challenges they had encountered when trying to access services on behalf of the child.

This area of discussion raised varying concerns for many of the participants and showed some similarities in the challenges that many children and families experience in the general population (Crane et al., 2016; Sayal et al., 2015; Smith-Young et al., 2020). Based on the experiences and perceptions of these participants, some described how access to diagnostic assessment, mental health services, specialist educational provision and pre/post diagnostic support services was a lengthy process and often unattainable. Frequent moves in residential and educational settings, lack of resources, complexities in attaining diagnostic evidence and rural locale were perceived to further contribute to the complexities.

4.4.3.1 Times from referral to diagnosis

Many participants described how they had encountered long delays in helping the Lac to attain an actual diagnostic assessment. For many participants, they described how referral to diagnostic assessment appeared straightforward and within realistic timeframes. However, accessing the actual diagnostic assessment, particularly disorders that were suspected ASD, took years in some of their cases.

“...we have got children in the looked after population that have been waiting a long time for an autism diagnosis...”

“What I find is that they do the assessments and then they’ll say, “We think that they may have ADHD, ODD, be on the spectrum, we’re referring to neurological department,” and then they’re on an eighteen months, two year, waiting list”

“ In the last few years locally here there’s been a shortage of paediatricians, and so trying to get any kind of – you know, whether that’s for looked after children or children that are in the care of their parents, you know, trying to get any kind of paediatric intervention has been very, very difficult. And I know that there was a boy that I was working with a few years ago that we thought had autistic traits and he was on a waiting list for years”

“The actual referral isn’t too bad. It’s just all that after it, isn’t it? You know, the appointments, the initial meetings, and then all the questionnaires you’ve got to fill out. Carer, school, social worker, parents. And obviously all that just takes a long time”

Access to an educational psychologist (EP) was described as difficult but this differed for one LA as they had an educational psychologist embedded in their working model. This enabled the social worker to have direct access to some knowledge which provided them with a positive support network before referring for a diagnostic assessment.

“And if it’s along the EP line that sort of is involved, you know, the capacity of Eps at the moment is just absolutely dreadful, you know, and they’re cutting services and yet you’ve got children who desperately need it”

“...but I do feel there’s a lot of battling back and forth about who provides the support, waiting lists for ed psych’s to be seen, to see them...so I’ve got a LAC child now that’s waiting to be seen, and because of funding and stuff she can only provide an observation and she can’t do a full assessment at the moment because she’s full to her capacity,”

“but it’s taking a while for ed psych to be able to see them because there’s a waiting list. Yeah, waiting lists for the ed psych’s in schools, and then you know, then again, they have to go to a panel and then after the panel they’ve then got to find the appropriate school resource”

4.4.3.2 Child and adolescent mental health services (CAMHS)

The systematic review found that mental health service usage was higher in the Lac population compared to their non-Lac peers. Although, it could not be determined that it was the challenges associated with a NDD that initiated the referrals to mental health services, mental disorders do frequently co-occur with children who have a NDD (Petrou et al, 2018; Reale et al, 2018). Therefore, this prompted exploration into the experiences of the social worker professionals when working with these children and to explore if there was similarity from the results found in the systematic review.

This service generated a lot of emotive responses from the participants. In relation to the experiences of the social workers working with these children very few found CAMHS a positive experience and the majority of participants expressed significant concern with regards to accessing the service due to unattainable thresholds for criteria. Lack of resources was described as being a significant barrier to accessing services. However, this was only based on a few perceptions and experiences.

Many participants described how the referral process was straightforward.

‘I’ve never got to the actual point of CAMHS, I’ve made lots of referrals [laughs] but I’ve never met the threshold with the children that I’ve referred. I’ve spoke to them loads, they’ve given me advice over the phone, passed me onto different agencies but I’ve never actually got into CAMHS with my cases at the moment...’

‘My experience in accessing CAMHS is pretty good because in our authority we’ve got a psychologist ...we can have consultations with before referral there. And our referral’s basically just a letter to CAMHS’

However, the majority had expressed their views on how inaccessible the service was. They perceived that meeting the criteria to access services and interventions seemed unattainable for many based on their experiences working with these children

‘CAMHS is a mystery to me...I can’t say any more than that’

‘I’ve got children that are probably still waiting two years down the line’

‘I – in all honesty, I’ve no idea what CAMHS’ criteria is anymore. Unfortunately, I just don’t understand what constitutes their criteria and what doesn’t...CAMHS needs an overhaul. No doubt about it. Needs an overhaul of what it is that they’re doing or what they see as the threshold for their criteria’

‘We’ve got access to – we’ve got CAMHS, but to get an appointment with CAMHS, or to get them to actually decide that the child meets the criteria for intervention is quite shocking really’

“ meeting criteria for CAMHS can take a year and a day and sometimes you just think what do we have to do to reach criteria”

Several participants had described how some children and family had to reach crisis point to be able to access the service.

“ unless they get to the point where it’s got so extreme that they’ve taken an overdose or they’ve done something and they go to hospital and then see the crisis team that way, then it just seems that any sort of cry for help that doesn’t get that far, you’ve got to wait quite a while to see somebody”

“...maybe they’re struggling with resources and stuff as well, but I struggle to know what you need to actually get in there, because I try and get in there to be preventative, they’re showing these warning signs, help us now before we’re in crisis. And but unless – I feel that unless you’re in crisis they won’t see you until the crisis has happened and then they’re trying to pick up the pieces from the crisis then, so it seems to be...”

A lack of resource was perceived as being a reason for inaccessible mental health services. However, this is only based on perceptions.

“ I can understand that they just simply don’t have the capacity to kind of work with every child, but it is really, really difficult for us to get a service out of them”

When CAMHS was accessed, it was observed by some participants that if the child did not meet the diagnostic criteria for a mental disorder they would be referred onto already overwhelmed community-based or third sector services.

‘...it’s a long process to get children in, a lot of it they say is behavioural so they won’t work with children because it’s behavioural, it’s not a mental health problem so that is quite a narrow kind of field that they’re working’

“Yeah, very often we get a response of, they don’t have – we’ve assessed it, we’ve had a multi-agency, or multi-disciplinary kind of team meeting, looked at the referral, and we don’t think that this person, or this young person, has a mental health diagnosis and we think that they need support from other community based services...really having a rethink about what their criteria is. So that it could incorporate perhaps more of the preventative, 'cos what they're saying to us almost on each occasion. They haven’t got a mental health diagnosis”

Geographical location was suggested and perceived to be another barrier that was associated with accessing CAMHS.

“I mean the other problem that we have with CAMHS sometimes is that – talking about school and stuff – we quite often have to take – the young person has to get to them, which I suppose is a disadvantage because it’s quite disruptive in terms of education and stuff, you know, they’ve got to get to the hospital in ... so there’s the travel time on either side of that plus whatever appointment they’ve got. So, I guess that isn’t ideal, it’s very rare that you would ever get them to sort of come out into the county to see a young person or anything”

4.4.3.3 Access to NDD specialist services

Some participants had experienced challenges in accessing specialised NDD services and educational provision for the Lac both pre/post diagnosis. Some participants perceived that accessing specific, specialised therapeutic interventions and services in both health and educational settings may be attributed to a limited professional knowledge of NDDs and a lack of resource. However, this is only based on their perceptions and experiences and were described as contributing factors. They described how accessing relevant services for some of these children had been lengthy and poorly resourced.

“...when we go to health professionals even they struggle, I’ve been to loads of paediatrician appointments and they don’t have a clue sometimes...we’ve got people with a psychology background who can provide us with advice and stuff but obviously they’re not specialised in the neurological conditions are they. There’s obviously the resources challenge, like, isn’t it? You know, the waiting lists, something like I said earlier, the early intervention and the support services that we had aren’t there anymore because of funding for – you know, that’s a struggle with caseload”

'...I think on the ones where there's practical stuff, like the dyslexia and dyspraxia, where they know that they've got to do the, you know, they can provide laptops, computers, you know, the blue screen reading stuff, the special pens, they're very good at doing that. Where's there's more cognitive and neuro stuff I think it's more difficult for them''

Some participants however described how having access to an educational psychologist on a regular basis provided them with an additional objective viewpoint and well received knowledge that enabled the participants to better support the child.

''Whereas we have pods now, so every week there'll be three social workers, a senior social worker and an educational psychologist will meet every week to discuss your cases now, so it's trying to do a shared responsibility of case discussion, and then the ed psych can kind of suggest some interventions which is really helpful...''

Conversely, some participants described how they found access to educational support services lengthy and claimed that the process was too long for many participants with a lack of resources being the main reason. Some participants expressed concerns that this might place the child at further risk.

'I think that the reason a lot of the time why it doesn't happen is because of lack of resources and time. I think we're all more aware of it now, so we know where to go, and what to ask for. I think on the ones where there's practical stuff, like the dyslexia and dyspraxia, where they know that they've got to do the, you know, they can provide laptops, computers, you know, the blue screen reading stuff, the special pens, they're very good at doing that. Where's there's more cognitive and neuro stuff I think it's more difficult for them''

''I would say obviously it takes too long but I understand why it takes too long because of resources and because there's got to be a certain amount of evidence hasn't there because they access the service''

“It depends on the school, I’d say some schools are better than others, but I do feel there’s a lot of batting back and forth about who provides the support, waiting lists for ed psych’s to be seen, to see them”

“the only problem is that even with support in place sometimes they’re still getting sent home from schools and things. Suspended maybe for a couple of days. And then that puts them at risk in the house then”

4.4.3.4 Frequent residential and educational moves

Frequent educational and residential moves were observed and suggested to be prominent barriers for Lac to access timely services and support. Access to service provision and support for Lac moving to rural areas was described as challenging. Many of the participants conveyed more concern for children who had multiple residential and educational moves, particularly when placed out of county.

“ In our team they’d have access to a psychologist, a social worker and a child and family practitioner, and obviously then you’ve got all the charities...definitely disparity between the east of the county and the rural bit of it in terms of access to services”

“Nothing stays consistent with them. So, it’s not just moving so moving the child, their placement, everything ends up moving with them and it makes it really, really complicated. So, you could have a young person who’s been educated in a ... school when they started that process but then they end up in ... or they end up further out of county, and that process then has to start again”

“It can take a long time I think because of moving schools and things... Out of county, obviously they’re bumped along, they’re never in one place long enough and it’s often missed”

“when I was looking after the out of county children it was incredibly frustrating because they were children who you’d be going into meetings and they needed a lot of support and you’d say well why hasn’t this child been statemented, and then you’d look back at their school moves and they’d been moving not just schools but county...”

“And when you look at a child who’s had multiple placement moves, it’s not just about the placement that they’re moving. So, they move education...”

“But I guess what does impact is moving schools, when they move placements, and again in ...we tend to keep them in the same school, but the downside is that they’re then having to travel a long way in taxis so they’re tired when they get to school”

“So, they may be moving counties within education. So, if we’ve got a child living in... and we’ve got to move their placement and they move to..., you’re moving into a new Local Authority, so their education’s got to change. And if they’ve started, for example, the route in ..., it doesn’t transfer over. It’s really complicated. Or if they’re in CAMHS in ..., they don’t stay with that CAMHS. They pull out then and it’s got to transfer over”.

4.4.4. Impacts on care settings

Both the systematic and narrative review found that some Lac with a NDD were more at risk of being placed in care setting and for longer periods. This prompted exploration as the primary responsibility of the social worker is to place a Lac in a suitable, safe and stable care setting.

Impacts on stability, length and type of care placement setting are discussed further below. Several sub themes are discussed in areas of multiple placements, suitability of care placements and perceived barriers to being fostered or adopted.

4.4.4.1 Multiple care placements

Several participants described how they had worked with children with an ADHD diagnosis and that these children had been placed in multiple care placements because of relationship breakdowns, often as a result of behavioural issues. They acknowledged that caring for a child with ADHD could bring additional challenges and place more demands on the parent/carers.

‘so, I've got one boy who's got an ADHD diagnosis. He was removed from his mum when he was three years old, so he was still little. His mum drank when he was in her belly and then drank when he was with her, in her care...He was then removed and has been in thirteen foster care homes until he's fourteen’

‘Well, you know, I've had an eleven-year-old come in a month ago, and there's been a lot of service provision in for him. And the reason he came in is just his parents just could not manage his behaviour. It wasn't that they were neglecting him in what you would imagine neglect to be, it was a neglect in a way 'cos they couldn't keep him safe because of his behaviour which was crazy, was took against them not against others, but they couldn't manage him. So, he's come in, you know, and he's been in their care. They adopted him when he was four’

4.4.4.2 Residential care

Some participants based on their experience and observations perceived residential care as a more positive, protective setting for the child with an NDD and those with severe behavioural problems. They described how safeguarding the child was their first priority and residential care seemed to provide this but only after first attempting multiple placement settings.

‘Yeah, quite a lot of them. We tried independent foster placements, plus all of his family, and he run off from everywhere. So, the only place to keep him safe, he's in residential care’

‘I'd say the majority of our kids in residential have got some diagnosis problem. And mainly I'd say that they hadn't been diagnosed yet. So their carers and previous placements had been unable to manage their behaviour, which led to placement breakdown, school breakdowns, and obviously then they end up in residential...’Residential stuff we've got, different ages...But I know of a boy who is seven who's in residential’

‘We do then look for family members that the child can go and stay with to have a break. I have had two children though, fifteen and thirteen, which is very rare, that we did remove and put Care Orders on and they both ended up in residential care’

One participant described how the behaviours associated with these conditions and lack of support services contributed to a child being placed in residential care. However, this was only based on their perceptions and experiences and will not be applicable to each child.

‘For my ..., yes, because there’s not enough therapeutic placements out there where there’s support of foster carers, where they’ve got the skills to be able to manage...And behaviours and stuff like that. And yeah, carers couldn’t manage – manage the behaviour really...Like I said, in a care home you’ve got that high number of staff and like they’re one to one and stuff like that, they’ve always got somebody there. But when one member gets worn down, you’ve got another one. You don’t get that in the home’

One participant described how having a stable, safe and caring environment appeared to be the most effective approach and had observed positive improvements in the child.

‘ And he’s been on tablets and it hasn’t worked, but after a year in foster care he’s actually improved amazingly so what does that say, that’s environmental factors having that difference then isn’t it?’

4.4.4.3 Foster placement or adoption

If a Lac is unable to be returned to their biological parent, the next step is to ensure that Lac are placed in a safe, long term caring environment. Some participants expressed concerns that a Lac with a diagnosed NDD might hinder or prohibit the child from being fostered or adopted, with more emphasis on adoption. However, this is only based on personal perceptions and is no way reflective of foster carers and adopters’ opinions.

‘I do think it could be detrimental, because you see that label ADHD and the first thing you think of hyper behaviour problems, and even though people push for the labels sometimes to help them if you know that in advance you know there’s a problem there, so specifically adopters I would say that that’s a problem’

“If they were given a choice between a child without a label and one with a label then they probably would want without label”

“Yeah, it makes them more difficult to match a foster carer...”

“ Fostered no, adopted... Okay, so what you’ll often see is oh well I’d consider somebody with a mild learning disability, but I wouldn’t want anybody with Down’s Syndrome. I’d consider a child with parents that are depressed but I wouldn’t want parents that are schizophrenic, right, so yeah adoption 100 percent. So, if you’ve got a child with an autism diagnosis they would be more difficult to adopt, then the child – where you’re saying to adopters you’ve got to embrace uncertainty, we don’t know, which is all children let’s be honest”

One participant perceived the behaviours of the child as a more impeding barrier to being fostered or adopted rather than the actual label. This again is based on perceptions only.

“No. I suppose it depends how severe they are. You get files and stuff like that. But I suppose it depends on the behaviours doesn’t it? How extreme their behaviours are, that’s – I think that’s a lot to do with fostering and stuff like that”

One participant had observed that some of these children had made placement more challenging, sometimes resulting in breakdowns in the adoption setting. However, it cannot be suggested that it was the challenging behaviours associated with a child with a NDD or a myriad of other factors such as environment that caused the relationship breakdowns.

“You know, ‘cos I’ve been doing it for so long I’ve seen quite a lot of adopted children revoking – revocation of the adoption order. So for instance where the child or young person has been adopted to a family, has lived with them for x amount of years, and then the matter’s come back into the local authority in a safeguarding point of view because of either relationship breakdown and you know it’s got to a crisis or whatever”

4.4.5 Impacts on health and social wellbeing

Both the systematic and narrative review highlighted some adverse impacts on the Lac with a NDD. Therefore, this prompted further exploration as social worker professionals have to navigate services to help and support these children overcome many of these adverse outcomes and would therefore have an awareness of some of the impacts on the Lac with a NDD.

The health and social outcomes were overall observed as poor for many of the Lac. However, this is only based on the children they had worked with. Some participants described how they perceived educational attainment to be an outcome that was improving. However, that is only based on their perception. The majority of participants described poor outcomes associated with low educational attainment, residential placements, self-harm, mental health, substance misuse and teenage pregnancies. Criminal involvement in the subject area of county lines, sexual grooming and exploitation was described as a concerning risk factor for many children regardless of having a NDD.

4.4.5.1 Education

Some participants had observed educational attainment as progressing in the right direction for some Lac but this was not the case for all.

“Yeah, I'd say they're generally poor. I think it's getting better; they are getting better...there's more going on to higher education and stuff like that”

“I'm going to show you that that's not me.” And you know, it's lovely when you see that. And they go off to university and everything like that”

“Educationally not attain very well, and I can think of a few cases where that's been not the case and a lot of young people that have been in care that then go to university really struggle, so you get them that far and they get into university and then it's a massive struggle for them and they drop out”

One participant reflected on the current Covid situation at the time and described how other socio-environmental factors were needed to be considered as contributory factors to poor educational attainment.

“So you know, domestic abuse, poverty, substance misuse, home conditions, you know, at the moment the lockdown, you know, we’ve got five or six children living in little flats, you know, a big thing is people accessing, children accessing school hubs. They can’t get to them, or there you can’t get online to you know, to access them or that the internet isn’t strong enough, or the tablets they’ve got aren’t good enough. Whereas children living in middle class houses that’s not going to be a problem is it, they’ve got different rooms they can go and work in, they’ve got their own bedrooms”

4.4.5.2 Physical and mental health

Several participants had observed adverse impacts such as domestic abuse, substance misuse, self-harm, early pregnancies, toxic relationships and poor mental health as some of the poor outcomes when working with these children. One participant expressed their concern that children placed from out of county could potentially be even more vulnerable.

“A lot of it is substance misuse, substance misuse. But we are getting better with a PA system and stuff for LAC, so we’re trying to get them into educational stuff. If they’re in education and they want to get a job it’s more positive, if they haven’t got that drive then it ends up in substance misuse, bad relationships, early pregnancies...”

“Yes, yeah, like fights and stuff, being caught with cannabis and things like that, drinking underage, stuff like that...”

“...it’s mental health problems, I’d say as well”

“ Substance misuse”

“ Selfharm”

“ No, we still see it. We still see it quite a bit. Domestic abuse and domestic violence. Yeah, drug use. Alcohol use. And later in life unfortunately, a bit more kind of severe mental

health diagnosis. Lately, over the last I'd say five years, seen more diagnosis of schizophrenia... Bipolar, schizophrenia and borderline personality disorder is what we see all the time''

''the kids who are out of county, placed from out of county, are often the most in need of support because the very fact that they've been placed out of county either means that their situation is too dangerous to be placed closer to home or they can't place them because their behaviours are too challenging so they have to kind of move them out of county. So those are the young people who actually really need the support''

4.4.5.3 Criminal Involvement

Crime was discussed several times, but the subject area of county lines associated with sexual grooming and exploitation was described as an extreme risk for these children with their additional vulnerabilities. This caused great concern for the participants when caring and working with these children.

''But the majority of mine have been really good, like they've got into college, then independent living and stuff like that. But then again there's others I know that are already in prison and already got kids, their kids are in the care system''

''...crime''

''When you think of things like County Lines, that is becoming more and more of a problem at the moment and it's just so easy for these adults to be able to recruit children without even having to have a face-to-face contact with them...Definitely target vulnerable children. I can see that with looked after children are vulnerable to that, especially if they haven't had the stability. They're not as safe, so a hundred percent, definitely, and it's easier because it can be done through social media. It can be done through text messages and things like that and I think it's bringing different issues''

'' they've got themselves into something, not realising what they've got themselves into and, before they realise it, they're in quite deep and it's really hard for them to be able to get out of that. They worry about the impact on their families. They worry about what could happen there. So, you know, trying to get them out of that is really difficult''

“our children are seeking love all the time, they’re the easiest kids in the world to groom”

“...sexual exploitation, poor relationships – both intimate relationships as well as with family and networks. Yeah, early pregnancies”

“we’ve got some now where it’s part of like a sexual expectation, that’s a big one, being pulled into sexual exploitation...”

“Crime”

4.4.6 Parental factors and impact

As mentioned already within this thesis, having a child with a NDD can create challenges for the parent and wider family. Therefore, the study aimed to explore the perceptions of the social worker on what challenges they had perceived during their working career in relation to the parent/s of these children...

Based on the experiences and working with these children some participants had described how parental capability, psychological, economic and social environment coupled with wider, multi-faceted determinants were perceived to be contributing to challenges and placing potential demands on services. Parental efficacy, mental, physical and social wellbeing, cyclical outcomes and socioeconomic influences are described as having an impact on the Lac with a NDD. A multi-disciplinary approach between sectors was described by participants as a positive working model to reduce reasons for referral into services. However, several of the participants had observed over their own working career that the primary needs of the child, parent and wider family had become more complex over time and therefore created even more extensive challenges.

4.4.6.1 Parent/carer efficacy and support

Several participants described how the psychological and physiological factors associated with some NDDs and the behavioural challenges that frequently manifest and co-occur had an impact on referrals into the services. They described how breakdowns within the biological home and care settings had a negative impact on the Lac with a NDD (Foley, 2011).

Researcher: 'How often is it, if you have a child with a neurodevelopmental disorder or something like that, might become looked after?'

Participant: 'It's quite high. It's quite high, yeah''

Participant: 'so they'll be referred in and the schools might refer them in...they've been diagnosed with ADHD already''

Researcher: 'A lot of these children?''

Participant: 'I'd say a lot of these children have got a diagnosis''

Researcher: 'If I was going to ask you one out of ten? Roughly''

Participant: '...I'd probably go as far as to say four''

Several participants described how parental support and management of the child's behaviours and complex environments were contributory factors and potentially a possible driver for services. The participants describe the fears and frustrations that several of the parents had in relation to keeping their child safe.

'...we have a lot lately of just struggling to deal with their behaviours, so not good enough parenting and not being able to parent the child, some people are phoning in themselves now for help because although some people see us as you're taking my child away, some people are phoning in for help because they're desperate because they can't parent their child as well so that's the other aspect of it as well. We have a lot of care and support cases where we're actually – they want our help because they're not managing their child very well''

'I would say that the complexity of the children is now ten-fold higher. So, I would say they're definitely within a lot of families and are in almost all the families that we deal with, the behaviour is an issue massively, but unless they come into us, we don't know, do we''

'It can be behavioural factors of the child or young person as well. So, for instance, relationship difficulties within families which then are presenting as, you know, what might be described as violent behaviours of a child or young person. And all community-based

services have been tried and tested and therefore we're referring it to the local authority as a last point of – you know, please do something, please help, you know''

''And parents sometimes feel that foster carers are the safer option''

4.4.6.2 Voluntary placement by the parent

As has been mentioned already in this thesis, some parents place their children in care setting as they are unable to provide the specialist care that the child needs or are unable to deal with challenging behaviours associated with some of these NDDs. Several participants had observed parent's voluntary placing their children in a care placement as a result of personal circumstances and not always attributed to abuse and neglect. Some perceived parental capacity and the ability to manage the child's behavioural problems as an increasing factor for referral into services from a safeguarding perspective. However, this is based on only a few cases when working with these children and again it is a perception. The reality of the voluntary placement could have been as a result of other complexities that the social worker was unaware of.

''so, a parent voluntarily puts their child into the care of the local authority. And because they feel that the needs of that child are so complex or the experience of that child is so complex, that the local authority are best to care for their child other than themselves. Do you know what I mean? A very hard decision to make''

''we try and work with our parents in partnership as best as we can. But sometimes parents aren't able for whatever reason, because of their own needs''

''I think a lot of it is substance misuse, we have a lot lately of just struggling to deal with their behaviours, so not good enough parenting and not being able to parent the child, some people are phoning in themselves now for help because although some people see us as you're taking my child away, some people are phoning in for help because they're desperate because they can't parent their child as well so that's the other aspect of it as well. We have a lot of care and support cases where we're actually – they want our help because they're not managing their child very well''

Based on their experience when working with these children, several participants suggested that the referral age into services for this population was described as being frequent in the transition between childhood and adulthood. They observed that the parent was no longer able to safeguard them due to the child's behaviours. However, this is only based on their experience and was not described by other participants.

‘It’s usually that age group where their behaviour will become more challenging, and parents feel that they just can’t manage them for whatever reason, and so they will become looked after because of their behaviour in the community and the school, and conflict within the home, rather than abuse and neglect...parents just can’t keep them safe and they then get exhausted’

‘The children that are coming into our care now come into us older’

‘Usually girls come into that age group, and usually I would say anywhere between thirteen and fifteen’

‘Yeah, the engagement is different, ‘cos you know what teenagers are like’

‘I think you see more problems in adolescents where maybe families are needing support, whereas parents who are doing everything that they can but they’re just not able to... I think you’re seeing a bit more now where parents have parented perfectly fine and been okay but maybe their teenagers have – it normally happens, doesn’t it? Got involved with the wrong crowd, got involved in things that maybe they wouldn’t have expected, and they’ve lost parental control of them. Yeah, it’s not so much through neglect’

4.4.6.3 Parental mental health

Based on their experiences, some participants had observed that the prevalence of mental health problems had appeared to be increasing in the parents of some of these children, but this was just an observation. Perceptions were that this coupled with other complexities created even more challenges for some of the parents.

Researcher: 'I know it's really hard to say but estimate roughly, let's say how many in ten of the parents that you deal with would have mental health problems''

Participant: 'Oh I'd say at least six or seven, it's a big one, yeah. So, like even just the slightest like anxiety or depression, the slightest mental health difficulty which will coincide with other problems then, so it's always part of the package, mental health''

'it's definitely a big factor learning difficulties and mental health problems''

'I haven't had any children with schizophrenia or bipolar on my caseload, I've had parents''

'They've got mental health service which lots of our parents get referred to based on anxiety and depression''

'Bipolar, schizophrenia and borderline personality disorder is what we see all the time''

'I'd say that winter and Christmas is a hard month for everyone, I suppose the weather and stuff and the darker evenings parents – and depression, so mental health problems is a big one''

'And the lifestyle, what the parents experience, how they are etc. If they're in and out of prison. If they're substance misusers. If they've got mental health. Peer support networks. Yeah. Neglect''

4.4.6.4 Parental Physical Wellbeing

Several participants described how some of these parents had experienced physical, emotional and sexual abuse. These impacts on the physical and emotional wellbeing were suggested to be contributory factors to why a child was involuntarily removed from the biological parent/s.

'Well they talk about a toxic trio don't they, so mental health, substance misuse and domestic abuse, and I think these aren't always separate, they're sometimes interlinked''

I think drugs and alcohol are more prevalent. I think violence is more prevalent. There's a lot of support out there, but I think the early intervention, there's just not enough funding

there so loads of those have fallen away. And some people just get stuck in that rut, don't they?''

''So, we got sexual abuse. Emotional abuse is a big one and that can link in with obviously neglect. Mixing a lot with domestic violence''

''Yeah, neglect. Which links in with physical abuse. And emotional abuse. So yeah, neglect and like substance, you know, substance misuse, domestic violence''

''So, I'd say neglect, abuse, domestic violence, substance misuse and mental health and learning difficulties are the main ones''

''...emotional abuse really, and what we mean by that is usually domestic abuse, sort of being around those kinds of dysfunctional relationships''

One participant further explained that some children can be removed as a result of varying definitions of neglect.

''but neglect happens in all different – like we have some neglect cases who things like overfeeding your child, you wouldn't think that as neglect would you? And just leaving them in front of the TV, not giving them stimulation, all that contributes to neglect''

4.4.6.5 Parental Learning disabilities and difficulties

Based on their experiences working with these parents, several of the participants had observed that a lot of the parents they worked with had learning disabilities and difficulties. However, this again is based on perceptions and it cannot be ascertained if these parents had all been diagnosed with a learning disorder or difficulty. Several of the participants were very clear that it was not the learning disorders or difficulties that contributed to a child becoming looked after but frequently was attributed to the perceived poor parental capacity as a result of the associated challenges.

Researcher: ''In your opinion do you think parental mental health or disability has an impact on children entering the care system?''

“Participant: Yeah, definitely. Yeah, we’ve had a bit of a flurry of cases really where parents’ sort of learning issues have come into play... parents with sort of cognitive difficulties or like not low enough to get a service from adult services but they clearly have difficulties understanding information, retaining information –”

“But overall I would say yes, more generally it probably does have an impact on, you know, the amount of young people and children that are accommodated where parental mental health or disability is an issue, yes”

“...a lot of parents have struggled to read and write themselves and they find ways of covering that up really, you know, of kind of nodding and looking like they understand and kind of hiding the fact that their literacy skills aren’t there”

“...that was another thing learning disabilities of parents is a huge cause as well of – ‘cos that we do these assessments and then they just can’t – they can’t do it, they can’t parent. ...it’s normally learning difficulties coincide with a number of other problems, so because they’re vulnerable adults they’d maybe be associating with risky individuals, or they’ll have mental health problems coinciding, so it’s not just their learning difficulty on their own. Their learning difficulty is causing a whole lot of risk factors, because we try to support learning difficulties as we can, there’s a lot of support out there but it normally comes with a string of other factors as well”

“There’s quite a few that we’ve got where the parents have like learning disabilities or mental health disabilities, and just having that sometimes, they just struggle and can’t manage. You know, looking after a child then, and meeting all their needs. No doubt they loves them to bits, and we all know that. But they just can’t meet the needs good enough should we say”

“And sadly, I think so, because I think if you’ve got a mum – yeah, I think so because if she’s – her main concern is that she should have had, you know, say, you’ve got a mum who’s got a, you know, a low GCSE score and she’s vulnerable and she’s not had the services or support from her family that she needs. So, therefore she’s trying to be the best mum she can be but she’s not had the help that she needed, so it’s going to impact on the care of her children”

“Yeah, yeah, so they’re sort of in kind of no-mans land then, and we’re desperately trying to work with them and sort of trying to think of ways that we can communicate differently. And

some of them might have autistic traits as well, you know, in terms of their ability to understand – you know, we'll be trying to use sort of picture calendars and things to try and put together what's happening on what day and what needs doing for a child during the day, in order to kind of try and communicate with them in a way that they can benefit from. But yeah, I mean we've had a case – we've got a case in proceedings at the moment where we are removing that child from the parents' care because we just can't find a way to make it safe. And in some ways that feels horrible and unethical and, you know, they're not deliberately harming the child but they just can't safely look after him, he keeps getting injured''

Although, some participants expressed concerns for the parents with learning disabilities, difficulties and mental health issues, they expressed that every effort and every pathway was explored to first ensure that the child remained with the biological parent.

'I suppose it's – the reason why I'm hesitating is because if you'd asked me that maybe ten years ago, I'd probably be saying, oh yes, yes, yes, definitely. Like that has a terrible impact on the child or young person. So therefore, you know if that parent has those needs, and is unable to provide what the child needs then yes, you know, definitely. The reason why I hesitated now was because in – I suppose – in my position in the team, because I'm very alive to those things, I'm a bit more cautious and ask a lot more questions about it really. So from my own professional experience I would say we're very – we're very good at unpicking what that means, just because, you know, a parent may suffer with mental health or with learning disabilities doesn't necessarily mean that they're not able to provide for their child or young person. They may need additional support, but it doesn't mean that that can't be, you know, with a safety plan, safety network, identifying who else has the strength in that to support the parents then it's possible. So that's why I hesitated, 'cos I think on a professional level in our team we're very good at kind of doing that''

'sometimes parents have got learning disabilities, and they – although, you know, their children perhaps haven't had the best start it may not necessarily be because of any abuse or neglect has happened''

4.4.6 Parental Socioeconomic influences

Some literature proposes that many of these children are suggested to be at more risk because of their socioeconomic environment. Parental poverty, social deprivation and poor socioeconomic background were described as being risk factors associated with becoming a Lac with a NDD or without a NDD. However, this is based purely on their own individual perceptions.

“if you’re comparing to children from the same socioeconomic background, the same streets, the same parents with the same levels of education, I don’t know how different it would be, ‘cos most of the children that we work with there’s definitely a class divide, most children are coming from pretty low socioeconomic backgrounds, with parents that have got pretty – they’re pretty low attainment themselves for whatever reason”

“If you were going to give a number on that, percentage wise, what would you say roughly of that, of the children coming in were from a poor SES?”

“Ninety-five percent or higher”

“I think obviously it’s a lot to do with lifestyle and poverty and stuff like that isn’t it? And you know, parents have to struggle and can’t manage, and they usually will make the wrong choices and it’s the kids that suffer then isn’t it?”

“I think poverty is a massive contributing factor towards the reasons why children do become looked after. And the impact on parents on how they manage it all... the resources to manage that”

4.4.7 Cyclical behaviours and outcomes

As the study aimed to explore some of the outcomes associated with the Lac who has a NDD, exploring if any similarities existed in parental outcomes might further contribute to existing literature. Several participants had experienced the re-occurrence of similar family scripts with those families that they had worked with. They described how some of the Lac who had been placed in a later care setting had experienced similar health and social outcomes to

their biological parents. However, they also described how some Lac who had been placed in an earlier care setting had also attained similar if not identical outcomes. Areas such as abuse, neglect, domestic violence, teenage pregnancies, alcoholism and mental health were described as the main re-occurring outcomes from their perspectives and experience working with these families.

‘So I would say not great, if I could think of probably most of the looked after children that I’ve worked with over the years, obviously some of them I don’t know, the ones I worked with in ... and ..., but certainly the ones I worked with in ... and ... not great, often will go on to have children that are open to services themselves’

‘Yes, say with mental health, so often but they’ve grown up with families where mental health, you know, mental health is a family script’

‘Just a vicious circle, isn’t it? I suppose we do have a lot of teenagers – young teenagers and stuff like that, fifteen, sixteen, seventeen year olds who been in the system that are pregnant and they come back in and history repeating itself –’

‘Yeah. I mean it’s like you just hear the surname and you’re like, oh no’

‘from what I’ve seen of families there seem to be patterns of behaviour or how to be a mum or how to be a dad, you know, from, you know, families’ own experiences of being, you know, having a mum or having a dad’

‘And if there’s always been abuse in your family, you know, say, and, you know, we’re talking about kind of low-level examples here, but I guess for some families, you know, things are more violent and more aggressive and more traumatic. And there is, you know, patterns of sexual abuse and there are patterns of physical harm and they are worse than just a tap on the bum. They are proper beatings, you know, with bruises and cuts and, you know, alongside neglect-type issues. It’s a bit more of a serious pattern of a working model then, do you know what I mean?’

‘And when you’ve got maybe youngsters having children, you know, when you’ve got sixteen, seventeen-year-olds having children and they’re known to social services and then those children that they have, become known to social services by default or by assessment, then you then get more complex patterns of behaviour and that must be really hard to change’

“The case that I was on about with the older boy who’s been diagnosed and the younger boy with problems, their parents have got learning difficulties and mental health problems, so yeah that’s a big one, I would say that’s in a lot of cases it seems to be coming down”

“Yeah, I think if the child is pulled out of the family from a late age, definitely. If they’re younger and there’s not much contact then less so. But we’ve even got, if there’s children going into care in their early teens and stuff a lot of them just go running back to their parents anyway and still have that relationship with their parents, because and so they do end up, they do end up mimicking them”

“Yes, I’d say, which you kind of as soon as you hear of it you go, oh god, it’s that street or something, you know? Which is a judgement, but you tend to do it don’t you, yeah”

“... is huge geographically...is where we get more of our referrals and they all, all our cases are interlinked sometimes, they’re all friends with each other, that’s what we struggle with. And there’s cousins and things like that, because we do genograms”

“I did work with a young person who was – well she was born in a prison. Her mother was in prison when she was born so she was born in prison. So social services involvement was right the way through for her and she’s now had her own child removed from her and she’s in prison”

“So it is, you know, we’re learning systemically now that what they call scripts – so you will have a parent who has a child and how they have been brought up will determine how they bring their child up ‘cos that’s all they know. So they’ll either follow the same script as how they’ve been brought up, or they’ll think do you know what, that is totally wrong, and they’ll change the script because they know it was wrong. But a lot of people follow the same script, and it is how they have been brought up. Particularly in areas like home conditions and choice of partner”

“But I know the issues on that family recur, you know, in terms of neglect and domestic violence and alcoholism. I know that those patterns are still going on. It’s complicated, isn’t it? It’s really complicated”

4.4.8 Social worker challenges and needs

The main aim of the study was to explore the perspectives of social worker professionals on the subject area of NDDs and the challenges and barriers that Lac with a NDD might encounter or experience in areas of family, services and long-term outcomes. As many social workers are suggested to have heavy workloads and social care services are frequently suggested to be overwhelmed and underfunded exploring what support was available for the social workers themselves in relation to the subject of NDDs might contribute to further understanding of the needs of this group Several participants expressed their concern with having a limited knowledge of NDDs and other areas of their role.

4.4.8.1 Training Needs

Several participants highlighted that although limited training was available, it was not in-depth enough to be able to fully understand and support the conditions. The majority of participants expressed a keen interest to improve their knowledge of NDDs so that they could help better support the children and families.

“And that’s what I find difficult as a social worker sometimes is that we have all these conditions that we don’t know much about, where they’re coming from, and sometimes parents expect you to be experts in it and they expect you to come in, you’re either – either they’re blaming you for taking the child away”

“Well, when you’ve got a caseload in your twenties you haven’t got the time to do that. You haven’t got the time to give that. And then you’ve got to live with that guilt. You’re supposed to be an expert but you haven’t got the time”

“So, I think really specialist training would be really positive I think”

“As a social worker, I would like to know more. Within my role, we go on training. I don’t always come away from training knowing what I felt I needed to know”

“More specialised in this – in disorders, specifically”

“...we don't look at any of developmental trauma or psychological harm or the – I don't think you – in my training we didn't even look at the ACEs,..”

4.4.8.2 Resource challenges

Overall, the majority of the social workers felt satisfied and supported in their role and wellbeing. For some participants, workloads, retention problems and a lack of resources and time were perceived as prohibiting them from enhancing their knowledge in NDDs and other areas of their role.

“Well we have to do so much training a year, we have to do a number of hours, so we get sent training on a regular basis and then we get to choose what we attend, and –... Yeah, but it is difficult sometimes when they send us on five day training courses that will cause a massive backlash to our work then, we will be on catch up for days or weeks, that will cause chaos. So some – you have to do it, but it causes a lot of stress because even though it's useful having training you're thinking, oh my god, I've got to catch up on all this now”

“It would just be a reduced caseload and stuff wouldn't it, but there's no way about that, like the day training courses are good because it's one day, you can deal with that, but then normally the most useful ones and the ones that are going to properly develop your knowledge are the three day five day ones which are scary to apply for because you just don't want to fall behind with work, you know but yeah”

“we still have a retention problem. We still can't retain social workers”

“you change that by a commitment by local authorities, by the Welsh government saying, right, newly-qualified when they're in the child protection team should have a ring-fenced caseload of ten to fifteen families and no more. Sorry, ten to fifteen children, no more”

“And there's a commitment there to nurture and grow social workers...because that turns over and over and over and we never recruit, we never keep. And I think if we put more energy at that end with newly-qualified social workers and truly nurtured them and truly helped them understand and walked with them with some of these really complex cases, where you have more experienced social workers, you know, truly working with them, carrying cases alongside them”

4.4.9 Social worker suggestions

Gaining insight into the perspectives and experiences of social workers in relation to Lac with a NDD was the primary aim of the study. Recommendations based on their extensive experience and knowledge of Lac might contribute to wider literature needed to support Lac with a NDD. Effective, innovative and realistic suggestions for neurodevelopmental, mental services, educational provision and improvements in policy and processes were suggested.

4.4.9.1 NDD diagnostic and assessment process

Many participants expressed their wish to be part of the diagnostic and assessment process for several reasons. Being part of the process would enable them to further their understanding and knowledge of NDDs. Additionally, it would provide them with an opportunity to provide the clinician or multi-disciplinary team with supplementary detail and a holistic overview of the child's background and family environment.

“So, what we tend to do I suppose is – I can't imagine myself ever being experienced enough in ADHD or Autism to challenge a paediatrician. I do think that when the diagnoses are happening, maybe there should be a consultation with a social worker if Social Services are involved”

“ideal world we would be one, yes, going to those meetings. We'd be inviting the referrers especially if its children's services referring in that we would be invited to those multi-disciplinary”

“assessment meetings so that we could have an input there. I think a better understanding of one, why they don't see that some of what we are referring in is necessarily meeting their criteria”

“I think that we need to get better at assessing, I think, in, well, when social workers who work in child protection and safeguarding teams are assessing harm and looking at the probability of harm and the responses of that parent and the understanding of that parent, I think they need to, um, they need more experience and they need more understanding”

‘I just think if there was more training rather than an emphasis on diagnosing, if there was more training and more support, when we’ve had problems with carers and we’ve had therapists maybe go in where we’ve been able to commission and they’ve done the DDP work, that’s been really positive’

4.4.9.2 Child & adolescent mental health service (CAMHS)

Some participants based on their experiences had proposed that accessing CAMHS was not attainable unless the child was in crisis. Recommendations to change the CAMHS processes, environment and increase resource were suggested as a preventative and proactive response rather than a reactive response.

‘Yeah, if I think about CAMHS, I mean CAMHS won’t see people in their houses, people are expected to transport people to CAMHS, some foster carers won’t do it, some parents haven’t got access to do it, so just like a bit more flexibility around the services would be good wouldn’t it? And sometimes children don’t want to see people in clinical settings, because there’s all sorts of things that could – just a little bit more kind of flexibility about where people are at rather than where the services are would be good’

‘I’d employ a whole heap more staff to work in these child and adolescent mental health services. Because it just seems you’re waiting on appointments and the appointments are sometimes quite far away when you deem – ‘cos again I’m no expert in mental health, so you deem whatever you’re hearing has happened the day before to be quite an emergency’

4.4.9.3 Upskilling

Some participants expressed the need for access to a designated specialist in NDDs and mental health. This would enable them to upskill their knowledge of NDDs to be able to better understand how to approach the care plan for the child. Upskilling foster carers was also proposed to positively affect more stability in the care placement. One participant recommended a specialist contact directory that would enable quicker and more effective signposting and communication for earlier intervention and support.

“What I would like would be people who were properly trained to a reasonably high level, not just somebody to go in and have a chat... Now, if there was somebody who was qualified in mental health who had the time to build a relationship with her as well as me doing it, but I go out just to see how things are happening, but they went out once a week and she knew they were coming maybe on a Thursday at six o’clock for an hour, and that was her time to sit there and they could try and help her. I think that would be really beneficial”

“Well it would be perfect if we had those specialists, if they’re out there in our teams, so each team had their own specialist who knew the cases well, who could track them with you, who could work alongside you in the core groups and stuff and advise to the right services in that area, that would be perfect”

“And I think if we invested a bit more in that, in upskilling our foster carers and the people around who are working with the children in the response, then we would have better outcomes.”

“If we had like a directory, because sometimes I don’t know what services are out there, we don’t get told about services, and sometimes like later down the line, have you thought about this, well if I knew about that at the start I would have referred. Sometimes there’s services you don’t see advertised, they think social workers have got this book of all the services that are available but actually we don’t get told of half of them, so like someone who could give us a directory of certain “topics like ADHD and all the services that are available in this area, to access and how to refer to them, that would be really helpful, definitely. And someone to update it because we may have had that five years ago but there’ll be totally different services available now, you know, it needs to be updated regularly”

Some participants recommended placing a designated specialist in NDDs and mental health in the educational setting. This would ensure the child and family could access early interventional support to prevent the child and family going into crisis.

“Just more early intervention, resources, money, train loads of people up. Even in schools, you know, and stuff like that, have – like they’ve got wellbeing officers in schools, but actually I would like there to be somebody with mental health experience and brain development and stuff like that in school. Maybe do parenting classes”

‘I think I'd put additional staff in schools would be the main one as well. And new like parent and toddler groups and stuff like that, for when, you know, with the experience, and stuff like that. Just that early intervention so there's somebody there that can help or pick up earlier. Proactive instead of reactive’

‘Well yeah, definitely more talking therapists for children’ that aren't, you know, that aren't severely unwell but are experiencing emotional distress.

‘To speed up the assessment system for those ones that the schools can't do themselves and they can't put the support in...’

‘right for instance, my bugbear in my role is Personal Educational Plans, PEP meetings. Now, this is my way of learning. If I could have somebody from education to show me why, to train me why this is important, I'd be more focussed and interested in it, and I'd be able to pass that on to the children I work with. And I do listen in the meetings right, but the decisions are made above my head because I don't understand the process’

4.4.9.4 Processes and procedures

Many of the participants expressed their concern for the non-standardised processes and systems that were currently in place for looked after children. Knowledge transference of the child's needs and required support, created challenges that had a detrimental impact on the child's wellbeing and educational learning, particularly when the child moved between local authorities.

‘No, so it needs – I mean the problem at the moment is that there's no commonality across Wales with the service that young people get if they are looked after, which isn't right really, it's dreadful’

‘everyone should be doing exactly the same because it shouldn't matter where you're placed, should it, you should still get exactly the same service, the level of service and the level of support. Because these kids are disadvantaged, it doesn't matter how you dress it up, they're disadvantaged because they have become looked after, haven't they, so they absolutely deserve everyone doing their very best and I think that it's just absolutely shocking

that if you were placed in one country you have a slightly different service to someone placed in another country. It's appalling, absolutely appalling''

''Yeah, well everyone's on a database, everyone's on a database, but they're all different databases. And another stupid thing, I do PEPs with the kids, every child's got to have a PEP. Every county in Wales has got a different PEP... and I mean it's the same with, you know, going back to statementing children as well. Why should it be that every time a school change happens that there's not a way of passing on the information and that you don't have to start back at the beginning again?''

''I would make it that everyone talks to each other or systems talk to each other across Wales, because I think we lose – when children move, when children move county, I think we lose information because everyone's got a different system basically''

''They are paper format... It's a lump of paper and you give it to them. And like statementing is better because they all look the same, they do all look the same. But the pre – getting like the pre-statement, why do we have to have different assessments done again in different counties? You know, it's not –''

''At the very beginning there needs to be more prevention and more support around looking at the child as a whole rather than just looking at pigeon holes of particular things... well everybody needs to come together and share their thoughts, their ideas, and their assessment of the situation so it becomes a whole picture rather than just – yeah, very kind of seeing things through a particular lens. Well I mean certain local authorities do it from a safeguarding point of view. They've got what they call like MASH teams and stuff like this. And the MASH team's generally made up of social workers, police, health visitors – who else? Somebody representative from education... but it's like right at the front door stage. So, my thought is well why can't we do that when it comes to emotional mental health as well really''

4.4.10 Social worker recommendations

A summary of recommendations is detailed below. These front-line professionals have a unique, daily insight into the needs of Lac from a social, educational and psychological

perspective. Recommendations in areas such of NDD and mental health services, educational provision and improvements in policy and processes were made to better support the child and family and potentially reduce referrals.

1. Participants expressed a desire to have input into the diagnostic process or have a designated specialist social worker in NDDs to enable them to more quickly support the child and provide a holistic viewpoint of the child's behaviours and environmental influences.
2. Upskilling foster carers so that they could also have a better understanding of the biological, social and psychological influences associated with some of these conditions would benefit the support of the Lac.
3. The CAMHS process for mental health services needed to be significantly more accessible with clearer, transparent criteria. A proactive rather than reactive response would better support the child.
4. Creating a single point of contact for CAMHS, specifically for Lac would enable the social workers to access proactive interventions should they have mental health concerns. This would enable the Lac to access mental health services and support more quickly and reduce the risk of the child and family going into crisis.
5. Creating a specialist role in the educational sector with specialism in NDDs would aid in earlier identifying underlying mental health problems to better support the Lac within the educational setting, alleviating pressures on teachers, school counsellors and third sector charities and potentially ease the demands for CAMHS.
6. A more standardised process and system was suggested to address the challenges in sensitive knowledge transference, particularly when the child moved multiple times and into different counties. This would avoid duplication of work and ensure that the transfer of information could be utilised to prevent re-application for services.
7. Implementing more multi-disciplinary working models in different areas of health and social care sectors to share knowledge and best practice were proposed to be more effective to meet the needs of the Lac.

4.5 Discussion

This is the first small q qualitative study to explore the perceptions, knowledge and experiences of social workers on the subject area of Lac and NDDs. ADHD, ASD, dyslexia and dyspraxia were the most prominent conditions described. This study describes how social workers in these locales have experienced challenges in the understanding and comprehension of NDDs which is further impeded by in-accessible services, lack of professional knowledge and resource barriers to be able to fully support these children. Furthermore, it describes some detrimental impacts on the Lac with a NDD based on their experiences working with these children in areas of wellbeing and further explores wider factors that might create complexities and challenges for both the child and their parent/carers who look after these children.

At the beginning of the study, it was important to explore if any of these social workers had encountered working with these children who had a NDD. ADHD was described often, followed by ASD, dyslexia and dyspraxia. As detailed already in this thesis, literature in this area is dearth. The same can be said for governmental research. There are some but very limited government publications that have explored the prevalence of NDDs in Lac residing in Wales. It was reported that 10% of children had ASD in the latest ‘Wales Children Receiving Care and Support Census, 2019’ report (WAG, 2020). However, rates of ADHD, dyslexia or dyspraxia had not been reported. Existing research propose that the prevalence of NDDs is increasing and is estimated to be higher in this population (Parsons et al., 2019; Willis et al., 2017). A recent governmental publication in Northern Ireland show similarity in the literature findings and estimated that out of 12% of Lac who had a disability, 46% had ASD and 37% had a learning disability (Department of Health NI, 2021). This highlights a significant gap in data knowledge for Welsh policy to explore to ensure suitable service provision is provided for Lac who have ADHD and other NDDs in Wales.

Several of the participants had observed based on their experience working with these children that some NDDs appeared to be increasing in this population One participant however, suggested that cultural or societal influence may be influencing the perceived presence of ADHD in this population. While another, suggested he/she had noticed ‘patterns’ in diagnosis. Although, ADHD is now firmly rooted in psychiatry and documented in the DSM and ICD manuals there are still highly qualified psychiatrists that question if ADHD is real or as a result of complexities and environment (Timimi & Taylor, 2004; Witkowski,

2020). Others further propose that frequently attaining a diagnosis of ADHD although important, can deflect from exploring other trauma related behaviours (Karlsson & Lundström, 2021; Shah et al., 2017). Conversely, some studies have found that societal and cultural influences can have a detrimental impact on the individual with ADHD relating to factors such as misinformation from media, differential behavioural symptomology in diagnostic attainment, cultural and gender bias (Asherson et al., 2012; Fadus et al., 2020). To further add to these complexities the diagnostic assessment tools and diagnostic assessment pathways are still suggested to be varied which again create challenges (Huang et al., 2020; Kim, 2012; Mowlem et al., 2019; Quintero et al., 2019; Rynkiewicz et al., 2016).

Prevalence rates are needed to initiate adequate funding for service provision however equally important is having a social care service that has been supported to understand the complexity of these conditions to meet the individualistic needs of these children. The first theme in this study explores this area based on the experiences and perceptions of some social workers who have worked with these children. Limited knowledge and a lack of in-depth training was a major concern for many of the participants which had a negative impact on their wellbeing. Their perceived lack of knowledge and understanding of NDDs caused a lot of apprehension, confusion, frustration and stress as they were primarily responsible for the overall wellbeing of these children. The majority of participants expressed a desire to receive more in-depth training so that they could better meet the needs of the Lac with a NDD and support the parent/carer to develop a relevant and appropriate care plan.

Understanding what behaviours were attributed to trauma, attachment or an NDD was challenging, stressful and difficult for the participants as all share similar behavioural symptomology. This shows some similarity in some existing research where even specialised clinicians in NDDs, who are involved in the diagnostic process find difficulties in untangling what constitutes a NDD diagnosis (Karlsson & Lundström, 2021). Although attachment was not explored as a NDD, the term frequently arose in participant responses. The similarity in behaviours was confusing for these participants which they perceived to be attributed to a lack of in-depth training and lack of other professional understanding of NDDs. Bowlby's attachment theory is heavily influenced in social work training as understanding the impacts on the biological, neurological and psychological needs of the child who has experienced high level stress related to ACEs is paramount for these professionals (Bowlby, 1979; Fitton, 2012; Harlow, 2021). Conversely, it could be suggested that this could potentially create confusion and mask exploring the possibility of a NDD or vice versa. Particularly as

attachment in children with NDDs could reflect the biological, sensory avoidance or seeking patterns that these children display and not as a result of the ACEs (Little et al., 2018). Or they could be a combination of both. Screening tools for these NDDs are still heavily discourses in literature. Many screening tools are still suggested to lack sufficient specificity and sensitivity to diagnose NDDs, particularly if we take gender, age or cultural differences into account (Bourson & Prevost, 2022; Burns et al., 2022; Mulraney et al., 2021; Samadi et al., 2022). A more multi-disciplinary assessment, like that approach often used to diagnose ASD is suggested to contribute to a more rigorous diagnosis but even screening and assessment tools used in these instances have been known to underdiagnose, misdiagnosis or overdiagnosis, creating more confusion for diagnostic accuracy (Davidovitch et al., 2022; Pehlivanidis et al., 2020).

This confusion in diagnostic accuracy was reflected in some of the social worker's responses as they had experienced occasions where several Lac had been missed or misdiagnosed by clinicians which created a dilemma and distrust in the diagnosis, from the social worker's perspectives. Many expressed a desire to be part of the multi-disciplinary diagnostic process so that they may impart a more holistic depiction of the child's needs to contribute to the final diagnosis.. The majority of participants expressed their desire to attain more training in this area so that they could better meet the needs of the child with a NDD and develop an appropriate care plan which should be explored by Welsh policy.

Diagnosing or labelling a child with any social or clinical term can be controversial and has been known to generate differential emotive responses for the child, family, practitioner and professional (Ahmedani, 2011; Hinshaw, & Scheffler, 2014). Social workers have the first and foremost initial insight into supporting Lac and understanding their needs. They have to adapt the whole person approach and explore the physical, mental and social wellbeing of these children. As many of these children are often associated with a myriad of stigmatic labels, giving a child an additional diagnostic label generated a lot of discourse in responses (Government UK, 2021; Wood & Selwyn, 2017).

Some participants based on their experience working with these children, viewed diagnosis and labelling as a protective factor facilitating additional support, particularly in the educational setting. This was described as having had a positive impact on the wellbeing of the child from their perspective on their ability to learn and created more stability in the care setting. Conversely, some participants described how labelling the child could be potentially

detrimental and ineffective based on their experiences. They expressed concerns that based on their perceptions, attaining an NDD label might deflect from exploring other underlying difficulties or trauma that would require extra support for the child which is congruent with some literature (Karlsson & Lundström, 2021). Conversely, trauma or attachment related conditions may discourage clinicians from exploring underlying behaviours that might suggest a NDD which has been suggested in some literature (Pinto, 2019). Nevertheless, the majority of participants described how placing the child's needs and not the diagnostic label was at the centre of services and was viewed as a more effective future care plan for the child. Literature suggest that supporting the child with a NDD would differ in a care plan but trauma and attachment should also be explored to ensure the correct specialist support is provided for the Lac (Fuld, 2018; Richards, 2013; Rumball et al, 2020).

What was interesting to note is that in some responses, the ASD diagnosis was more readily accepted as a true diagnosis as it took a lengthy process and was diagnosed using a multi-disciplinary team. An ADHD diagnosis on the other hand created doubts. Perceptions were that it could be more easily attained and diagnosed by a paediatrician and medication more readily prescribed to help with behaviours. Diagnostic processes for ADHD differ on a global level so the findings cannot be generalised (Karlsson & Lundström, 2021). However, there is suggestion that ADHD is frequently over-diagnosed, misdiagnosed or missed altogether (Kentrou et al., 2019; Rodriguez et al., 2018). Conversely, other studies suggest that it can be just as difficult to attain, particularly for girls with ADHD (Fridman, 2017; Mowlem, 2019). More research is needed to explore ADHD in Lac and the challenging role of the social worker (Karlsson & Lundström, 2021).

Lac are suggested to have higher prescription and medication usage which has been highlighted already in this thesis. Exploring if this was reflective from a social worker perspective and based on their experience working with these children might further contribute to existing literature. Some NDDs, particularly ADHD are often treated with medication to reduce challenging behaviours, therefore, it was hypothesised that medication prescription might elicit conflicting thoughts and opinions (Mandell et al., 2008; Olfson et al., 2003; Raghavan et al., 2005; Rast et al., 2021; Scozzaro, & Janikowski, 2015). Some participants from an external perspective, viewed marked improvement in behaviours when medications were prescribed which secured a more stable care placement for the child and in the educational setting. This is congruent with another study that proposed that there had

been a decrease in foster care workloads as a result of the Lac receiving medication (Fallesen & Wildeman, 2015).

Conversely, some participants described how they had perceived medication exacerbating some behaviours and in some cases was found not to be required due to a positive care placement. Again, this finding is from an external perspective and there could have been a myriad of reasons that had impacted on the behaviours of the child. However, there is similarity in some existing literature that suggests that medication can frequently help behaviours or conversely exacerbate them or cause side effects (Alfageh et al., 2019; Cortese et al., 2018; Rossignol & Frye, 2014; Rubin et al., 2015; Popow et al., 2021; Toomey et al., 2012).

Several participants described how they valued a secure, stable care setting as a more positive option and medication as a last resort. As medication usage is proposed to be high in the Lac population, this should be further explored with other social work professionals as they are the ones who work closely with Lac and have a unique, privileged insight into their individual needs (Karlsson and Lundström, 2021).

As medication is only part of the intervention and process for some children with a NDD, exploring the opinions on what service provision and support was available in this locale might contribute further to existing literature. This included the Lac with a NDD, parent/carer, wider family and the social worker themselves. Early identification and intervention for any condition is an essential part of the process to empowering the child to thrive. For the Lac, service provision is an essential part of their care plan which requires access to specialist support. This includes engaging the parent/carer or other support networks. . An unexpected finding based on some of the participants responses were that they had experienced working with Lac, who had to wait lengthy times to access particular services and provision which conflicts with governmental aims for this population (Cardiff University, 2022).

Some described how diagnostic assessment and attainment for ASD varied from months to several years for some Lac and was described as a very lengthy process. They described how this had a knock-on effect on attaining early intervention and accessing specialist support. This shows some similarity in a recent report already detailed in the thesis which suggested that Lac with ADHD required more swift access to service provision (Government UK, 2020). In existing literature, for the child yet to be diagnosed; the process can be an arduous

and limitless struggle to understand and comprehend (Tierney et al., 2016). Their lack of understanding of the condition can often impact their peer relationships, create isolation and place them in vulnerable settings such as bullying, self-harm, sexual exploitation or at worst suicide (Bargiela et al., 2016; Hirvikoski et al., 2016; Tierney et al., 2016, Ung et al., 2016; Wei et al., 2015).

However, based on some of the social worker's experiences, even when the child had attained a diagnosis, they were discharged and referred on to third sector services which were perceived to be overwhelmed with requests. In existing literature, this lack of pre/ post support can leave the child with a NDD, parent/carer and wider family in crisis, putting immense strain on the family dynamic (Crane et al., 2016). This raises further questions for policy to explore if support is available for Lac with a NDD. As for the general population, this seems to be a reoccurring theme in research (Brookman-Frazer et al., 2012; Crane et al., 2016; Harpin, 2005; Karimzadeh et al., 2020).

Disconcertingly, were the accounts of perceived inaccessibility to CAMHS. Poor mental health and co-occurring mental disorders are significantly prevalent in the Lac population and in children with a NDD (Ford et al, 2007; Lai et al., 2019; Reale et al, 2018). Several participants based on their experiences working with these children described how the child was only able to access CAMHS if he or she had transitioned into a crisis situation. However, this finding conflicts with the dosReis et al (2001) study as Lac in that context had a higher usage of mental health services compared to their non-Lac peers. However, the recent report by the JTAIs, reflect the social workers' accounts of this qualitative study and found that Lac had to wait lengthy times to access mental health services (Government UK, 2020). Disparities between authorities in accessing services was also described as challenging, which is reflective of the frequent occurring postcode lottery for accessible services (Langley et al., 2014). Some of the accounts described how even when the child accessed CAMHS, many were discharged as the child's behaviours did not equate to a classified mental disorder. This lack of access to mental health services was a major concern for many of the social workers as it made some of them feel ineffective in their ability to support the mental health of these vulnerable children. From a preventative perspective, policy should further explore what other mental health service provision is available for a child with NDD (Government UK, 2020).

Accessing support services was described as being impeded by geographical location and moving multiple residential and educational placements. A postcode lottery was stated in some responses in relation to their experience working with these children. Disparities in services between counties and access to specialist services were described as particularly challenging for those who lived in more rural areas. Having frequent educational and residential moves can have a significant impact on both educational attainment and wellbeing (Hutchings et al., 2013; Perkins, 2017). Based on some of the social workers accounts, when the child moved placement, particularly out of county the whole diagnostic, educational or CAMHS process would have to restart, further adding to the lengthy, timely processes. It was stated that the transfer of information between counties and LA's for the child was exchanged as a file in paper format. Although, this cannot be generalised on a national level, this finding should be further explored as this has data protection implications and could hinder access to timely service provision. Being able to transfer sensitive information through a more appropriate, electronic means should be explored to enhance this process.

The stability and suitability of care settings for these children were discussed. Several participants, described how some Lac with NDDs, such as ADHD, for whom they were responsible for had been placed in multiple care placements and eventually in residential care as a result of the challenging behaviours that are often associated with this condition. Some of the parents had voluntarily placed these children in care as they felt this to be the safest option for the child. This shows similarity within other research where children with ADHD and ASD have been shown to be over-represented in residential care (Bartlett et al., 2021; Buescher et al, 2014; Karlsson and Lundström, 2021). This is also supported by the findings from the narrative review of this thesis where Lac with ADHD and ASD were more likely to be placed in a residential care home and are less likely to be placed in a familiar, kinship care setting compared to those with no disorder (Bilaver et al., 2013; Meltzer et al., 2003).

Literature suggest that there are some protective factors to these placements and many children without NDDs are additionally placed in residential care. However, more research is needed to explore whether specialist foster care or kinship care might better meet the needs of these children (Government UK, 2021a).

Many of the participants conveyed concerns based on their perceptions that a diagnosis might hinder opportunities for Lac to become fostered or adopted, attributed to the perceived behavioural challenges associated with these conditions. Although only perceptions and only based on a few participant responses, this is an area that might be something to explore in

future research. Children with a NDD are frequently stigmatised by societal perceptions as they are associated with significant behavioural, psychological and social challenges (Swaab et al, 2021). However, many are able to function extremely well on a daily basis with the correct support (Gunty, 2021). Literature suggest that by having an in-depth understanding and awareness of these conditions is often a protective factor required to support both the child and family to develop self-coping strategies that can be used throughout their lifetime, enabling them to be independent and reduce the need to access health and social care services (Gunty, 2021; Song et al, 2018).

As noted previously within this thesis, Lac continue to attain poor health and social outcomes. This sadly showed similarity in some of the social worker responses. Low educational attainment, residential placements, self-harm, mental health, substance misuse, inter-personal relationships and teenage pregnancies were described as being poor outcomes for some of these children. One social worker had seen some of the children progress to university but had left without completing their degree. This is reflective of some studies which broach questions around stigma around the label of Lac and a lack of support in educational settings (Evans et al, 2017; Long et al., 2017; Mannay et al, 2017). This raises questions for policy for exploration into what support is available for these children when they leave the care setting as already proposed by Evans et al (2017).

Lac was a term introduced by the Children's Act 1989 that was used to define, represent and safeguard these children (Simkiss, 2012). A decade later after the Act, research emerged which depicted a bleak portrayal of health and social outcomes for these children. High prevalence rates in special educational needs, poor academic attainment, learning disabilities, behavioural problems, mental health, early pregnancy and criminal system involvement (Mather et al., 1997; Gorin & Hayden, 1998). Some of the responses made by the participants in this small q qualitative study show similarity in the same bleak outcomes another two decades later. Research proposes that SES and family poverty are significant risk factors. However, many children who have been adopted from care still go on to attain similar health and social outcomes, even from a young age (Brown et al., 2017a; Hussey et al., 2012; Keyes et al., 2008). Therefore, it could be argued that the same pattern of outcomes must have some similar denominator which must be further explored. Although, if we consider the multifactorial complexities associated with these children, this might not easily be attained if ever.

In relation to these poor outcomes, several participants expressed significant concern around the subject area of county lines, sexual grooming and exploitation. The participant's concerns increased, when the child had been placed out of county which often left them more vulnerable. Some literature already proposes that children with a high amount ACEs or are looked after are at higher risk of experiencing sexual exploitation and human trafficking (Reid et al, 2018; Williams & Finlay, 2019). This raises further concerns and requires further urgent research not just for the Lac but with regards to Lac with a NDD. Children with ASD and ADHD can frequently find difficulties in social communication and developing healthy and safe relationships (Heifetz et al, 2020). Some find challenges in interpreting what is a friendship or a romantic relationship which can be easily manipulated into something riskier placing these children at even more risk (Brown-Lavoie et al, 2014, Brown et al., 2017b). Additionally, there is the risk that some children with ASD or ADHD frequently mimic peer behaviours and often adopt the behaviours to fit in, regardless of adversity (Chou et al., 2020; McVey et al., 2017). This is an area that requires more research in the context of the Lac with a NDD as they could potentially be at more risk compared to their Lac peers because of their associated challenges. As already detailed within this thesis, some Lac with varying NDDs are at higher risk of experiencing adverse outcomes associated with this area of sexual abuse.

The systems theoretical model dominates the social workers practical approach, when deciding whether a child enters a more long-term care setting or can be returned to the biological home (Barkley, 2009; Ward et al., 2014). Their initial responsibilities are to explore the parental capacity or capability, family background and environment that may have an impact on the child (Ward et al., 2014). Understanding if any behaviours are a result of the social, psychological or economic environment is critical to providing relevant support for both the parent/s and child (Ward et al., 2014). Abuse and neglect are the prominent primary reasons for referrals into services in the England and Wales (66% vs 59%). However, family dysfunction and family in acute distress account for 22% in England and 30% in Wales (Government UK, 2021b; Gov.uk, 2021b). The study aimed to explore if challenges associated with family might contribute to a child being referred into services and becoming looked after. Some participants described how the efficacy, mental, physical and social wellbeing of the parent, wider cyclical outcomes and socioeconomic influences might be some of the contributory factors for a child becoming looked after.

Some of the participants described how challenging behaviours had escalated in this population which sometimes affected parental capacity. They perceived the lack of support

and inability to manage the child's behaviours sometimes prompted the parents to make difficult decisions to safeguard their children. Some children with no signs of abuse or neglect had been voluntarily placed in care, as a way of ensuring that the child was kept safe. This reflects research conducted on the general population where parents who have children with NDDs have limited access to support which results in family disruptions and breakdowns (Brookman-Frazee et al., 2012; Harpin, 2005; Karimzadeh et al., 2020). Voluntary placements in care are frequent in Finland attributed to parental mental health or inability to manage the child's behaviour difficulties which is no reflection on the parent or the child (Kääriälä et al., 2021). Interventions and therapeutic treatments are the primary aim of social workers before an out of home care placement is even considered. However, in this study NDDs are yet again prominent in this population. Exploration into what service provision is available for Lac with a NDD and for the parents would contribute to a better understanding of the needs of these children and families.

Some of the participants highlighted how the transition between childhood and adulthood was a vulnerable time where referrals into care for these children increased. This is a tumultuous period for any child with the changes occurring on a physiological, biological, psychological and social level (Sawyer et al., 2018). However, the physical, mental and social challenges experienced by the child with a NDD are suggested to outweigh those that affect their peers with no NDD (Oswald et al., 2016; Rokeach & Wiener, 2020; Sedgewick et al., 2019; Young & Cocallis, 2021). This is often the period where areas of conflict and confusion occur for the child with a NDD as a result of the new social demands and interactions. The lack of control around the social environment, the new formation of social relationships and friendships become socially exhausting and increase sensory sensitivity and anxiety levels (Halsall et al., 2021; Oster et al., 2020). This social anxiety and impaired social interaction create feelings of confusion, frustration and fear which can often progress to angry outbursts and sometimes challenging behaviours (Bargiela et al., 2016; Chronis-Tuscano, 2022; Gerard, 2018; Tierney et al., 2016; Wilson et al., 2016; Young & Cocallis, 2021). It could be suggested that this could be a contributing factor explaining why children with a NDD end up in a care placement within the transition between childhood and adulthood.

The prevalence of poor mental health in Lac has always suggested to be higher compared to their peers (Kääriälä & Hiilamo, 2017; Ford et al., 2007; Meltzer et al., 2003). However, there is limited research on the mental or psychological profile of the parents of these children. Therefore, the study aimed to contribute to this research and explore this area from

a social worker perspective. Some participants based on their experiences perceived that the prevalence of mental health was increasing as well as mental and learning disorders/difficulties in parents of Lac who have children with or without a NDD.

They described how parental mental health and emotional wellbeing were intrinsically linked and were often associated with a detrimental impact on the physical wellbeing of the parents in areas of substance misuse, domestic abuse and sexual abuse, often co-occurring which led to the child becoming looked after. This is congruent with some literature and was described as the 'toxic trio' by one of the participants' responses (Holly & Horvath, 2012; Middleton & Hardy, 2014). Conversely, recent literature has suggested that this phrase is frequently used within the social work field and may sometimes be misused when assessing the familial situations and hinder further exploration of other potential underlying causes for the child becoming Lac (Morris et al., 2018; Skinner et al., 2021).

Although neglect was suggested to be as a result of the toxic trio in some cases, one participant expressed their opinion that neglect could be perceived in numerous ways. In this instance the participant discusses neglect in the form of overfeeding a child and leaving them in front of a TV. This might be the reality of the situation and therefore be perceived as emotional and physical neglect. However, one must also consider that in the context of a child with a NDD, this overfeeding and leaving them in front of a TV with no stimulation might be what the child requires on a physiological, social and emotional level (Hample et al., 2020). Children with ASD frequently experience problems with interoception dysregulation which impacts on their ability to interpret when they are either hungry or not (Hample & Amspacher, 2020). Therefore, it could be anticipated that overfeeding the child could be as a result of this sensory deficit rather than neglect as he/she would never stop feeling hungry which is very difficult to manage if not supported correctly. This may be true if we consider eating disorders such as bulimia or binge eating in individuals with both ASD and ADHD (Nickel et al., 2019). Additionally, leaving the child in front of the TV with no stimulation, could be as a result of the child being overwhelmed by social demands or sensory sensitivities occurring within the home or educational setting. The child with a NDD would frequently use similar behaviours to this to recharge and reduce sensory stimulation in an attempt to regulate their emotional responses (Stiller & Mößle, 2018). No approach or perception is wrong providing it meets the individualistic needs of the Lac. However, exploring the issues from varying perspectives would be beneficial to supporting the child in a holistic manner.

Several participants had experienced an increase in their workload with supporting parents with learning disabilities or difficulties during their extensive social work career. Some participants described how they had found that abuse and neglect were not frequently associated with parents with learning disabilities or difficulties but it was more about the lack of parental capacity that had raised concerns. The ability to process complex information or assess risky situations sometimes placed the parents themselves and their child/children in vulnerable predicaments. This was interesting as current research conducted by the Welsh Government found similarity in their research (Burch et al., 2019). The research additionally found that 41% of parents had ‘what appeared to be a mild learning disability including with reference to difficulties in: reading and writing, processing and weighing up information, retaining information / remembering things, and responding to instructions; and/or Autistic Spectrum Disorder’ (Burch et al., 2019, pp 50).

Parental capacity or efficacy can sometimes be affected by wider contributory factors that might initiate referral or place demands on services (Ward et al., 2014). Determining the parental capacity or capability is an integral dimension that forms part of the social worker role, when aiming to reunify the Lac with the biological parent, providing it is safe to do so. For the Lac with a NDD, the reunification process would require a specialised support and intervention to ensure that the placement would remain stable and safe as a result of the challenges often associated with some of these NDDs as mentioned already within this thesis. One could argue that if access to specialist support, interventions and NDD knowledge is still limited and not always attainable as has been suggested in the literature. this would have a significant impact on the parent being able to change or adapt their parental capacity or capability (Brookman-Frazer et al., 2012; Crane et al., 2016; Harpin, 2005; Karimzadeh et al., 2020).

Furthermore, in the context of understanding or attaining a NDD diagnosis for their child, consideration for the language used in parental questionnaires should be contemplated. Questionnaires such as the Conners’ Teacher and Parent Rating Scales (CTRS/CPRS) or semi-structured diagnostic interviews (Parent Interview for Child Symptoms and Teacher Telephone Interview) are used to pre-screen children for ASD and ADHD based on parental perspectives (Ickowicz et al., 2006; Kopp & Gillberg, 2011; Parker & Corkum, 2016). Terminology such as deviant, idiosyncratic, metaphoric are terms used within some of these questionnaires, that most individuals would find difficult to interpret. Understanding the terminology used in the questionnaires and how it applies to the child’s behaviours, both

currently and historically is critical information required for the diagnostic assessment of NDDs (Guthrie et al., 2013; Madsen et al., 2018). This lack of understanding or interpretation could potentially hinder or affect the outcome of the diagnostic assessment process if not correctly informed. This is likely to be more so for those parents who have extreme low educational attainment, learning difficulties or disabilities, particularly if they are unable to read and write which can often be the case (Burch et al., 2019).

Although, the concept of sociolinguistics was not explored in this study. One might consider the notion of restricted and elaborated codes in this instance (Bernstein, 1962). Basil Bernstein developed a sociolinguistic concept and theorised that the language of the working class was a restricted code and the language for the middle class was an elaborated code (Bernstein, 1962). It was ascertained that if an individual used and understood elaborate language within their social environment, they were significantly more likely to be able to articulate their needs, have increased social capital and social mobility (Sadnovik, 2001). Therefore, this potential linguistic barrier associated with the parents of Lac who have learning disabilities or difficulties could impede on the understanding of the diagnostic terminology, processes and accessible support. The participants were clear that they did not see the learning disability, difficulty or mental health as the main drivers for the child becoming a Lac but lack of reading ability and understanding created additional challenges for some of these parents.

Another interesting account made by some of the participants was the re-occurring family scripts and similar cyclical outcomes for children and families who were in the care system. One participant stated that genograms and inter-generational research into the families was a recent model that was being used to possibly identify pre-disposed vulnerabilities for early intervention. This is a model that is increasing in social work practice and has found to be beneficial in helping to support the Lac and family (Huss & Kapulnik, 2021; Majhi et al., 2018). One could suggest that this might appear a biased and pre-emptive approach. However, it does offer an alternative method for exploring re-occurring family scripts from a wider context which can be useful for a proactive or precautionary approach (Huss & Kapulnik, 2021; Firmin, 2019; Majhi et al., 2018). This proactive approach could be beneficial for earlier identification and intervention if we consider the re-occurring genetic or hereditary, biological implications of NDDs (Azeredo et al., 2018; Gialluisi et al., 2021; Grønberg et al., 2013; Kumar, et al., 2016).

Based on the participants experiences, dynamics such as poverty and a poor socioeconomic background were perceived to be major contributory factors to a child becoming looked after. In this study, it was quoted as being prevalent in 95% of this population and was a re-occurring theme in the findings. While this is only based on the perceptions of a few social worker responses, many studies have found that SES may be a contributory factor for a child becoming Lac along with the addition of ACEs which requires further exploration (Zilberstein, 2016; Simkiss, 2019).

Socioeconomic disadvantage and poverty are intrinsically linked as many individuals within society that hold low SES are more likely to face barriers on a structural, cultural, social and economic level, further hindering them from climbing the social ladder to improve their economic situation and increase human capital (Whiteman, 2014). This was reflected in some of the participant responses as they described how other contributing factors such as poor housing, lack of resources and access to services or just lacking the capacity to access services were further wider determinants that placed the Lac at further risk of becoming looked after. In terms of the Lac with a NDD, exploring if this risk could potentially be higher would contribute to the literature as they already face barriers on a structural, cultural, social and economic level (Häggman-Laitila et al., 2018).

A recently conducted study in Bradford explored associations between SES and having an ASD diagnosis. They found no association with SES but further proposed that the results of the study could suggest that individuals with a poor SES may be underdiagnosed (Kelly et al., 2019). Other studies have found differing results for both ASD and ADHD. Rowland et al (2018) found that SES combined with a parental history of ADHD did determine prevalence of the child with ADHD and Durkin et al (2017) found an association with low SES and ASD prevalence. However, both studies acknowledge that other environmental factors could have been contributory.

Social workers have to undertake, adapt and attain a multitude of key roles when supporting these children (Asquith et al., 2005). With the increase in workloads and lac of resource sometimes available, exploring the social workers own training and support needs was important as they are the primary contact for many of these children. The majority of the participants expressed content with their role and felt that their wellbeing was being supported which is a positive reflection of the visions laid out by the 'British Association of Social Workers (BASW)'. They valued and appreciated the multi-disciplinary approach and

shared responsibilities for the Lac which alleviated some pressures. which is reflective of some research (Bostock et al., 2018; Herod & Lymbery, 2002).

For some participants, resources, time restraints and retention of social workers were noted as challenges that prohibited them from pursuing their training needs. This was not an unexpected finding as the social worker's role is often associated with heavy workloads, lack of resources, including individual and organisational challenges (McFadden et al., 2015; Ravalier et al., 2021; Wacek, 2017). All participants had undergone continuous professional development in their roles and continued to do so but time available was very limited. Many expressed the desire to upskill their knowledge of not only NDDs but other areas of the role such as mental health to better understand the needs of the child and family or have access to specialists in this field. More training in county lines, technological advances, domestic and substance misuse were also considered necessary enhance their abilities to effectively undertake their role, which is reflected in other studies (Galvani, 2017; Minnick, 2021). County lines is relatively a new field of research and concerns for looked after children and children with mental health issues or disabilities are growing as they are often the target for county gangs as a result of their vulnerabilities (O'Hagan & Edmundson, 2021; Windle et al, 2020).

For the Lac with a NDD such as ASD or ADHD, the risks could potentially be higher as a result of the challenges associated with these disorders. Many children and adults with ASD or ADHD exhibit risky behaviours, lack awareness of dangerous environments and can be easily manipulated into risky situations as a result of their low self-esteem and poor peer relationships. These social challenges coupled with an innate need to conform and feel part of a social group, can create a vulnerability that perpetrators take advantage of using coercive tactics to recruit them. This in turn can lead to poor outcomes in substance misuse, drug and sexual trafficking and other dangerous situations (Christoffersen, 2022; Chronis-Tuscano, 2022; Roe-Sepowitz & Jabola-Carolus, 2021; Young & Cocallis, 2021). Research is still limited in relation to county lines and how it impacts the Lac in the UK, even more so in relation to the Lac with a NDD as they could potentially be at much higher risk.

The descriptive findings in this study have highlighted many challenges, barriers and potential complex social and environmental factors for Lac with a NDD. Although, this is only a small study, it does warrant further exploration in future studies from a national context.

4.6 Strengths and limitations

A key strength of this small q qualitative study is the use of purposeful sampling as social workers have a wealth of experience involving Lac in a wide range of health and social care sectors. Their insights and perspectives are unique but integral to research as they are able to provide research with an external perspective on working alongside these children. They additionally have a unique insight into the wider family challenges and social determinants that sometimes evolve around these children (Palinkas et al., 2015).

A semi-structured topic guide is an interactive method of research and can be theory generating; allowing social interaction to occur between the researcher and participant. However, this social interaction can sometimes negate the data as it can be influenced by the bias, values and beliefs of the researcher (Smith & Noble, 2014). To further address personal bias, I had open discussions with my colleagues, supervisor and I also internally reflected throughout the research process so as not to impose my ideology or thoughts (Haynes, 2012; Shufutinsky, 2020). However, this reflexive practice was not documented which would have strengthened this study.

However, these approaches raise potential biases which the study aimed to address. No requirements were specified to seek participants that did or did not have an in-depth knowledge of NDDs to reduce potential sample bias (Bethesda, 2001; Smith & Noble, 2014). However, the participants that did take part could have had a more in depth interest in NDDs which might have affected the findings with preconceived ideas of what the challenges and barriers were as opposed to having participants who did not have an interest. Recall bias could have been present in some of the participants responses however, the continuity of similar responses for some of the thematic categories would suggest otherwise. Finally, the study was a small sample and findings derived from only two local authorities. However, many of the responses detailed in the results do show some similarity in other findings in governmental reports (Burch et al., 2019; Government UK, 2020; Ward et al., 2014).

4.7 Key findings

Although these are detailed as findings, these are only based on the experiences and perceptions of a few social workers. However, the similarity in responses from two different LA's potentially highlight that some of these findings could initiate future research to contribute to existing literature in Lac with a NDD.

- Participants in this study had limited knowledge and training on NDDs which created challenges and their perceptions were that it impeded on their ability to meet the unique needs of the Lac with a NDD.
- Participants described how diagnostic processes and assessments were lengthy and that could sometimes take years to attain.
- Participants described how access to service provision, particularly CAMHS was not accessible for many Lac with or without a NDD.
- Participants described, based on their experiences that Lac with a NDD were often placed in multiple placements and are frequently placed in a residential care setting as a result of their unique and sometimes challenging needs.
- Participants expressed their concerns but only based on perceptions, that Lac who had been diagnosed with a NDD were perceived to be more difficult to fostered or to be adopted.
- Participants described, based on their experiences working with these children that Lac with a NDD or sometimes without, attain poor health and social outcomes in areas of low educational attainment, residential placements, self-harm, mental health, substance misuse and teenage pregnancies. Criminal involvement in the subject area of county lines, sexual grooming and exploitation were expressed as a deep concern.
- Based on perceptions and some experiences, participants described how complexities in parental efficacy and lack of specialist support place might place these children at higher risk for becoming looked after.
- Based on perceptions and some experiences, participants described how poor mental health, learning disabilities and difficulties appeared to be prominent and increasing in the biological parents of Lac with or without a NDD.
- Participants, based on their experiences described how they had seen cyclical outcomes for both biological parent and child in areas of abuse, neglect, domestic violence, teenage pregnancies, alcoholism and mental health. were noted as cyclical outcomes
- Participants, based on their experiences described how parental poverty, social deprivation and poor socioeconomic background appeared be a cyclical risk factors associated with becoming a Lac with or without a NDD.

4.8 Conclusion

The descriptive findings in this study highlight some of the complexities and intrinsic influences of varying theoretical models such as the systems theory and biopsychosocial models and how they may influence the social worker role when supporting these children (Barkley, 2009). The highlighted areas may be important to initiate further exploration from a national context and influential for those that support the Lac, the parent/carer and social worker. In the final chapter of this thesis, I consider and examine how these findings relate or not to the results found in the other chapters of this thesis and to wider existing literature.

Chapter 5: Electronic cohort study on Lac versus all children/young people in Wales

5.1 Introduction

The results of the thesis so far have shown that NDDs do exist in the Lac population and that they are significantly higher when compared to non-Lac. Therefore, this chapter investigates whether the prevalence rates attained from the meta-analysis for Lac reflect current estimates in Wales. It further examines whether there is similarity in several of the key findings detailed in the other chapters.in relation to service usage.

5.1.1 Background & rationale

Data Science has become a fast, developing and revolutionary method of extracting, analysing and interpreting big data (Blei & Smyth, 2017; Khoury & Ioannidis, 2014; Lerner et al., 2018; Zhang et al., 2017). Predominantly, it has been utilised in sectors such as business, social sciences, social media and engineering to attain as much possible, accurate, valid, quantitative results for predictive purposes and generate important insights (Adam et al., 2017; Shah et al., 2015; Zhang et al., 2017). More recently, attention has shifted to the area of health data science, with the recognition of the benefits that could arise from intrinsically linking the fields of medicine, biology and public health (Adam et al., 2017; Zhang et al., 2017).

Accessing enriched data in health statistics has historically been limited for varying reasons such as software and hardware compatibility, privacy and utility law and anonymity concerns (Adam et al., 2017). However, with the advancement of technology and the expansion of big data collection on a global level, health data science is becoming an exciting opportunity to gain access to new data that could provide integral insights into the wider health problems and service provision (Adam et al., 2017; Blei & Smyth, 2017). With the introduction of electronic databases, this new field of data science has already evolved and has begun to successfully identify individuals at high risk of disease, medical conditions and even psychological vulnerabilities (Lerner et al., 2018; Shah et al., 2015). It has been suggested that it has the capability to systematically attain quality and effectual data that will improve

health interventions and aid in protecting and safeguarding those that access the health services (Zhang et al., 2017).

As software and technology continues to advance, health data science has the potential to become a robust research methodology that could potentially analyse both qualitative and quantitative data simultaneously and potentially yield significant objective and statistical data to produce valid, reliable and robust results; in real time (Coulton et al., 2015; Zhang et al., 2017). Data science needs to have a strong alignment in statistics, computational and human involvement to interlink and achieve these results (Blei & Smyth, 2017).

Health data science has the capacity to yield significant results that could potentially revolutionise the health care industry. As the field of health data science progresses, it could bridge the knowledge gap between the health and social care sectors to advance services and interventions and further address issues that affect those most vulnerable in society (Coulton et al., 2015; Shah et al., 2015; Zhang et al., 2017). Nevertheless, as suggested, there are many challenges to overcome, address and consider, to ensure that the results of health data science are valid, robust and accurate for all that are involved in this process.

It is important to note that the data captured can only be valuable if the individuals who design, analyse and construe the data, have a good understanding of how it applies to the individual or groups that it represents (Khoury et al., 2014; Zhang et al., 2017). Therefore, to further improve the accuracy and results of the data, it is suggested that a multi-disciplinary joined up approach involving expertise in statistics, computing and all relevant professionals and service users should be an essential requirement for any future data science research project, particularly in healthcare (Khoury et al., 2014). Creating an information exchange, linking and sharing knowledge between sectors can only enhance the accuracy and validity of the results and create the most effective health care interventions and preventative measures (Adam et al., 2017; Zhang et al., 2017). Nevertheless, this sharing of knowledge creates new challenges to consider in the subject area of privacy and utility laws.

Privacy and utility laws are an area that needs full engagement in the field of health data science, particularly for those that fall under the most vulnerable in society (Zhang et al., 2017). Soria-Comas & Domingo-Ferrer (2016) suggest that areas such as consent, anonymity and transparency should be considered throughout the whole data science process. Although privacy is a complex area to address; anonymised data is suggested to be a possible way

forward. However, that also comes with unique challenges in areas such as linkage attacks and possible decreased utility (El Emam et al., 2015; Soria-Comas & Domingo-Ferrer, 2016).

Anonymity plays a critical role when conducting data science research into the social groups that are most vulnerable in our society (Zhang et al., 2017). Data science can further develop our understanding of wider social determinants, health outcomes and even the aetiology of health inequalities and gaps in knowledge; particularly for those groups who are most vulnerable in our society (Shah et al., 2015; Zhang et al., 2017). Lac are one of those most vulnerable groups in society.

5.1.2 Objectives

The increased prevalence of NDDs in children/young persons have had a significant impact on educational, health and social care service provisions in the general population (Crane et al., 2018; Ryder & Norwich, 2019; Young et al., 2021). Early identification and intervention are key components that are needed to meet the individualistic needs of these children/young adults to improve future health and social wellbeing (Manolova, 2017). However, timely service provision is still unattainable for many, leaving the child/young adult, parent/carer and wider family in confusing, complex and challenging environments (Crane et al., 2016; Sayal et al., 2015).

The individualistic needs of NDDs are unique and complex which require proactive, planning for specific, specialised support throughout the lifetime of the individual in education, health and social care settings (Koegel et al., 2014; McGoey et al., 2002; National Research Council, 2001; Root et al., 2022). Many children if not supported correctly, can frequently experience a detrimental impact on their mental, physical health and overall social wellbeing which frequently leads to poor mental health, debilitating anxiety, depression, sexual abuse, self-harm, suicide, eating disorders, family breakdown and potential exclusion from society (Bargiela et al., 2016; Fleming et al., 2020; Hatton, 2018; Hirjak et al., 2018; John et al., 2022; Kääriälä & Hiilamo, 2017; Tierney et al., 2016). The complex nature of NDDs coupled with the potential poor outcomes noted, place added urgency and emphasis on attaining a better understanding of their unique needs. Lac often come from a poor socio-economic background and have often experienced ACEs. Therefore, it is important to explore and

further understand the needs of this group, particularly from a preventative and safeguarding perspective.

Knowledge of Lac with NDDs is still extremely limited in literature in relation to areas of prevalence, associated risks and service needs on both a national and international level as has been evidenced so far in this thesis (Parsons et al., 2019; Pinto, 2019; Willis et al., 2017). There is currently no literature to date that has used linked administrative data to explore some of these areas in relation to the Lac with a NDD in Wales. For this novel study, looked after children (Lac) represent those children in looked after care settings but not children in receipt of care and support in Wales. All children/young people (Acyp) represent all children/young people in Wales. The study aims to address several questions:

- What are the prevalence rates, diagnostic ages, gender and ethnicity of the Lac population with a NDD compared with all children/young persons (Acyp) with a NDD in Wales?
- What is the service usage for both Lac with a NDD and Acyp with a NDD?

5.2 Methods

This study was detailed a priori by a ‘Information Governance Review Panel (IGRP) Protocol’ and was approved by the Secure Anonymised Information Linkage (SAIL) independent Information Governance Review Panel (IGRP) (Demmler et al., 2020). However, due to the extent of available data held within SAIL; the study had to limit the exploration of certain areas detailed within the protocol so that the focus could be aligned with the other sections of this thesis. See limitations section for more detail. The study is reported in line with the recommendations made in the RECORD extension of the STROBE checklist (Benchimol et al., 2015).

5.2.1 Study Design

There are often two types of study design, analytical and descriptive. This is an analytical study which uses an observational technique as it aims to observe an outcome, that is the prevalence of a NDD. Subtypes of observational studies can include varying designs such as cross-sectional, case controls or cohort and can be retrospective or prospective (Woodward, 2013). All have their strengths however the cohort study is usually considered to be a strong design but can have its own limitations (Hulley et al., 2013). Prospective cohort studies are considered to be the most robust as the measurements used can be predefined, to ensure risk factors are recorded correctly, as much as is possible. Retrospective studies, on the other hand have to depend on the data that are provided at that time which is not always consistent and does not always capture the risk factor if not recorded or identified (DiPietro, 2010; Hulley et al., 2013). Furthermore, selection bias can occur as the outcomes have already happened (Euser et al., 2009; Woodward, 2013).

Although, there are limitations to most designs, this study is a cohort study that compares two samples from one population and uses a retrospective approach to see who has developed the outcome of interest (Hulley et al., 2013).

5.2.2 Setting

The (SAIL) databank is a platform which holds a variety of health and administrative datasets and routinely collates data derived from both health and social care sectors in Wales. This was used to access data and information related to the objectives of this study. It is supported by the National Institute for Health Data Research UK (HDR UK), the data is treated in accordance with the Data Protection Act 2018 and complies with the General Data Protection Regulation. To protect the identity of individuals, a unique anonymised linking field (ALF_PE) is formulated using the individuals name, address or NHS number. Eight data sets were initially of interest for this study and were defined in the IGRP protocol prior to access. As the study aimed to explore two populations of interest (Lac versus Acyp), the Welsh Demographics Service Dataset (WDS) which holds anonymised demographics for all individuals in Wales who use NHS services, was used as the primary source to create the cohorts of interest. This is considered to hold the most up to date and reliable data and

enables linkage to other datasets using the ALF_PE identifier. Access to the recently added, Looked After Children Wales Dataset (LACW) was sought to enable a subset of unique ALF_PE to be linked to other datasets of interest to compare populations. This ALF_PE was used to identify the Lac within the other datasets. The episode level information in this dataset only captures those Lac who had been recorded as previously been Lac or were recorded as being a Lac between 2016-2018 based on census data but the temporal coverage data range in SAIL is between 21.06.99 – 31.05,2021. (see Table 5.1).

Access to the Children Receiving Care and Support Census (CRCS) dataset was also sought as it included the Lac variable. However, as it only contained three months of data in a year and did not include any children aged under 4; this was excluded from the study design. See limitations and recommendations for further detail.

The Welsh Longitudinal General Practice dataset (WLGP) captures information on general practice interactions from 333 out of 432 general practices in Wales. This GP data at the time of analysis covered 77% of all GP practices in Wales and was sought to explore the prevalence of NDDs (Demmler et al., 2020). This included examining the Patient Episode Database for Wales (PEDW) which also provides information on all in-patient admissions.

Access to the National Community Child Health Database (NCCHD) dataset was sought initially as it detailed variables associated with diagnostic codes for significant conditions. However, as the diagnostic codes could be accessed through WLGP and PEDW, and the age range was only 0-4; this dataset became exempt in the study design.

The Outpatient Referral Dataset (OPRD) which holds data on outpatient referrals from primary care to secondary care was used to explore the referrals and potential service needs of this population.

Finally, as the study aimed to explore the educational needs of these children, the Education Wales Dataset (EDUW) was considered the most appropriate dataset as it contains data for all schools and pupils in Wales, which include data on other educational settings such as Educated other than at School (EOTAS).

Data dictionaries are an integral part of the design process as they provide detailed information on the meaning and types of variables available within the datasets. Data classes are used to further group variables that share some common context. For this study, data dictionaries and data classes derived from various sources such as the ‘Health Data Research

Innovation Gateway' (HDRUK), SAIL platform and 'National Health Service' in Wales were used to validate the variables required for the analysis (HDRUK, 2020; NHS, 2021; SAIL, 2022). Input was also sought from the Welsh government statistical data collation team to ensure that the output was valid and reliable in terms of both the Lac and CRCS populations as they had only just been included in the SAIL databank. See **Table 5.1** for variables explored to link datasets.

Table 5.1 Characteristics of SAIL used to link datasets

SAIL Datasets	Temporal Coverage (date range)	Data Classes	Data variables	Definition of variable
Welsh Demographics Service Dataset (WDS)	01-01-1990 -26-07-2021	N/A	ALF_PE WOB	Anonymised linking field Week of birth
Looked After Children Wales Dataset (LACW)	21-06-1999 - 31-05-2021	LACW_PUPIL_ALF	ALF-PE WOB GNDR_CD	Anonymised linking field Week of birth Sex (gender) of individual
Welsh Longitudinal General Practice dataset (WLGP)	01-01-2000 - 01-07-2021	WLGP_GP_ALF_CLEANSED	ALF_PE GND_CD EVENT_CD EVENT_DT	Anonymised linking field Sex (gender) of individual Read code Date of the event
Patient Episode Database for Wales (PEDW)	01-04-1995 - 01-04-2022	PEDW_SPELL PEDW_DIAG	ALF_PE SPELL_NUM_PE DIAG_CD	Anonymised linking field Encrypted spell number ICD Diagnostic code

		PEDW_EPISODE	SPELL_NUM_PE EPI_STR_DT SPELL_NUM_PE	The start of an episode
Outpatient Referral Dataset (OPRD)	01-04-2009 - 01-07-2021	OPRD_REFERRAL	ALF_PE OPRD_CLIN_REF_DT OPRD_PAT_CLIN_REF_AGE_YEARS OPRD_PAT_ETHNIC_GRP_CD OPRD_TREAT_SPEC_CAT OPRD_TREAT_SPEC_DESC	Anonymised linking field The clinical referral date marks the start of a period for waiting for an outpatient consultation or treatment The age of the individual at the clinical referral date Ethnicity group code The category of the treatment code This is the speciality under which the individual will be or is treated

Education Wales Dataset (EDUW)	01-02-2004 - 09-07-2020	EDUC_PUPIL_ALF	ALF_PE	Anonymised linking field
			GNDR_CD	Sex (gender) of individual
			PUPIL_ID_PE	Local pupil identifier. One ALF_PE may have multiple PUPIL_ID
		EDUW_EOTAS_SEN	SENTYPE	Special educational need
			PUPIL_ID_PE	Local pupil identifier. One ALF_PE may have multiple PUPIL_ID
		EDUC_HIRU_EOTAS_PROVISION	CATEGORY OF PROVISION	Category of provision
			“YEAR”	Academic year of attendance
			PUPIL_ID_PE	Local pupil identifier. One ALF_PE may have multiple PUPIL_ID

5.2.3 Ethical Considerations

Ethical approval for this study was not required as the data collated was anonymised and could not identify individuals. An IGRP protocol had to be screened and approved by a (SAIL) independent Information Governance Review Panel (IGRP), which are members from the UK NHS Research Ethics Committee, experts in information governance and members of the public, prior to accessing the datasets (Demmler et al., 2020). However, to further protect the identity of the individuals a caveat is also included. Any number of events under 5 cannot not be disclosed in the results as that could potentially identify individuals, particularly for those with a rarer conditions or small samples like the Lac.

5.2.4 Participants

This cohort study compared two samples from one population using a retrospective approach to see who developed the outcome. (Hulley et al., 2013). The population for this study were children/young persons in Wales which consisted of 1,748,348 million children and young person's born between January, 1(1984) to December, 28 (2015) in Wales, aged between 3 and 21 years which only allowed data to be captured up to December, 31 (2018). The two samples were Lac who were children/young persons who had been placed in the care setting (Lac) and were recorded as looked after within the LACW dataset. The other sample was defined as Acyp which included all 1,748,348 million children and young persons in Wales which included the Lac sample. Children that are looked after (Lac) were defined as the exposure group and all children and young persons in Wales aged between 3 and 21 (Acyp) were defined as the unexposed group.

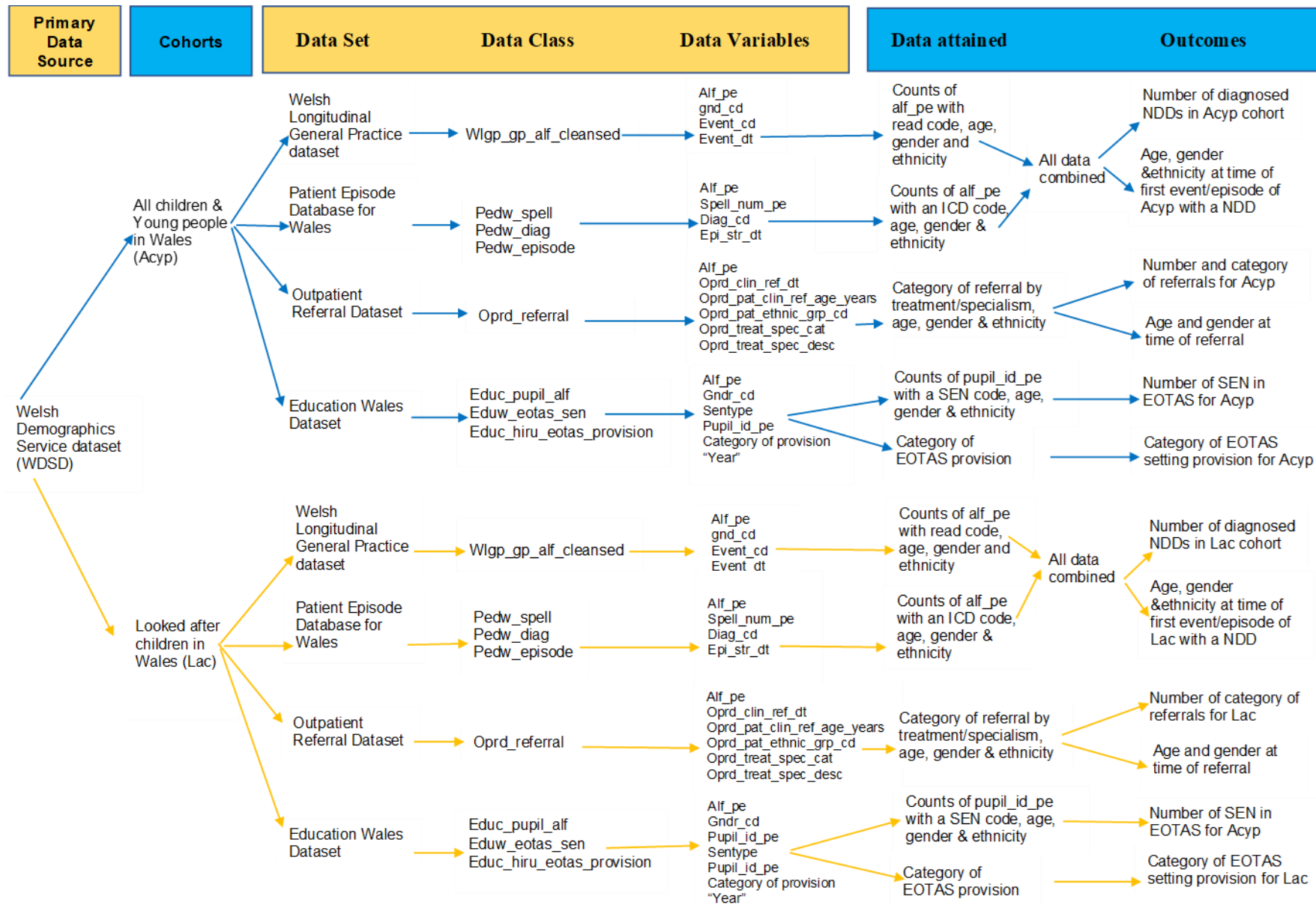
Rationale for this period is that legislation such as the Disability Act (2005) and subsequently, the Equality Act (2010) enforced and defined mental disability as a 'mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities'. These key legislative acts had a significant impact on data collation during this period (Boyd, 2012; Read et al., 2010). Further important legislation, section 98 of the Children's and Families Act' which placed duty and responsibilities on local authorities; allowing young people in foster care to remain in their placement until they turn

21. Subsequently, from April 2016; the Social Services and Wellbeing Act 2014, adopted this guidance as documented in part 6 of the act (Cardiff University, 2022). Research, understanding and awareness of these disorders has advanced dramatically over the last several years (Ornoy & Spivak, 2019; Ozonoff et al., 2018).

Many of these disorders can be diagnosed as early as two years of age, however, for many individuals, the diagnostic process can take up to ten years as a result of the complexity in behavioural symptomology (Ornoy & Spivak, 2019; Ozonoff et al., 2018). As the study was exploring lifetime prevalence attaining data up to the age of 21 would enable a more reliable estimate to be calculated.

Six datasets dated between January 1 (2005) and December 31 (2018), which included various data classes and variables were linked together by primary keys using IBM DB2 9.7 SQL. The flow diagram below details which datasets, data classes and data variables were linked to address the research questions. See **Figure 5.1**.

Figure 5.1 Flow diagram of SAIL linkage for looked after children & all children/young persons in Wales (Lac identified within the Acyp sample)



5.2.5 Definition of Outcomes

The NDDs of interest were examined using pre-defined and verified Read Version 216 diagnostic codes in primary care data (WLGP) and ICD-10 (1992) diagnostic codes in secondary care data (PEDW- hospital admissions). Read codes were validated using the same methodology outlined in the Health Informatics Trial Enhancement project which has provided a secure and efficient validation method for algorithms (Demmler et al., 2020). All clinical codes used can be found in **Table 5.2**. Individuals were only included if the ALF_PE had a probabilistic match of over 90%, including exact week of birth and gender. The first event/episode in PEDW or WLGP represents the first event/episode in which a NDD code was identified. This rationale for this was to avoid duplication as each ALF_PE can have duplicate records, as a result of accessing varying secondary care provisions through different pathways.

Table 5.2 Read & International Classification of Diseases (ICD) codes explored in SAIL

Category	Read Version 2 code	Description	ICD 10 codes	Description
Bipolar	XaY1Y	Bipolar 1 Disorder	F31	Bipolar affective disorder
	Eu310	Bipolar affective disorder, current episode hypomanic		
	E114	Bipolar affective disorder, current episode manic		
	E115	Bipolar affective disorder, current episode depression		
	Eu316	Bipolar affective disorder, current episode mixed		
Eating disorders	E271.	Anorexia nervosa	F50.0	Anorexia nervosa

	Eu500	Anorexia nervosa	F50.1	Atypical Anorexia nervosa
	Eu501	Atypical anorexia nervosa	F50.2	Bulimia nervosa
	E2751	Bulimia (non-organic overeating)	F50.3	Atypical Bulimia
	Eu502	Bulimia nervosa	F50.8	Other eating disorders
	Eu503	Atypical bulimia nervosa	F50.9	Eating disorder, unspecified
	E275.	Other and unspecified non-organic eating disorders		
	E2750	Unspecified non-organic eating disorder		
	E275y	Other specified non-organic eating disorder		
	E275z	Non-organic eating disorder NOS		
	Eu50.	Eating disorders		

	Eu50z	Eating disorders, unspecified		
	Eu50y	Other eating disorders		
Attention Deficit Disorders/Hyperkinetic disorders	E2E0.	Child attention deficit disorder	F90.0	Attention deficit with hyperactivity, hyperactivity disorder, syndrome with hyperactivity
	E2E00	Attention deficit without hyperactivity	F90.1	Hyperkinetic conduct disorder
	E2E01	Attention deficit with hyperactivity	F90.8	Other hyperkinetic disorder
	E2E2.	Hyperkinetic conduct disorder	F90.9	Hyperkinetic disorder, unspecified
	E2Ez.	Hyperkinetic syndrome NOS		
	Eu901	Hyperkinetic conduct disorder		
	Eu9y7	Attention deficit disorder		

Autism Spectrum Disorders/pervasive developmental disorders	E140	Infantile autism	F84.0	Childhood autism
	E1400	Active infantile autism	F84.1	Atypical autism
	E140z	Infantile autism NOS	F84.5	Asperger's syndrome
	Eu84.	Pervasive developmental disorders	F84.8	Other pervasive developmental disorders
	Eu840	Childhood autism	F84.9	Pervasive developmental disorder, unspecified
	Eu841	Atypical autism		
	Eu845	Asperger's syndrome		
	Eu84Z	Pervasive developmental disorder, unspecified		
Dyslexia	E2F02	Developmental dyslexia	F81.0	Specific reading disorder, developmental dyslexia
	E270.	Specific reading disorder	F81.1	Specific spelling disorder

	E2F00	Reading disorder unspecified		
Other scholastic disorders	Eu81.	Specific developmental disorders of scholastic skills	F81.9	Developmental disorder of scholastic skills, unspecified
	Eu81z	Developmental disorder of scholastic skills, unspecified	F81.8	Other developmental disorders of scholastic skills
Dyscalculia	E2F1.	Dyscalculia	F81.2	Specific disorder of arithmetical skills, developmental acalculia or arithmetical disorder, dyscalculia
Dyspraxia	E2F4.	Dyspraxia		
Other motor disorders/ Specific developmental disorder of motor function	Eu82.	Specific developmental disorder of motor function	F82	Developmental coordination, dyspraxia
Obsessive Compulsive disorder	E2030	Obsessive compulsive disorder	F42.8	Other obsessive-compulsive disorders

	E2032z	Obsessive compulsive disorder NOS	F42.9	Obsessive compulsive disorder, unspecified
	Eu42z	Obsessive compulsive disorder, unspecified		
TIC disorders	E272.	Tics	F95.0	Transient tic disorder
	E2722	Chronic motor tic disorder	F95.1	Chronic motor or vocal tic disorder
	E2723	Gilles de la Tourette's disorder	F95.2	De la Tourette
	Eu9y5	Stuttering [stammering]	F95.8	Other tic disorders
			F95.9	Tic disorder, unspecified
Reactive attachment disorder/ Disorders of social functioning with onset specific to childhood and adolescence	Eu941	Reactive attachment disorder of childhood	F94.1	Reactive attachment disorder of childhood
Schizophrenia disorder	E10.00	Schizophrenia	F20	Schizophrenia

Table 5.3 Special educational needs (SEN) & ‘educated other than at school’(EOTAS) variables (codes & definitions) used to explore EOTAS data

Special Educational Need (Code & Definition)	Educational other than at school (EOTAS) setting (Code & Definition)
DYSL SPLD – Dyslexia	PRU Pupil Referral Unit
DYSC SPLD – Dyscalculia	FEC Further education college
DYSP SPLD – Dyspraxia	SCH Maintained primary, middle, secondary or special school
ADHD SPLD – Attention Deficit Hyperactivity Disorder	NMS Non-maintained special school
MLD Moderate Learning Difficulties	TUI Individual tuition and tuition at pupils’ homes or at hospital
GLD General Learning Difficulties	GAT Youth Gateway
SLD Severe Learning Difficulties	WRE Work related education
PMLD Profound & Multiple Learning Difficulties	TPR Training providers
BESD Behavioural, Emotional & Social Difficulties	VOG Voluntary organisations
SLCD Speech, Language and Communication Difficulties	PSP Bought in private sector provision
HI Hearing Impairment	IND Independent schools
VI Visual Impairment	FEE Pupil attending provision not maintained by the authority, or outside of the authority, for which the authority pays
MSI Multi-Sensory Impairment	NIP Awaiting provision or not currently in provision
PMED Physical and Medical Difficulties	OTH Other
ASD Autistic Spectrum Disorders	
DNA Does not apply	

5.2.6 Data Cleaning

If data were available, a dataset table which included all the data from all the linked datasets was formulated individually for each NDD of interest to enable further analysis. The tables were then cleaned by removing all null values and any duplicates by the variable ALF_PE.

This ensured no individual had a duplicate diagnosis recorded for the same NDD, as a result of incorrect data input or processing. To keep within the IGRP protocol guidelines, any dates of first event/episode date before 2005 and after 2018 were removed. Ages of the individuals were also double checked by using the week of birth and date of event/ episode to ensure that the age limit between 3 and 21 was adhered to as outlined in the IGRP protocol. The same method was used for all formulated tables.

The EDUW dataset was explored as Lac are suggested to have a higher prevalence of special educational needs (SEN) compared to their peers (Oakley et al., 2018; Sebba et al., 2015). Furthermore, as already detailed within this thesis, children with a NDD can often have co-occurring learning disorders or difficulties and are often placed within specialist educational provision as they are unable to be supported in the mainstream setting (Thomas, 2013). However, due to a lack of unique ALF_PE held within the sub datasets and data classes of interest; this prevented the exploration of Lac and Acyp in the educational mainstream setting. The PUPIL_ID was readily available in the EDUW dataset and in the majority of the subsets, however this equated to extremely large numbers of rows as a result of one ALF_PE having several PUPIL_ID identifiers.

Therefore, the study linked the EDUW_ALF_PE to the EOTAS sub data sets using PUPIL_ID as primary key, as these were much smaller in size. Although, the ALF_PE was not available in the EOTAS sub datasets, the small numbers of PUPIL_ID detailed within this dataset made cleaning the data more manageable for analysis. A new data table was created. See **Figure 5.1** for data classes and variables used to link datasets to create tables for analysis. Data were only available for Lac and Acyp from 2010-2015.

The EOTAS table was cleaned following the same method as above. However, a child may have several ALF_PE's detailed if they remained within the same educational setting for several years or had moved during the year to a different educational setting. As no read or ICD codes were available in the data tables, the variables and codes for identifying children with a NDD were defined by special educational needs terminology collated by the EOTAS data collection guidance outlined by Welsh government (WAG, 2019). See **Table 5.3**. Age of Lac and Acyp did not require calculation as the ages fell within the inclusion age bracket (3-21).

5.2.7 Statistical methods

Data was then imported into SPSS and/or Microsoft Excel for analysis. Prevalence rates, age of event or first episode and gender were calculated and combined see **figure 5.1**. Odds ratio and 95% confidence intervals (CI) were used to estimate the mean effect (Bashir, & Conlon, 2018). Where the confidence intervals for odds ratio (OR) did not cross one and/or were narrow, these were considered to be significant. If the confidence intervals crossed one and/or were wide, they were considered to be inconclusive (or indicating no effect). Descriptive statistics were utilised to examine service referral needs, age, gender. Special educational needs and category of provision were described for Lac and Acyp in EOTAS setting.

All outputs were validated and reviewed by the SAIL team to ensure adherence to IGRP protocol, SAIL anonymisation and processes. No ethical approval or participant consent was required as the Institutional Review Board, UK NHS Research Ethics Committee was approved by SAIL IGRP before commencing the study.

5.3 Results

5.3.1 Participants

The two cohorts for this study were derived from the WSD dataset. The Acyp cohort was created, which consisted of 1,748,348 children and young persons (Acyp) born between January, 1(1984) and December, 28 (2015) in Wales, aged between 3 and 21 years which only allowed data to be captured up to 31-12-2018. The Lac cohort which consisted of 7,264 children, derived from linking the LACW dataset to the primary cohort (Acyp) by ALF_PE and WOB.

5.3.2 Outcomes

Nine NDDs with corresponding read or ICD codes were found within the SAIL datasets. These were Attention/deficit hyperactivity disorders (ADHD), Autistic spectrum disorders (ASD), Developmental disorder of scholastic disorders (DDSS), unspecified, eating disorders, (ED), Reactive attachment disorders (RAD), Tic disorders (TIC) and obsessive-compulsive disorder (OCD). Bipolar and dyslexia could not be explored as no prevalence in

Lac population. Dyscalculia and dyspraxia could not be explored as a result of data error within SAIL (all 75, 292 rows had the same ALF-PE). Schizophrenia was not found in the datasets but could have been attributed to the fact that this can be often diagnosed later in life (Fountoulakis et al., 2022).

As a result, each NDD was individually explored and analysed. Sixteen data tables were created, using SQL query language, which included 7 for Lac and 7 for the Acyp population. All codes found are detailed in **Table 5.4**. This included 2 more separate tables for exploring Lac and Acyp with a SEN in the EOTAS setting. Results were then compared. Some data relating to the NDDs that could be analysed are not disclosed as a result of small numbers that could be used to identify the individual. See **Table 5.4** for more detailed information.

Table 5.4 Read & ICD codes found in SAIL datasets

Category	Looked after children		All children/young persons	
	Read code	ICD code	Read code	ICD code
Attention/ Deficit hyperactivity disorders	E2E01	F90.0	E2E00	F90.0
	Eu901	F90.9	E2E01	F90.1
	Eu9y7		Eu901	F90.8
			Eu9y7	F90.9
Autistic Spectrum Disorders	Eu840	F84.0	E1400	F84.0
	Eu841	F84.1	E140z	F84.1
	Eu84	F84.5	Eu840	F84.5
	Eu84z	F84.8	Eu845	F84.8
			Eu84z	F84.9
Scholastic disorders	Eu81Z	F81.8	Eu81Z	F81.8
		F81.9		F81.9
Dyslexia	-	-	E2F00*	F81.0*
	-	-	EzF02*	F81.1*
Dyspraxia	N/A	N/A	N/A	N/A
Dyscalculia	N/A	N/A	N/A	N/A
Eating disorders	Eu500	F50.0	Eu500	F50.0
	E275y	F50.2	Eu501	F50.1
	Eu50z	F50.8	E2751	F50.2
	Eu50y	F50.9	Eu503	F50.3
			E2750	F50.8
			E275y	F50.9
			E275z	
			Eu50z	
		Eu50y		
Reactive attachment disorder	Eu941	F94.1	Eu941	F94.1
Tic disorders	E2723	F95.1	E2722	F95.0
		F95.2	E2723	F95.1
			Eu9y5	F95.2
				F95.8
				F95.9
Obsessive Compulsive disorders	**	**	E2030	F42.8
			Eu42z	F42.9
Bipolar	-	-	Eu310*	F31*
NB. Codes highlighted in bold had the highest prevalence in each category of disorders				
(-) No data in Lac population				
(*) Could not be compared to Lac population				
(**) Numbers for codes too small to disclose				
(N/A) Data error in SAIL				

5.3.3 Main results

5.3.4 Prevalence of NDDs

The results show that at the time of data collation, Lac had a higher prevalence of ADHD (3.4 v 0.2%), OR = 14.9 [13.1-17.0], ASD (4.0 v 0.5%), OR = 8.97 [7.9-10.1], DDSS (4.1 v 0.3%), OR = 16.8 [8.9-14.9], ED (0.3 v 0.1%) OR = 3.4 [2.2-5.1], RAD (0.5 v 0.0%) OR = 84.7 [57.3-125.3] and TIC disorders (0.3 v 0.0%), OR = 6.9 [4.5-10.6] compared to their peers who were not looked after at the time of the data collation (Acyp) in Wales. OCD could not be compared as count could not be disclosed, due to small numbers. No comparisons were made for bipolar, dyslexia, dyspraxia and dyscalculia as they had zero counts in the Lac population. No other NDDs were found (See **Table 5.5**).

Table 5.5 Prevalence of neurodevelopmental disorders in Looked after children and All children/young people (Acyp) in Wales

Condition	Looked after children in Wales (n = 7,264)		All children & young people in Wales (n = 1,748,348)		Odds Ratio, 95%CI
	Event	Prevalence %	Event	Prevalence %	
Attention/Deficit hyperactivity disorders	250	3.4	4149	0.2	14.9 [13.1-17.0] *
Autistic spectrum disorders	293	4.0	8153	0.5	8.97 [7.9-10.1] *
Developmental disorder of scholastic skills, unspecified	300	4.1	4458	0.3	16.8 [8.9-14.9] *
Eating disorders	24	0.3	1683	0.1	3.4 [2.2-5.1] *
Reactive attachment disorder	34	0.5	97	0.0	84.7 [57.3-125.3] *
Tic disorders	22	0.3	761	0.0	6.9 [4.5 -10.6] *

(*) $P < 0.0001$
 No available data for bipolar, dyslexia, dyspraxia & dyscalculia

As governmental data had only captured children who were Lac or had become Lac between 2016-2018, the prevalence of NDDs captured for both populations were further explored between the dates of 02.01.2016 – 31.12.2018. The findings below still show that Lac had a higher prevalence within this period. The results show that at the time of data collation, Lac had a higher prevalence of ADHD (1.3 v 0.1%), OR = 18.1 [14.6-22.3], ASD (1.3 v 0.2%), 6.5 [5.3 - 8.0] and DDSS, unspecified (1.4v 0.1), OR = 24.9 [20.3-30.5] ED, RAD and TIC disorders had zero counts. (See **Table 5.6**).

Table 5.6 Prevalence of neurodevelopmental disorders in Looked after children and All children/young people (Acyp) in Wales–between 2016-2018

Condition	Looked after children in Wales (n = 7,264)		All children & young people in Wales (n = 1,748,348)		Odds Ratio, 95%CI
	Event	Prevalence %	Event	Prevalence %	
Attention/Deficit hyperactivity disorders	93	1.3	1254	0.1	18.1 [14.6-22.3] *
Autistic spectrum disorders	94	1.3	3517	0.2	6.5 [5.3 - 8.0] *
Developmental disorder of scholastic skills, unspecified	102	1.4	1000	0.1	24.9 [20.3-30.5] *

(*) $P < 0.0001$
 No available data for eating disorders, reactive attachment disorders & Tic disorders

5.3.5 Mean age and gender of first event/episode of Lac versus Acyp

The mean age of the first event or episode for all Lac males with a NDD ranged between 8.6 v 12.0 yrs and Lac females ranged between 10.5 v 14.5 yrs. The mean age of the first event or episode for all Acyp males with a NDD ranged between 10.1 v 15.5 and Acyp females ranged between 12.2 v 17.1 yrs. Male gender was significantly over-represented in the prevalence of

all NDDs for both groups, with the exception of eating disorders, which was predominantly female. However, descriptively, females had a much later first event/episode than males for all NDDs in both groups. See **Table 5.7**. Ethnicity was not detailed due to a significant amount of missing or withheld data, which would have decreased the validity and reliability of this study's findings. Events and age corresponding with Lac who had Tic, OCD and ED were not presented due to small numbers that could identify individuals. However, it was still important to include the statistics for Acyp to contribute to existing literature on NDDs. A two sample T test was conducted on ADHD, ASD, RAD and ED using mean age. Apart from RAD, all had significant P values.

Table 5.7 Mean age and gender for Lac and Acyp with a neurodevelopmental disorder

		Looked after children (n = 7,264)		All children/young people (n = 1,748,348)		
	Gender	Count (%)	Age *	Count (%)	Age*	P value
ADHD	M	194 (77.6)	10.8	3217 (77.5)	12.5	P < 0.001
	F	56 (22.4)	12.9	932 (22.5)	14.0	
ASD	M	227 (77.4)	9.1	6291 (77.1)	10.1	P < 0.001
	F	66 (22.5)	11.6	1872 (22.9)	12.2	
DDSS, unspecified	M	190 (63.3)	9.9	2678 (60.1)	12.3	P < 0.001
	F	110 (36.7)	10.5	1780 (39.9)	13.5	
Eating Disorders	M	-	12.0	209 (12.4)	14.0	P < 0.002
	F	-	14.5	1474 (87.6)	16.9	
RAD	M	18 (52.9)	8.6	50 (51.5)	10.3	P < 0.26
	F	16 (47.1)	13.2	47 (48.5)	12.9	
Tic disorders	M	-	-	605 (79.5)	11.9	N/A
	F	-	-	156 (20.5)	12.4	
OCD	M	-	-	130 (43.5)	15.5	N/A
	F	-	-	169 (56.5)	17.1	

(*) Mean age of first event/episode in years

(-) Data could not be disclosed

Bipolar & dyslexia had zero counts for Looked after children

ADHD – Attention/deficit hyperactivity disorders, ASD – Autistic spectrum disorders, DDSS – Developmental disorder of scholastic skills, RAD – Reactive attachment disorder, OCD- Obsessive compulsive disorder

P<0.05 is significant

5.3.6 Service provisional needs

The study attained data for all service referrals made for both Lac and Acyp with ADHD, ASD, DDSS, ED, RAD, TIC and OCD disorders. It is important to note that these referrals were coded at the start of a period for waiting for an outpatient consultation or treatment. However, as both groups had counts of service referrals which had small numbers which could not be disclosed as a result of small numbers to protect the identity of the individual. The results only show the first ten primary unique referrals made to secondary care for both groups. Descriptive tables for all NDDs found are detailed below. OCD could not be compared as count could not be disclosed, however the Acyp data was still detailed to contribute to existing NDD literature on the general population. CAMHS and paediatrics were the most common referrals for both groups. CAMHS was the primary referral for both Lac with ADHD, ED, RAD and TIC disorders. It was also the primary referral for Acyp with ADHD, ED, RAD and OCD. Paediatrics was the primary referral for Lac with ASD and DDSS. It was also the primary referral for ACYP with ASD, DDSD and TIC.

5.3.6.1 Attention/Deficit hyperactivity disorders (ADHD)

The ten primary unique referrals made to secondary care for Lac and Acyp with ADHD are as detailed below in **Table 5.8**. The highest primary referral for both groups were Child and Adolescent Psychiatry with Lac having a higher percentage of referrals (35.4 v 20.7%). Lac also had a later mean referral age (12.9 v 12.2 yrs).

Table 5.8 Top ten service referrals for ADHD

Looked after children			All children/young people		
Service	Count (%)*	Age (yrs)**	Service	Count (%)*	Age (yrs)**
Child & Adolescent Psychiatry	494 (35.4)	12.9	Child & Adolescent Psychiatry	3794 (20.7)	12.2
Paediatrics	269 (19.3)	11.5	Paediatrics	3250 (17.8)	10.3
Trauma & Orthopaedics	152 (10.9)	12.8	Trauma & Orthopaedics	2718 (14.8)	14.1
ENT	94 (6.9)	11.8	Adult mental illness	1451 (7.9)	19.3
Ophthalmology	61 (4.4)	10.0	ENT	1413 (7.7)	11.9
Adult mental illness	38 (2.7)	18.7	Ophthalmology	763 (4.2)	10.4
Oral Surgery	34 (2.4)	13.2	Oral Surgery	617 (3.4)	15.0
Learning disability	33 (2.4)	12.2	Dermatology	411 (2.2)	14.1
Dermatology	30 (2.2)	12.6	General surgery	395 (2.2)	15.2
Paediatric Neurology	24 (1.7)	10.8	Gynaecology	363 (2.0)	18.4

(*) Represents percentage for all referrals hence no 100%

(**) Mean age of referrals for male and females

5.3.6.2 Autistic Spectrum disorders (ASD)

The ten primary unique referrals made to secondary care for Lac and Acyp with ASD are as detailed below in **Table 5.9**. The highest primary referral for both groups were Paediatrics with Lac having a higher percentage of referrals (26.8 v 24.1%). Lac also had a later mean referral age (10.3 v 9.5 yrs).

Table 5.9 Top ten service referrals for Autistic Spectrum disorders (ASD)

Looked after children			All children/young people		
Service	Count (%)*	Age (yrs)**	Service	Count (%)*	Age (yrs)**
<i>Paediatrics</i>	323 (26.8)	10.3	<i>Paediatrics</i>	4931 (24.1)	9.5
<i>Child & Adolescent Psychiatry</i>	218 (18.1)	12.0	<i>Child & Adolescent Psychiatry</i>	3440 (16.8)	11.4
<i>Trauma & Orthopaedics</i>	102 (8.5)	12.5	<i>Trauma & Orthopaedics</i>	2150 (10.5)	12.9
<i>ENT</i>	96 (8.0)	10.6	<i>ENT</i>	1758 (8.6)	10.5
<i>Learning disability</i>	91 (7.5)	13.0	<i>Ophthalmology</i>	1023 (5.0)	9.9
<i>Paediatric Neurology</i>	53 (4.4)	10.6	<i>Oral Surgery</i>	843 (4.1)	13.3
<i>Oral Surgery</i>	53 (4.4)	12.9	<i>Learning disability</i>	761 (3.7)	14.8
<i>Ophthalmology</i>	53 (4.4)	8.9	<i>Adult mental illness</i>	619 (3.0)	19.2
<i>Restorative dentistry</i>	35 (2.9)	13.3	<i>Dermatology</i>	619 (3.0)	13.0
<i>Dermatology</i>	24 (2.0)	12.7	<i>General surgery</i>	489 (2.4)	14.6

(*) Represents percentage for all referrals hence no 100%

(**) Mean age of referrals for male and females

5.3.6.3 Developmental disorders of scholastic skills, unspecified (DDSS)

The ten primary unique referrals made to secondary care for Lac and Acyp with DDSS, unspecified are as detailed below in **Table 5.10**. The highest primary referral for both groups were Paediatrics with Lac having a higher percentage of referrals (29.9 v 22.3%). Acyp had a later mean referral age (10.0 v 9.9 yrs).

Table 5.10 Top ten service referrals for Developmental disorder of scholastic skills (DDSS), unspecified

Looked after children			All children/young people		
Service	Count (%)*	Age (yrs)**	Service	Count (%)*	Age (yrs)**
Paediatrics	557 (29.9)	9.9	Paediatrics	4718 (22.3)	10.0
Child & Adolescent Psychiatry	264 (14.2)	12.9	Trauma & Orthopaedics	2773 (13.1)	13.0
Trauma & Orthopaedics	209 (11.2)	11.3	ENT	1896 (9.0)	11.0
ENT	147 (7.9)	9.9	Child & Adolescent Psychiatry	1711 (8.1)	12.3
Ophthalmology	109 (5.8)	9.3	Ophthalmology	1389 (6.6)	10.2
Learning disability	90 (4.8)	13.4	Oral Surgery	880 (4.2)	13.8
Paediatric neurology	73 (3.9)	10.0	Learning disability	805 (3.8)	15.5
Oral Surgery	52 (2.8)	11.2	Dermatology	613 (2.9)	13.6
Restorative dentistry	39 (2.1)	13.7	Paediatric neurology	578 (2.7)	9.7
Paediatric surgery	24 (2.0)	8.5	Neurology	536 (2.5)	18.5

5.3.6.4 Eating disorders

The ten primary unique referrals made to secondary care for Lac and Acyp with ED, are as detailed below in Table 5.11. The highest primary referral for both groups were Child & Adolescent Psychiatry with Lac having a higher percentage of referrals (50.9 v 23.4%). Acyp had mean referral date age (15.0 v 14.8 yrs).

Table 5.11 Top ten service referrals for eating disorders (ED)

Looked after children			All children/young people		
Service	Count (%)*	Age (yrs)**	Service	Count (%)*	Age (yrs)**
<i>Child & Adolescent Psychiatry</i>	86 (50.9)	14.8	<i>Child & Adolescent Psychiatry</i>	1174 (23.4)	15.0
<i>Trauma & Orthopaedics</i>	23 (13.6)	14.7	<i>Adult mental illness</i>	601 (12.0)	19.3
<i>Paediatrics</i>	12 (7.1)	14.6	<i>Paediatrics</i>	581 (11.6)	13.8
<i>Adult mental illness</i>	9 (5.3)	18.0	<i>Trauma & Orthopaedics</i>	548 (10.9)	15.5
<i>ENT</i>	9 (5.3)	14.1	<i>Gynaecology</i>	261 (5.2)	19.1
<i>Ophthalmology</i>	7 (4.1)	14.2	<i>ENT</i>	220 (4.4)	14.7
<i>Gynaecology</i>	-	-	<i>Dermatology</i>	168 (3.4)	16.4
<i>Orthodontics</i>	-	-	<i>Ophthalmology</i>	159 (3.2)	16.0
<i>Dermatology</i>	-	-	<i>General surgery</i>	123 (2.5)	18.2
<i>Paediatric dentistry</i>	-	-	<i>Oral Surgery</i>	115 (2.3)	17.8

(*) Represents percentage for all referrals hence no 100%

(**) Mean age of referrals for male and females

(-) Data cannot be disclosed for identification reasons

5.3.6.5 Reactive attachment disorders (RAD)

The ten primary unique referrals made to secondary care for Lac and Acyp with RAD, are as detailed below in **Table 5.12**. The highest primary referral for both groups were Child & Adolescent Psychiatry with Lac having a higher percentage of referrals (41.8 v 32.9%). Lac also had a later mean referral age (15.2 v 14.7 yrs).

Table 5.12 Top ten service referrals for Reactive attachment disorders (RAD)

Looked after children			All children/young people		
Service	Count (%)*	Age (yrs)**	Service	Count (%)*	Age (yrs)**
Child & Adolescent Psychiatry	38 (41.8)	15.2	Child & Adolescent Psychiatry	68 (32.9)	14.7
Paediatrics	15 (16.5)	8.0	Trauma & Orthopaedics	29 (14.0)	15.3
ENT	-	-	Paediatrics	26 (12.6)	9.2
Trauma & Orthopaedics	-	-	Adult mental illness	19 (9.2)	19.0
Dermatology	-	-	ENT	13 (6.3)	9.8
Gynaecology	-	-	Gynaecology	8 (3.9)	17.6
Learning disability	-	-	Learning disability	7 (3.4)	12.1
Orthodontics	-	-	Dermatology	-	-
Nursing Activity	-	-	Oral surgery	-	-
General Surgery	-	-	Paediatric neurology	-	-

(* Represents percentage for all referrals hence no 100%

(**) Mean age of referrals for male and females

(-) Data cannot be disclosed for identification reasons

5.3.6.6 Tic disorders (TIC)

The ten primary unique referrals made to secondary care for Lac and Acyp with TIC, are as detailed below in **Table 5.13**. The highest primary referral for Lac was Child & Adolescent Psychiatry (27.3%) with a mean referral age of 9.5 yrs. While the highest primary referral for Acyp was Paediatrics (18.5%) with a mean referral age of 10.1 years.

Table 5.13 Top ten service referrals for Tic disorders (TIC)

Looked after children			All children/young people		
Service	Count (%)*	Age (yrs)**	Service	Count (%)*	Age (yrs)**
Child & Adolescent Psychiatry	12 (27.3)	9.5	Paediatrics	289 (18.5)	10.1
Ophthalmology	8 (18.2)	8.4	Trauma & Orthopaedics	243 (15.6)	14.4
Trauma & Orthopaedics	6 (13.6)	12.5	Child & Adolescent Psychiatry	228 (14.6)	12.4
Paediatrics	-	-	ENT	147 (9.4)	11.6
Oral surgery	-	-	Adult mental illness	117 (7.5)	19.4
Nursing activity	-	-	Ophthalmology	64 (4.1)	11.3
Learning disability	-	-	Oral Surgery	51 (3.3)	14.4
Paediatric Neurology	-	-	Dermatology	44 (2.8)	13.2
ENT	-	-	Neurology	40 (2.6)	18.0
Nephrology	-	-	Urology	38 (2.4)	15.9

(*) Represents percentage for all referrals hence no 100%

(**) Mean age of referrals for male and females

(-) Data cannot be disclosed for identification reasons

5.3.6.7 Obsessive compulsive disorders (OCD)

Lac had too small numbers to use for comparison however, it was still important to show the service referrals for Acyp with OCD to contribute to existing literature on NDDs in the general population. **Table 5.14** shows that the primary service referral for Acyp with OCD was Child & adolescent Psychiatry (17.7%) with a mean referral age of 14.1 yrs.

Table 5.14 Top ten service referrals for All children/young persons with obsessive compulsive disorders (OCD)

OCD		
Service	Count (%)*	Age (yrs)**
<i>Child & Adolescent Psychiatry</i>	354 (17.7)	14.1
<i>Trauma & Orthopaedics</i>	241 (12.1)	15.9
<i>Adult mental illness</i>	239 (12.0)	19.4
<i>Paediatrics</i>	182 (9.1)	12.5
<i>Gynaecology</i>	137 (6.9)	19.1
<i>ENT</i>	125 (6.3)	15.5
<i>Dermatology</i>	74 (3.7)	17.1
<i>Oral Surgery</i>	74 (3.7)	16.5
<i>Ophthalmology</i>	66 (3.3)	15.4
<i>General surgery</i>	57 (2.9)	19.2

(*) Represents percentage for all referrals hence no 100%

(**) Mean age of referrals for male and females

5.3.6.8 CAMHS & Paediatric Referrals

As CAMHS and Paediatrics were the more prominent referrals for both populations. The results were further examined to compare the mean referral age to CAMHS for these NDDs combined. **Table 5.15** shows that although Lac have a higher percentage of CAMHS referrals compared to Acyp. The overall mean referral age was minimally lower in the Lac group compared to Acyp (12.9 v 13.0). OCD could not be represented here as the numbers were too small and as such might risk identification of the individuals.

Table 5.15 Combined mean age of Child & Adolescent Mental Health Service (CAMHS referrals)

Neurodevelopmental disorder	Looked after children		All children/young people	
	Count (%)	Age (yrs)	Count (%)	Age (yrs)
<i>ADHD</i>	494 (35.4)	12.9	3794 (20.7)	12.2
<i>ASD</i>	218 (18.1)	12	3440 (16.8)	11.4
<i>DDSD</i>	264 (14.2)	12.9	1711 (8.1)	12.3
<i>ED</i>	86 (50.9)	14.8	1174 (23.4)	15
<i>RAD</i>	38 (41.8)	15.2	68 (32.9)	14.7
<i>TIC</i>	12 (27.3)	9.5	228 (14.6)	12.4
Mean age		12.9		13.0

Table 5.16 shows that although Lac appear to have a higher percentage of Paediatric referrals compared to Acyp, apart from ED. The overall mean referral age was minimally higher in the Lac group compared to Acyp (10.9 v 10.6). Tic and OCD could not be represented here as the numbers were too small and as such might risk identification of the individuals.

Table 5.16 Combined mean age of Paediatric referrals

Neurodevelopmental disorder	Looked after children		All children/young people	
	Count (%)	Age (yrs)	Count (%)	Age (yrs)
<i>ADHD</i>	269 (19.3)	11.5	3250 (17.8)	10.3
<i>ASD</i>	323 (26.8)	10.3	4931 (24.1)	9.5
<i>DDSD</i>	557 (29.9)	9.9	4718 (22.3)	10
<i>ED</i>	12 (7.1)	14.6	581 (11.6)	13.8
<i>RAD</i>	15 (16.5)	8.0	26 (12.6)	9.2
<i>Mean age</i>		10.9		10.6

5.3.7 Educated other than at school (EOTAS)

The results show that within the six-year period (2010-2015), Lac with a SEN had a higher prevalence within the EOTAS setting (n = 1027, 14.1 %) compared to Acyp (n = 10, 244, 0.6%) with an OR =27.9 [26.1-29.9]. It is important to note that a child/young person may be included several times in this part of the analysis if they remained within an EOTAS setting over a period of years. Furthermore, they could have changed provision within the same year, which can be often the case, which might part explain the higher prevalence. Male gender was significantly overrepresented in both populations (See **Table 5.17**).

Table 5.17 Number of Lac and Acyp with a SEN in EOTAS between 2010--2015

	Looked after children (n = 7,264)	All children/young people in Wales (n = 1,748,348)	Odds Ratio [CI]
	Count (%)	Count (%)	
Number of children with SEN in EOTAS setting over period**	1027 (14.1)	10,244 (0.6)	27.9 [26.1-29.9] *
Male	834 (81.2)	7873 (76.9)	
Female	193 (18.8)	2371 (23.1)	

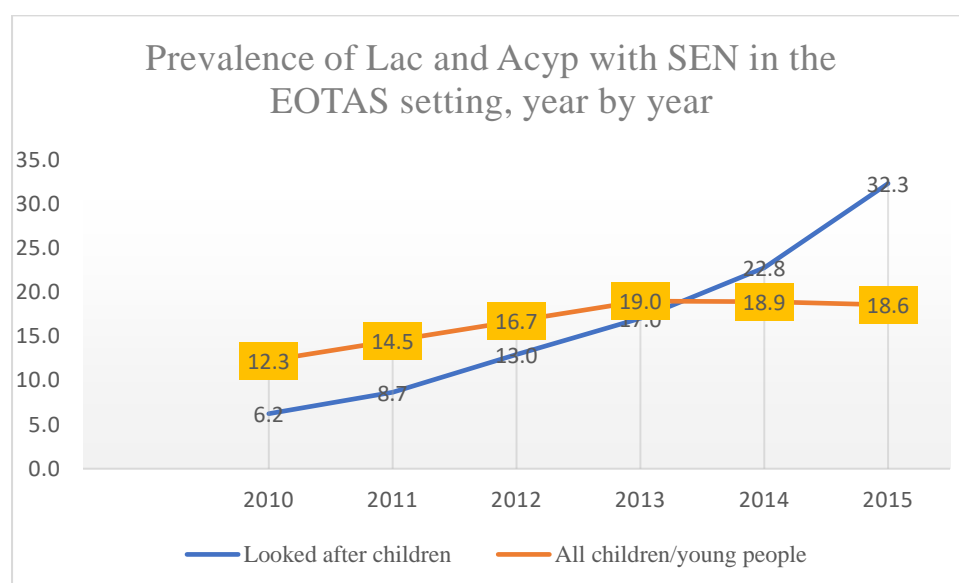
** Some children will be duplicated within the numbers if they remained in the EOTAS setting over the period.

Further analysis was then conducted to explore how many of the Lac and Acyp with a SEN were placed in an EOTAS setting year by year. The descriptive findings show that the percentage of Acyp with SEN was much higher in The EOTAS setting between 2010-2013 compared to Lac (see **Table 5.18**). However, this changed in 2014-2016. Lac had a higher percentage of children with SEN placed in the EOTAS setting. A line graph visually shows how Lac with a SEN in an EOTAS setting increased over the six-year period while the prevalence of Acyp decreased (See **figure 5.2**).

Table 5.18 Number and percentage of Lac and Acyp in EOTAS by year (2010-2015)

Year	Looked after children with SEN (n = 1027)	All children/young people with SEN (10,244)
	Count (%)	Count (%)
2010	64 (6.2)	1256 (12.3)
2011	89 (8.7)	1487 (14.5)
2012	133 (13.0)	1715 (16.7)
2013	175 (17.0)	1946 (19.0)
2014	234 (22.8)	1939 (18.9)
2015	332 (32.3)	1901 (18.6)

Figure 5.2 Line graph showing percentage of Lac versus Acyp with SEN in EOTAS setting year by year (2010-2015)



Children/young people with a SEN of behavioural, emotional and social difficulties (BESD) had the highest prevalence and accounted for 58% of case placements for Lac with a SEN versus 58.9% for Acyp with a SEN. For the NDDs of interest, ASD was 7.6% for Lac versus 6.3% for Acyp and ADHD was 5.1% for Lac versus 2.9% for Acyp (See **Table 5.19**).

Dyslexia (DYSL) although documented within the datasets could not be shown due to low numbers for identification purposes.

Table 5.19 Breakdown of Special Educational needs in EOTAS dataset (2010-2015)

SEN TYPE	Looked after children (n= 1027)	All children/young people (n= 10244)
	Count (%)	Count (%)
<i>Behavioural, emotional and social difficulties</i>	596 (58.0)	6030 (58.0)
<i>Moderate Learning Difficulties</i>	132 (12.9)	1498 (14.6)
<i>Autistic Spectrum Disorders</i>	78 (7.6)	643 (6.3)
<i>Speech, Language and Communication Difficulties</i>	58 (5.6)	553 (5.4)
<i>Attention Deficit Hyperactivity Disorder</i>	29 (2.8)	293 (2.9)
<i>Severe Learning Difficulties</i>	27 (2.6)	181 (1.8)
<i>Physical and Medical Difficulties</i>	25 (2.4)	328 (3.2)
<i>Profound & Multiple Learning Difficulties</i>	14 (1.4)	102 (1.0)
<i>General Learning Difficulties</i>	10 (1.6)	215 (2.1)
<i>Hearing Impairment</i>	*	
<i>Multi-Sensory Impairment</i>	*	332 (3.2) **
<i>Dyslexia**</i>	*	
<i>Visual Impairment</i>	*	60 (0.6)
<i>Dyspraxia</i>	*	
<i>Dyscalculia</i>	*	9 (0.0) **
Total	1027	10,244

(*) Data could not be disclosed for identification reasons

(**) Prevalence was combined to protect the identity of individuals

The most prominent EOTAS provision for both groups with SEN was the Pupil referral unit (PRU). Overall, Acyp with SEN (46.5%) had a higher % of placements in the PRU compared to Lac with 39.5% (see Table 5.20).

Table 5.20 Breakdown of EOTAS educational provision for Lac & Acyp with a SEN between 2010-2015

Type of provision	Looked after children (n=1027)	All children/young people (n=10,244)
	Count (%)	Count (%)
Pupil Referral Unit (PRU)	406 (39.5)	4759 (46.5)
Independent schools (IND)	253 (24.6)	1328 (13.0)
Maintained primary, middle, secondary or special school (SCH)	109 (10.6)	572 (5.6)
Individual tuition and tuition at pupils' homes or at hospital (TUI)	65 (6.3)	1153 (11.3)
Non-maintained special school (NMS)	49 (4.8)	327 (3.2)
Bought in private sector provision (PSP)	42 (4.1)	415 (4.1)
Training providers (TPR)	27 (2.6)	501 (4.9)
Pupil attending provision not maintained by the authority, or outside of the authority, for which the authority pays fees (FEE)	27 (2.6)	154 (1.5)
Other (OTH)	17 (1.7)	281 (2.7)
Awaiting provision or not currently in provision (NIP)	13 (1.3)	123 (1.2)
Further education college (FEC)	12 (1.2)	373 (3.6)
Work related education (WRE) & Voluntary organisations (VOG) **	7 (0.7)	213 (2.1)
Youth Gateway (GAT)	*	45 (0.4)
Total	1027	10244

(*) Zero counts

(**) Combined for identification reasons

The data was further analysed to explore the educational provision for both Lac and Acyp with ADHD and ASD as they were the only NDDs that had data that could be disclosed (Dyslexia) due to small numbers. The highest three EOTAS provisions are detailed for both ASD and ADHD. The PRU setting was the most prominent EOTAS setting for both Lac and Acyp with ADHD. The Independent schools (IND) setting was the most prominent EOTAS setting for both Lac and Acyp with ASD. (see **Table 5.21**).

Table 5.21 Highest three EOTAS provisions for ADHD & ASD between 2010-2015

Attention deficit hyperactivity disorders		
EOTAS provision	Looked after children (n=52)	All children/young people(n=293)
	Count (%)	Count (%)
<i>Pupil Referral Unit (PRU)</i>	28 (53.8%)	194 (66.2%)
<i>Maintained primary, middle, secondary or special school (SCH)</i>	11 (21.2%)	32 (10.9%)
<i>Independent schools (IND)</i>	7 (13.46%)	24 (8.1%)

Autism Spectrum Disorders		
EOTAS provision	Looked after children (n= 78)	All children/young people (n=643)
Independent schools (IND)	39 (50%)	264 (41%)
Pupil Referral Unit (PRU)	19 (24.3%)	149 (23.1%)
Pupil attending provision not maintained by the authority, or outside of the authority, for which the authority pays fees (FEE)	6 (7.7%)	N/A
Individual tuition and tuition at pupils' homes or at hospital (TUI)	N/A	79 (12.2%)

5.4 Discussion

The results show that between the study period examined ASD, ADHD, DDSS, unspecified, ED, TIC and RAD had a higher prevalence in the Lac population compared to Acyp in Wales. Even when data was further explored and analysed, ADHD, ASD and DDSS, unspecified had a higher prevalence in Lac. Male gender was significantly overrepresented in the overall findings and the mean age of first event/episode for both populations was during the pre/early teenage years. Although, there are limitations to this study which are further discussed. The findings raise some important questions for the stakeholders involved in supporting these already vulnerable children.

The higher prevalence % of ASD in Lac versus Acyp (4% v 0.5%) OR = 8.97 [7.9-10.1) was a novel finding for Lac literature in Wales and much higher than the prevalence % found in the meta-analysis (2.4 v 1.01%) RR = 2.23 [1.63, 3.05]. These prevalence rates for Lac appears to be much higher than the global estimation of ASD at 1%. This finding concurs with that of Sebba & Luke (2015) who found similar prevalence % rates for Lac with ASD in their educational study conducted in England (5.4%). If we explore the Acyp % rate, although smaller than the global estimated rate of ASD (1%), McConkey (2020) found a prevalence of 1.92% in the school population in Wales, however this was based on census results which could have either produced over-reported or under-reported results based on response or non-response bias (Okafor, 2010). Additionally, a recent study using similar methodology found the overall prevalence of ASD in Wales for adults to be 0.51% which is very similar to the % rate found here for the Acyp population in this study (Underwood et al., 2021).

ADHD was also significantly higher in the Lac group compared to Acyp in Wales (3.4% versus 0.2%), OR = 14.9 [13.1-17.0]. However, the prevalence % rates were significantly lower than the results found in the meta-analysis (16.22% versus 6.67%), RR = 2.69 [1.44, 5.01]. This could be contributed to the fact that the majority of the eligible studies had been conducted in the USA where diagnostic rates of ADHD appear much higher compared to European figures (Faraone et al., 2003; Smith, 2017). There is much discourse on the prevalence of ADHD not just on an international but global level (Smith, 2017). The diagnostic process varies country to country and research suggests that many of the studies that have explored the prevalence of ADHD in the USA have been based on parent/teacher

reports which could impact on the validity of the findings (Faraone et al., 2003; Smith, 2017). However, several of the studies found for this meta-analysis, used databases where the diagnosis of NDDs were not based on parent/teacher reports but had been clinically assessed and diagnosed to enable access to medical help, which strengthens the findings of this meta-analysis.

The results of this study are interesting as an updated systematic review proposed that the average global prevalence for ADHD is estimated to be at 5% yet the findings from this study only found a 0.2% prevalence for Acyp (Sayal et al., 2018). Although, this prevalence % rate for Lac with ADHD in Wales is in line with this estimated global prevalence it does raise questions about whether data collation is representative of ADHD. One could argue that ADHD may be over diagnosed in the Lac population or that ADHD is being under diagnosed in the Acyp in Wales. If we further explore the breakdowns of the NDDs by diagnostic code which are shown in **Table 5.2**. The majority of ADHD diagnoses derived from the diagnostic code E2E01. This is defined as ‘Attention deficit with hyperactivity’ in the Read code manual and F900 which is defined as ‘Attention deficit with hyperactivity, hyperactivity disorder, syndrome with hyperactivity’ in the ICD 10 manual (see **Table 5.1**). One could suggest that the externalising behaviours associated with attention deficit with hyperactivity could play a significant role in the higher prevalence rates, particularly if we consider the other significant less visible, ADHD disorders which do not present with hyperactivity in this study, such as those diagnosed with attention deficit disorder, without hyperactivity. If we consider this, we must also explore the other NDDs such as ASD. Childhood autism was the highest diagnostic code for both groups (Eu840, F84.0). This NDD is often associated with more visible, externalising behaviours while, children with Asperger’s are associated with less visible and subtle behavioural symptomology (Smith, 2021). One could suggest that the externalising and more visual behaviours could be contributing to accessing an earlier diagnosis for both ASD and ADHD.

The highest prevalence of Developmental disorders of Scholastic Skills (DDSS), unspecified was an important finding. Although, all prevalence rates for these NDDs contribute to Lac literature, the DDSS finding is interesting, particularly as the Lac population has a higher prevalence of special educational needs (SEN) compared to their peers who are not looked after (Oakley et al., 2018; Sebba et al., 2015). DDSS encompasses a wide umbrella of learning disorders and difficulties so we cannot specify for this study what specific learning difficulties underpinned this diagnostic code. Nevertheless, the later mean age for first event

or episode found in this study raises further questions for policy as early intervention is key to improving educational attainment.

The expectation would be that these children would have been able to access specialist educational provision pre-diagnosis to support their learning. Any time-lapse in support for any learning disorder or difficulty would be detrimental to their educational attainment and future socioeconomic status (Mariño et al., 2018). Future research would benefit from exploring this further for the Lac population.

Social factors such as inadequate schooling is often associated with speech, scholastic and coordination disorders which contribute to learning difficulties (Arrhenius et al., 2018). Nevertheless, scholastic disorders and learning difficulties, particularly dyslexia are also associated with ADHD, ASD and have high co-morbidity (Brimo et al., 2021; Leejin & Myoung, 2018; McGrath & Stoodley, 2019; Russell & Pavelka, 2013). However, the study could not find any diagnostic codes for Lac with specific dyslexia. It is estimated that 10% of people in the UK have some level of dyslexia. Therefore, it is not inconceivable that dyslexia may have fallen under the diagnostic umbrella code of scholastic disorders (Government UK, 2017; Prasad & Sagar, 2021). The Centers for Disease Control and Prevention suggest that if symptomology does not meet the criteria to constitute a principal diagnosis, it should be diagnosed with DDSS (CDC, 2022). Or incorrect data input and collation could have contributed to this lack of data as dyslexia, including dyscalculia and dyspraxia were recorded in the EOTAS data set. However, they were minimal. This lack of available data held within the datasets requires further exploration, as it is important to note that dyslexia and other NDDS are categorised as learning disorders, which require a specific, specialist approach and specialised provision to help the learning experience of each child (Brimo et al., 2021).

A close second highest NDD in Lac was ASD. This higher prevalence rate could have been attributed to an increased awareness of ASD in Wales. Policies and third sector campaigns run by the National Autistic Society and the 'National Integrated Autism Service' which has been developed since 2016, have raised much awareness of ASD and provided much needed information and resources to help families that support individuals with ASD (Autism Wales, 2022). However, this should also have applied to the Acyp population. Data input is not always standardised and can be questionable at times based on varying factors such as the skills, awareness of the user, the system processes used and the differences in data variables

captured as is reflected in the limitations of this thesis (Khoury et al., 2014; Zhang et al., 2017).

There is also the possibility of overdiagnosis or misdiagnosis in ASD, which could have contributed to this higher prevalence which is reflective of research (Hull & Mandy, 2017; Merten et al., 2017). There is also the confusion with the behavioural symptomology of attachment and trauma which can further complicate the understanding and diagnostic process (Little et al., 2018). As already discussed within this thesis, some professionals may consider diagnosing a child as the best way to help support the child and enable access to services. What is critical is that regardless of the diagnosis, these children require a unique, individualistic service that meets their needs, whether it is NDD, attachment or trauma related.

Conversely, it must be noted that this prevalence of ASD could potentially be even higher as suggested by Underwood et al (2021). The later mean age for first event/episode for females with ASD in both the Lac and Acyp population was an important finding. Research suggests that many females may face a potential gender bias in diagnostic assessments as those with lower intelligence quotient, developmental delays and less cognitive ability seem to meet the diagnostic criteria outlined for ASD (Christianz et al., 2016; McPartland et al, 2012; Worley & Matson, 2012). Females who display with perceived, high functioning behavioural symptomology such as higher cognitive ability, good social communication and interaction skills and fewer perceived impairments hinder the diagnostic assessment for years, as they do not meet the suggested andro-centric diagnostic criteria (Hull & Mandy, 2017; Lockwood et al., 2021; McPartland et al., 2012; Tubío-Fungueiriño et al., 2021). This could be suggested to a contributory factor to the results of this study. Although, the results were in line with the current ratio for girls with ASD is estimated to be at 3:1. This later mean age could suggest that the early identification of females with ASD in Wales needs further exploration (Loomes et al., 2017; Tierney et al., 2016). If we consider this then we must also consider females with ADHD, as they are also suggested to be frequently missed as a result of differing behavioural symptomology compared to males (Lynch & Davison, 2022; Nussbaum, 2012). The mean age of first event/episode for females with ADHD in both groups were much later than for males which supports the notion that females may be attaining a later diagnosis. This also applied to the mean ages for RAD and DDSS, unspecified. What was interesting, was that even though the prevalence of ED was much higher in females compared to males in the Acyp group (87.6 v 12.4), the mean age of first event/episode was still much later compared

to males (16.9.v 14). This also applied to female Lac with ED but numbers could not be disclosed for anonymity reasons as already discussed within this thesis.

NDDs are not always screened for in the Lac group as suggested by Ogundele (2020) who found that 'neuro-disabilities' were high in Lac. This lack of screening conflicts with the qualitative findings of this thesis as several participants had noted that dyslexia and dyspraxia were quite common in the Lac population. However, this could have been as a result of differentiation in service access and provision between postcodes and the study was also based on two local LA's

Early diagnosis for children with these NDDs is essential to help improve future wellbeing as proposed by the NICE guidelines (NICE, 2017). Therefore, the mean age of first event or episode for all NDDs explored is an important finding as it suggests that diagnosis may be more prominent in the early teen years which does not suggest an early diagnosis as outlined by the NICE guidelines. As already detailed within this thesis, children with NDDs find this the most difficult era to deal with as a result of the social environment dynamics dramatically changing (Halsall et al., 2021; Herrington et al., 2016; Oster et al., 2020; Tierney et al., 2016). The transition to secondary school, is where many children hit crisis point during this period of their lives and become socially exhausting with increased sensory sensitivity, anxiety levels which can often lead to depression and entry into CAMHS (Tierney et al., 2016; Tubío-Fungueiriño et al., 2021).

Co-morbidities such as anxiety and depression are frequently associated and co-occur with ASD and ADHD (Tierney et al., 2016, Yang et al., 2013; Young et al., 2013; Young et al., 2021). The study did not explore anxiety and depression, however, this could have contributed to the findings of this study where the most prominent referral documented for ADHD, ED and RAD was the referral to CAMHS. However, this was not the case for children/young adults with ASD, although it was the second most prominent referral. Descriptively, the mean % of CAMHS referrals were much higher in the Lac population which may suggest that their need for mental health services is greater than those in the Acyp group. However, there was limited difference in the mean age of referral for both groups (12.9 v 13.0 yrs). The high % and mean age of referrals to CAMHS is an important finding as it highlights the age when these Lac and Acyp with a NDD may be at risk of developing mental health problems in Wales. Welsh government should consider investing in nesting more resources in CAMHS to help support these mental health needs.

Furthermore, as the referrals were coded at the start of a period while waiting for an outpatient consultation or treatment, it cannot be ascertained whether or not these children/young people had actually accessed the services. The qualitative findings of this thesis found that accessing CAMHS was unattainable for many of these children who by the nature of their ACEs and additional complexities would have a high risk of developing some form of mental health problems at some point in their lives. Many of the participants had initiated referrals to CAMHS but had not actually accessed the service. Therefore, this could have attributed to the high prevalence of CAMHS referrals documented in the findings. This is also supported by a recent independent review that found that children in care are frequently struggling to access mental health services (Government UK, 2021). Some Lac with NDDs were also found to be excluded from accessing mental health services as a result of their condition being classified as neurodevelopmental and not a mental disorder. Although this cannot be generalised, it could be suggested that CAMHS are not trained or provisioned to deal with these NDDs and could be hesitant in providing a service and apprehensive of undermining the emotional wellbeing of these children. More research from a national perspective is needed to explore the number of children who have actually accessed CAMHS. This is important for the stakeholders involved with this vulnerable group to urgently explore if this reflects the experiences of other areas of Wales. To the researcher's knowledge there is no available, specialised mental health service provision for children with a NDD. CAMHS needs to be accessible for all and policy needs to ensure that CAMHS is provided with the necessary provisions to meet the individualistic needs of these children from an early age. The effects of not doing so could be detrimental to the future physical, social and emotional overall wellbeing of these children.

Paediatrics was the primary referral for Lac with ASD and DDSS. It was also the primary referral for Acyp with ASD, DDSD and TIC. The results also show that the mean age of referral for both groups were much lower than those for CAMHS. This may be as a result of paediatrics being the service that often provides a gateway to more specialised and wider ranging sub-speciality services. Furthermore, as many of Lac have experienced ACEs, the related impacts on their health as a result of these ACEs could also contribute to this high prevalence of referrals to paediatrics. However, the percentage of referrals made to CAMHS were very close in numbers, which could suggest that the emotional, mental health needs of these children are equally as significant as their physical health needs.

Alongside these important health and emotional needs sits the educational need that provides these children/young adults with the tools needed to bridge social networks, increase social capital and socioeconomic status (Greening, 2017). As already discussed within the thesis, poor educational attainment and a high prevalence of special educational needs (SEN) has frequently been associated with Lac, often attributed to ACEs, maltreatment and neglect (O’Higgins et al, 2015; Sebba & Luke, 2019). NDDs are often associated with learning difficulties and more prominent needs for special educational provision (May et al., 2021). Furthermore, many children with NDDs are often excluded from mainstream school, particularly those with ADHD and ASD (Hatton, 2018; John et al., 2022). The findings show that over a six-year period, Lac with a SEN had a higher prevalence in the ‘EOTAS’ provision compared to Acyp in Wales (14.1 versus 0.6%). However, this figure included all children with a SEN, the most prominent being behavioural, emotional and social disorder. However, after further analysis, the percentage of Lac with SEN in the EOTAS setting increased over this period, compared to the Acyp group which decreased (see **figure 5.2**). This is a significant finding for policy to further explore why this may be occurring.

The most prominent provision for the majority of these children with SEN was the Pupil referral Unit (PRU) with males being overrepresented. The PRU is an EOTAS setting that provides children with an alternative educational provision if the child is unable to attend the mainstream setting, with an aim to reintegrate them when possible (Jalali & Morgan, 2018). There are varying reasons why the child is placed within the PRU. However, it is often as a result of the child’s behavioural, emotional or social needs which is reflective in the results of this study (Jalali & Morgan, 2018).

As the thesis explored NDDs, upon further analysis, the same outcome applied for both Lac and Acyp with ADHD but not for ASD where the independent school (IND) was detailed as the more prominent setting for both Lac and Acyp. Children with ADHD are over-represented in the PRU setting as reflected by some research (Van Herwegen et al., 2019). This is often attributed to the externalising behaviours associated with the disorder (Thomas, 2013). Although, this educational provision has been designed to provide a stop gap between educational provisions, a study that explored PRUs, found that the reintegration of children with ADHD back into mainstream was difficult and required better training and awareness at mainstream school level (Thomas, 2013). The frequent externalised behavioural symptomology within the educational setting placed them at higher risk of being placed in a PRU. This is further supported by another study that proposed that professionals in the

educational sector required more training in NDDs to better support these children to improve reintegration (Van Herwegen et al., 2019). Research would benefit from exploring the experiences of children with ADHD who have been placed in a PRU, to gain a better understanding of the impacts on the child.

Lac and Acyp with ASD were more likely to be placed in an independent school (IND) setting. The independent schools are often fee-paying or private schools that operate independently of Local Authority or government regulations (Duffy et al., 2012, WAG, 2014). Although they are perceived to be beneficial for some children, one could argue that they are not regulated to ensure correct provision is in place, particularly if we consider specialist provision for ASD or ADHD (WAG, 2014). One could also argue whether these settings promote social inclusion or exclude them from their peers within the mainstream setting. More research is needed as no wider literature could be found that have explored this area for both the Lac and Acyp with ASD, or any other NDD.

Although, the IND was the highest provision for Lac and Acyp with ASD, 24.3% of Lac and 23.1% of Acyp with ASD were also placed in a PRU setting. When we consider ASD, there is also another potential risk to consider. Children with ASD frequently struggle socially but mask this impairment by having a unique, adept ability to mimic peers to adapt to their social environment (Kok et al., 2016; Lockwood Estrin et al., 2021). Therefore, placing them in an environment where children have a high prevalence of behavioural, emotional and social needs could place these children with ASD at further risk of developing more challenging behaviours and/or co-morbid mental disorders. More research is urgently needed to explore if IND or PRUs are the correct service provision for both Lac and Acyp with ASD or ADHD.

What is clear from the findings is that males were significantly over-represented in the majority of the key findings documented within this study. This applied to both the Lac and Acyp populations. Although, this is a novel finding for research conducted in Wales, there is wider literature that suggests that the over representation of males diagnosed with NDDs could be as a result of environmental, genetic, hormonal, social bias and/or andro-centric diagnostic criteria (Granocchio et al., 2021; Lai et al., 2015; May et al., 2019; Mowlem et al., 2019). More research on the reasoning for this higher prevalence in males is needed.

Although the study sought to explore much needed research on ethnicity and NDDs; the significant amount of missing or undisclosed data was difficult to interpret and may have affected the reliability of this study's findings. Structural biases are known to exist within this

domain and the capture of ethnicity information. It can also be difficult to attain ethnicity information as a result of consent, cultural differences or poor data collection systems which impact on the reliability of the data (McGrath-Lone et al., 2021). General consent should also be considered as missing data can also be more prevalent in hard-to-reach groups or minority groups (Al Baghal, 2016).

Ethnicity prevalence in NDDs is still a very much under explored area of research (McGrath-Lone et al., 2021). Cultural influences have been proposed to be a possible barrier to attaining a diagnosis for these populations as a result of a lack of awareness of the presentation of these NDDs, the varying behavioural presentations of these NDDs within different ethnic populations may not fit some of the biased diagnostic assessments and criteria. (Castillo & Gilger, 2018; Slobodin & Masalha, 2020; Someki et al., 2018; Yu et al., 2020)

The association with the stigma attached to these NDDs could be suggested to be more of a barrier for certain ethnic populations, as many individuals still perceive these NDDs as being detrimental to the child's future especially within a social context or a reflection of their parenting or hereditary influences (Castillo & Gilger, 2018; Slobodin & Masalha, 2020; Someki et al., 2018; Yu et al., 2020). Children are sometimes shunned from communities as a result of their disabilities and this frequently results in the social exclusion of both the child, parent and family (Ningsih et al., 2022; Shorey et al., 2020). More research is needed to explore the prevalence, perceptions and experiences of these groups from an ethnicity perspective.

5.5 Strengths and Limitations

There were both strengths and limitations to this electronic study due to the nature of the population being explored and the limited data available. One strength is that prior to the study, an IGRP protocol was submitted and approved by the governing body which has been suggested to be a method that can reduce potential bias in the results (Smith & Noble, 2014). (See attached **appendix 7**).

However, many of the objectives outlined within the protocol could not be attained as a due to the extent of data currently available in SAIL. The ALF_PE is the recommended unique, anonymised linkage identifier that is suggested to be the gold standard identifier for linking datasets together as it has a probability match of $\geq 90\%$ (Blakely & Salmond, 2002; Demmler

et al., 2020). However, this identifier was omitted in key areas of the Lac datasets available which prohibited further exploration of the data. The Lac episode dataset detailed category of need, placement type, local authority code, reasons for start and end of episode and the main dataset for Lac held detailed information on disability code and asylum code amongst other important variables.

Furthermore, the CRCS dataset which included the Lac variable held some fundamental information that would have enhanced the results of this study. Variables included youth offending, substance misuse, mental and physical health of the child, defined categories of disability, including ASD, reasons for child protection registers such as sexual abuse, physical abuse, emotional abuse and parental mental health, learning disability and capacity. However, as a result of the collation periods, only three months of each year were collated. Therefore, the lack of complete data would have impacted on the validity of the findings for this study.

Other key identifiers were explored in the educational datasets such as PUPIL_ID and SYSTEM_ID. However, these identifiers can frequently be applied multiple times to the same individual, particularly if they move educational setting, which might have affected the results in relation to duplication of individual records. Hence the rationale for exploring the EOTAS dataset as it had a much smaller number to analyse for the time constraints associated with this thesis.

Another limitation to consider was that the Lac dataset is still in its infancy with regards to collation of data. It has only been collated from year 2016/2017 through the mandatory 'Looked after children Census'. As the protocol defined 2018 as an upper limit, this excluded any data after 2018 and was limited to only several years of collated data. It replaced other datasets such as the 'Looked After Children (SSDA903)', 'Adoptions of looked after children (AD1)', 'Educational qualifications of care leavers (OC1)' and 'Care leavers on their 19th birthday' (OC3). The census collates data based on their legal and placement details. Therefore, we cannot be certain that a child documented as Lac at the time of the linkage is still a Lac presently. Some may have transitioned into adoption, been placed back into the system as a child in need, or a child in protection, or have been discharged from the social services and reunified with their biological parent/families. The Lac dataset used represents those children/young persons who had been placed in a care setting at the time of the census collation, which complies with the pre-defined aim of this thesis.

There are additional factors to consider such as differing LA data collection systems, data input error and the currently incomplete migration of some LAs into the integrated Welsh Community Care Information System (WCCIS). Therefore, the study acknowledges that these may be contributory to potential missing or incorrect data. However, this limitation would apply to both the Lac and Acyp populations at the time of analysis (Gov.uk Wales, 2021; Harron et al., 2020; WAG, 2018; WAG, 2020).

A comparison between the results found in this study and those found in the meta-analysis could not be conducted due to the heterogeneity of studies. Furthermore, the meta-analysis in this thesis only found eligible studies on the prevalence of ASD and ADHD. Although, not statistically viable to compare they do share some similarities. Both studies show that prevalence percentages and odds ratios of having ASD and ADHD are significantly higher in the Lac population compared to those children/young people who were defined as non-Lac or Acyp.

Some of the children/young people in both populations may have been dually diagnosed with some of these NDDs as they can frequently co-occur. However, the same process for diagnostic analysis was applied to both the Lac and Acyp populations and was pre-defined in the protocol. It is important to note however, that having a dual diagnosis of these NDDs has suggested to have a further detrimental impact on the health and social wellbeing of the individual which strengthens the study's findings (JSNA, 2014).

No geographical or socioeconomic data was explored for this study. Future research in this domain would contribute to a possible wider understanding of NDDs in terms of access to services and any association with socioeconomic status.

It could be suggested that the prevalence of NDDs may be underestimated as using PEDW and WLGP records will only have captured children with NDDs within those settings. Some of these children who have been diagnosed with a NDD may not have been seen within these settings. There is also the likelihood that many children have yet to be assessed for a NDD, which could have had an impact on the figures. In 2019, it was suggested that some children were waiting over 24 months to be assessed in Wales (WAG, 2019c). In addition, this study only explored ICD 10 codes which suggests that NDDs diagnosed using other codes like the ICD 9 may have been missed. Again, this further suggests that the prevalence might be underestimated. However, this would apply to both Lac and Acyp rates. Additionally, the

analysis did not account for the timing of events. Therefore, it cannot be determined whether the referrals to paediatrician came before diagnosis or post-diagnosis.

5.6 Key findings

- Lac have a higher prevalence of ADHD, ASD, Developmental disorders of Scholastic skills, unspecified (DDSS), ED, RAD and TIC disorders compared to their peers who were not looked after at the time of the data collation (Acyp) in Wales.
- Bipolar, dyslexia, dyspraxia and dyscalculia had not been diagnosed in any of the Lac population during the period explored.
- The mean age of the first event or episode for Lac with a NDD ranged between 8.6 - 14.5 yrs and for Acyp (10.1 - 17.1 yrs).
- Male gender was significantly over-represented in the prevalence of all NDDs for both groups, with the exception of eating disorders.
- Females had a much later first event/episode than males for all NDDs in both groups
- Ethnicity could not be explored due to a lack of complete data.
- The high prevalence of DDSS, unspecified requires further exploration to improve the educational attainment for these children.
- CAMHS and paediatrics were the most common service referrals for both Lac and Acyp with a NDD.
- Lac have a higher percentage of CAMHS referrals compared to Acyp.
- The overall mean referral age to CAMHS was minimally lower in the Lac group compared to Acyp (12.9 v 13.0).
- Lac have a higher percentage of Paediatric referrals compared to Acyp, apart from ED. The overall mean referral age was minimally higher in the Lac group compared to Acyp (10.9 v 10.6).
- Over a six-year period, Lac with a SEN had a higher prevalence within the EOTAS setting (14.5%) versus Acyp (1.4%).

- Prevalence of Lac with a SEN in the EOTAS setting is increased, while Acyp with a SEN is decreased.
- Lac and Acyp with ADHD are more likely to be placed in a pupil referral unit.
- Lac and Acyp with ASD are more likely to be placed in an independent school.

5.7 Conclusion

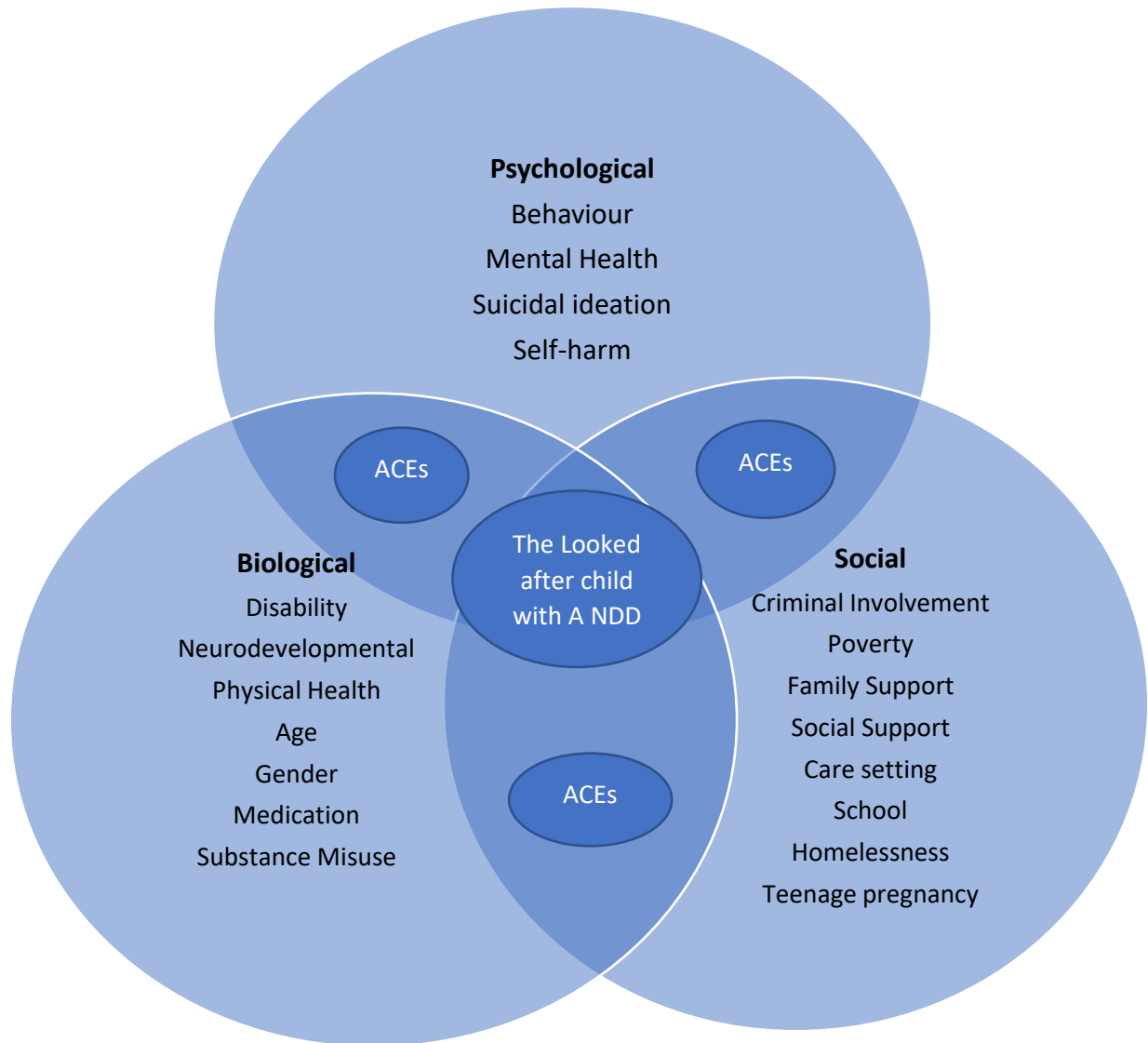
Lac with NDDs in Wales are a poorly understood vulnerable population that require urgent investigation due to their unique and individualistic needs. The findings from this study contribute to both Lac and Acyp literature in Wales. Further studies from a nationwide context, are needed to explore if the prevalence of NDDs in the Lac population are higher than Acyp as has been shown in this study. In the final chapter, I consider and examine how these findings relate or not to the overall results found in the other chapters of this thesis and to wider existing literature. A discussion on the implications of the results on research, policy and practice will be detailed and recommendations made.

Chapter 6: Final discussions & recommendations

This thesis required a pragmatic, diverse and flexible research paradigm due to the complexities, unpredictability and dynamic environments that enshroud Lac and therefore used a mixed methods approach to answer the research questions. This final chapter integrates all the findings into a brief discussion, highlighting any similarities, parallels or ambiguities. The chapter begins with an adapted biopsychosocial model that portrays how and what broad biological, psychological and social factors were found in this thesis in relation to the Lac with a NDD, followed by a more in-depth depiction of the integrated findings which are further discussed with reference to wider literature. Lastly, I discuss recommendations for research, policy and practice and end with a final conclusion.

The biopsychosocial model, which formed a theoretical framework for my thesis was used to gain an understanding of the potential wider biological, psychological, social impacts that may affect the Lac with a NDD. Therefore, I created an adapted version below to show a summary of the broad, thesis findings applied to this model. The model depicts the biological, psychological and social impacts that some Lac with a NDD experience, derived from the findings in this thesis. ACEs which represent abuse (emotional, sexual, physical), neglect (emotional, physical) and household challenges (parental substance misuse, parental mental health and domestic violence) have been placed in between the biological, psychological and social sections to highlight the additional complexities found in this thesis for the Lac with a NDD and how they add a further multifaceted dynamic to this model (CDC, 2021).

Figure 6.1 An adapted Biopsychosocial model of Wellbeing for the Lac with a NDD (MHDD, 2022)



Although, the biopsychosocial model highlights the broad findings in this thesis the next part of the chapter will discuss these more in detail and relate them to the specific findings of this thesis. The next section highlights the prevalence of NDDs in Lac and some of the adverse impacts found in this thesis. Figure 6.2 details all four methods utilised in this thesis and highlights the similarities in the findings which are further discussed.

Figure 6.2 Prevalence of NDDs and impacts on the Lac with a NDD

Methods	Systematic Review	Narrative Review	Small q study	Electronic Data Linkage
Findings		Impacts on Lac	Impacts on Lac	High prevalence of NDDs
Neurodevelopmental Disorders	ADHD, ASD, DDSS, TIC, DDMF, BD	ADHD, ASD, BD	ADHD, ASD, DYSL	ADHD, ASD, DDSS, TIC, ED, RAD
Mental Health	High mental health usage	Suicidal Ideation	Mental health problems Self-Harm	Primary referral category & high % of MH referrals
Criminal Justice		Criminal Involvement	Criminal Involvement	
Abuse	Emotional/Physical/Sexual	Physical & Sexual	Domestic	
Placement Settings	Risk of foster care placement	Risk of long-term care Residential Care	Residential Care Multiple placements	Pupil referral unit Independent school
Homeless		Homelessness		
Education & Learning		Learning difficulties	Low educational attainment	Higher prevalence of SEN in EOTAS setting
Physical Health	Higher prescription and usage of medication	Physical Health difficulties	Substance Misuse Teenage pregnancies	

6.1 Prevalence of NDDs in the Lac population and impacts

The systematic and narrative review were utilised to explore the prevalence of NDDs in the Lac population and further explore the impacts on the Lac with a NDD from a global perspective based on what literature was available. The electronic data linkage study explored these areas from a national perspective and the small q study was conducted at a local level. However, even though all findings derive from varying geographical perspectives figure 6.2 shows similarities in the higher prevalence of particular NDDs and similarities in the adverse impacts on the child with a NDD.

The higher prevalence of NDDs in Lac compared to their non-Lac peers found in the systematic analysis and in the electronic data linkage study reflect new and emerging studies since the thesis was conducted (Engel et al., 2022; Kääriälä et al., 2022; Keefe et al., 2022). One study found that ADHD was present in 11% of foster care children versus 6.1% in non-foster care children which reflects closely the findings of the systematic review (17.22 versus 6.57%) (Keefe et al., 2022). However, this was based on Medicaid claims. A recent Scottish record linkage study also found that ADHD (based on medication) was present in 5.1% of Lac versus 1.0% in non-Lac which again reflects closely the findings of the data linkage study in this thesis (3.4 versus 0.2%). Prevalence rates as already discussed within this thesis can be higher for a variety of reasons however there is some consistency in the literature where prevalence of NDDs is higher in this population.

From a national perspective, the high prevalence rate for NDDs is a novel finding for literature in Wales. This high prevalence of NDDs should be something for policy makers to explore to ensure there is adequate specialist awareness, training and resources available to meet the needs of these already vulnerable children and their families. Unmet needs as already discussed within this thesis can result in adverse outcomes and have a significant impact on future life chances (André et al., 2022; Diallo et al., 2022; Ercan et al., 2022; Jadav & Bal, 2022). Additionally, even though the qualitative study was a small q study, many of the respondents perceived ADHD or ASD to be the most prominent NDDs in the Lac population which is reflective of the systematic review and SAIL results. A recent study by Côté & Clément (2022) interviewed 20 children from residential care and found that ADHD was the most frequently reported disorder which shows some similarity in the perceptions of the participants in this study but no diagnoses of ASD was found.

The mean age of the first event/episode found which ranged from between 8.6 - 14.5 yrs for Lac and 10.1 - 17.1 yrs for Acyp is a finding that policy would benefit from exploring as these ages do not suggest early diagnosis as has already been discussed within this thesis. However, this is based on GP and PEDW data only and the findings did highlight that Lac with a NDD had a lower average mean age of first event/episode which may suggest that they are being captured earlier than Acyp. Nevertheless, early diagnosis and intervention are key to improving life chances for these children. There are also the economic costs to consider; the costs associated with some of these NDDs can run into billions of pounds (Blaxhill et al., 2021; Sciberras et al., 2022). Early identification and intervention might reduce costs by reducing demands on future health, educational and social care services (Blaxhill et al., 2021; Dilly & Pavlov, 2022; Sciberras et al., 2022).

There could be a multitude of factors that may contribute to this higher prevalence of NDDs in Lac which have been discussed within this thesis. Non-standardised diagnostic assessment tools and differing neurodevelopmental diagnostic pathways are just some to consider. Further exploration into other biological, psychological, social and environmental factors may contribute to understanding what may be causing this high prevalence and would be equally important for the overall wellbeing of the Lac (Defresne & Mottron, 2022). However, this would not be an easy challenge as the complexities that encompass these children's lives would be difficult to untangle and be very complicated.

The impacts on the Lac with a NDD are concerning on a biological, psychological, social and environmental level as is shown in figure 6.2. The high usage of mental health services and mental health problems, which is not new to literature for Lac, but based on the findings appears to be even higher in Lac with a NDD. This could be attributed to a multitude of factors however, co-occurring mental disorders as already discussed within this thesis are very prominent in children/young persons with a NDD which may be contributing to these higher figures (Buro et al., 2022; Fuller-Thompson et al., 2022; Hollocks et al., 2022). Sex differences should also be considered when exploring mental health in Lac with a NDD as females with an NDD have been suggested to be at higher risk of developing other mental disorders compared to their male counterparts (Davies et al., 2023). Another study found that women with ADHD were four times more likely to experience general anxiety disorder compared to males with ADHD (Fuller-Thompson et al., 2022). Again, from a national perspective, the high percentage of referral rates for both Lac and Acyp with a NDD to CAMHS and the mean age at referrals (Lac 12.9 yrs and Acyp 13 yrs) was an important

finding as it could suggest that this is the time when they may be at higher risk of developing mental health challenges. These were both novel findings for literature in Wales. It could not be ascertained what reasons children were referred for but may have been related to the ACEs many of these children experience. Nevertheless, this high percentage of referrals to CAMHS should be something for policy makers to explore to ensure there is adequate specialist awareness, training and resources available to meet the needs of these children.

The increased risk of sexual, physical and emotional abuse found in the systematic and narrative review and which was also highlighted in the small q study warrants further attention in research in relation to the Lac with a NDD. These types of abuse are again not new to the literature on Lac, but I could not find any other wider literature that has explored this on Lac with a NDD apart from those found in this thesis. Nevertheless, there may be literature available, as I only explored articles in the English language. Recent literature has found that autistic students experience more sexual, physical and emotional aggression than their non-autistic peers (Brown-Lavoie et al., 2012; Rothman et al., 2021). Another study found that autistic individuals may normalise sexual abuse placing them in even more vulnerable situations as has been suggested within this thesis (Carbajal & Praetorius, 2020). Other studies have found that adults with childhood ADHD were more likely to be victims of sexual assault and that they are at more risk of experiencing domestic or intimate partner violence (Buitelaar et al., 2020; Wymbs & Gidycz, 2021). Trauma has a significant impact on any child with and without a NDD. However, if we incorporate the social communication and interaction challenges that many of these children have, this could be placing Lac with a NDD at further risk as suggested by Sevler et al., 2013).

Sevler et al (2013) found that it was not just the core deficits of the NDD but the family situation and bullying environments, which might have contributed to some criminal involvement. Both the systematic and narrative review found that Lac with Bipolar disorder and ADHD may be at higher risk of criminal involvement related to the juvenile justice facility which suggests a petty crime. However, this was only based on two studies. Capuzzi et al (2022) screened 159 male prisoners and found that 32.4% met the criteria for ADHD symptoms but also suggested that a history of medication, physical abuse and social environment could have contributed to these symptoms which create even more perplexities. As already discoursed within this thesis, the literature is still relatively new in this area and is evident that more research is needed to explore the multitude of complexities that encompass these individuals.

This involvement in criminal activity was also proposed to be an adverse impact on Lac with a NDD in the small q study but more related to sexual grooming, exploitation and county lines. A comment made by one of the participants ‘our children are seeking love all the time, they’re the easiest kids in the world to groom’ remains with me as I complete this thesis. These children are already at significant risk in these areas as a result of their social and psychological environment. They have an innate need to be part of something, a group, a social identity where they are made to feel welcomed, wanted or loved. However, for a child/young person who has a NDD, this need to be part of something can engulf their thoughts and their lives as they do not feel like they fit in anywhere as a result of their challenges. They can often place themselves in vulnerable situations just to feel part of a group, they will often mimic behaviours even if they are detrimental to their wellbeing. What they perceive as ‘love’ can be confusing as a result of their challenges in interpreting what is a friendship or a romantic relationship which has already been discussed within this thesis which suggests that they may be at further risk of being sexually groomed, exploited or involved in county lines. (Brown-Lavoie et al, 2014, Brown et al., 2017b). This area requires more research to be conducted to protect and safeguard both Lac and Lac with a NDD, including every children/young persons in the population.

Having a stable and safe placement is integral to the Lac’s wellbeing. Both the systematic and narrative review found that Lac with a NDD were more at risk of being placed in foster care and residential care. There were suggestions that a lack of adequate support and services may have contributed to these outcomes. However, this was only based on a few studies. One recent study found that some children/young persons with ADHD had been placed ≥ 10 placements (Smith et al., 2022). This was also highlighted in the small q study where several of the participants proposed that the Lac with a NDD, who they had supported, had had multiple placements and some had eventually ended up in residential care. They suggested that this was often attributed to the challenging behaviours or from a safety perspective which could suggest a lack of specialist support service for the families or carers that care for these children. An interesting article by McCausland & Dowse (2022) that was conducted recently explores the ‘criminalisation of young people with cognitive disability in residential care’. In their case studies they find that residential care had not been the most appropriate care setting for the individuals with ADHD and had contributed to the criminalisation of their behaviours. The environment coupled with their NDD challenges and other factors had a detrimental impact on their wellbeing. As already discussed within this thesis residential care can be a

protective environment or setting for these children however, there is a need for more literature in this area to support this.

Homelessness is often associated with the Lac as a result of not having had a stable and safe placement in their lives, among varying other factors (Kelly, 2020; Nilsson et al., 2019). This narrative review only found one study that explored homelessness and Lac with a NDD. However, wider literature has suggested that children with ADHD and Bipolar disorder are at more risk of being homeless (Iwundu et al., 2020; Murillo et al., 2016). However, these were not Lac or Lac with a NDD. A recent study found that prisoners who had been Lac compared to those who had not been Lac had high levels of neurodisability and substance misuse and had experienced more homelessness (Kent et al., 2023). Substance misuse was also described by some participants in the small q study in this thesis as an adverse impact for some of these children. It cannot be determined if having a NDD places these children at higher risk of becoming homeless or having a substance misuse. Nevertheless, ADHD has been associated with having a substance misuse disorder in several articles (Elsabban et al., 2022; Haasbroek & Morojele, 2022; Samal et al., 2022). More research examining if there are any associations for the Lac with a NDD with these adverse outcomes would be beneficial. Earlier screening for neurodisabilities in this population may help prevent outcomes such as these as suggested by Kent et al (2023).

In the same study, they found that Lac were also more likely to have been placed in a pupil referral unit compared to their non-Lac peers (Kent et al., 2023). This is somewhat reflected in the findings from the SAIL study where Lac with ADHD are more likely to be placed in a pupil referral unit, but this also applied to Acyp with ADHD also. Acyp with ADHD in this thesis had a higher prevalence in the pupil referral unit compared to Lac with a NDD (66.2 versus 53.8%). Children with ADHD can function and learn within a mainstream educational setting provided they have the correct specialist provision and support. New interventions are being created which have shown to improve the academic attainment within the school setting (Harrison et al., 2022; Singh et al., 2022; Yıldırım Demirdöğen et al., 2022). The same applies for Acyp and Lac with ASD, many children with ASD are able to attend mainstream school provided they are supported correctly (Datta et al., 2023; Hodges et al., 2022).

In the SAIL findings, the pupil referral unit was the second highest educational placement in this instance. Both Acyp and Lac with ASD were more likely to be placed in an independent school (41 versus 50%) which is something else to explore. For some children, these

placements may be needed in an attempt to reintegrate them back into mainstream (Thomas, 2013). However, this is not always attainable as has been discussed within this thesis due to a lack of training or correct provision. There is also an economic cost to this as placing these children in these educational settings can be extremely expensive for local authorities to support. Although the SAIL findings are only based on Welsh data, research in this area from a UK perspective would contribute further to understanding the prevalence and reasons for both Lac and Acyp with a NDD.

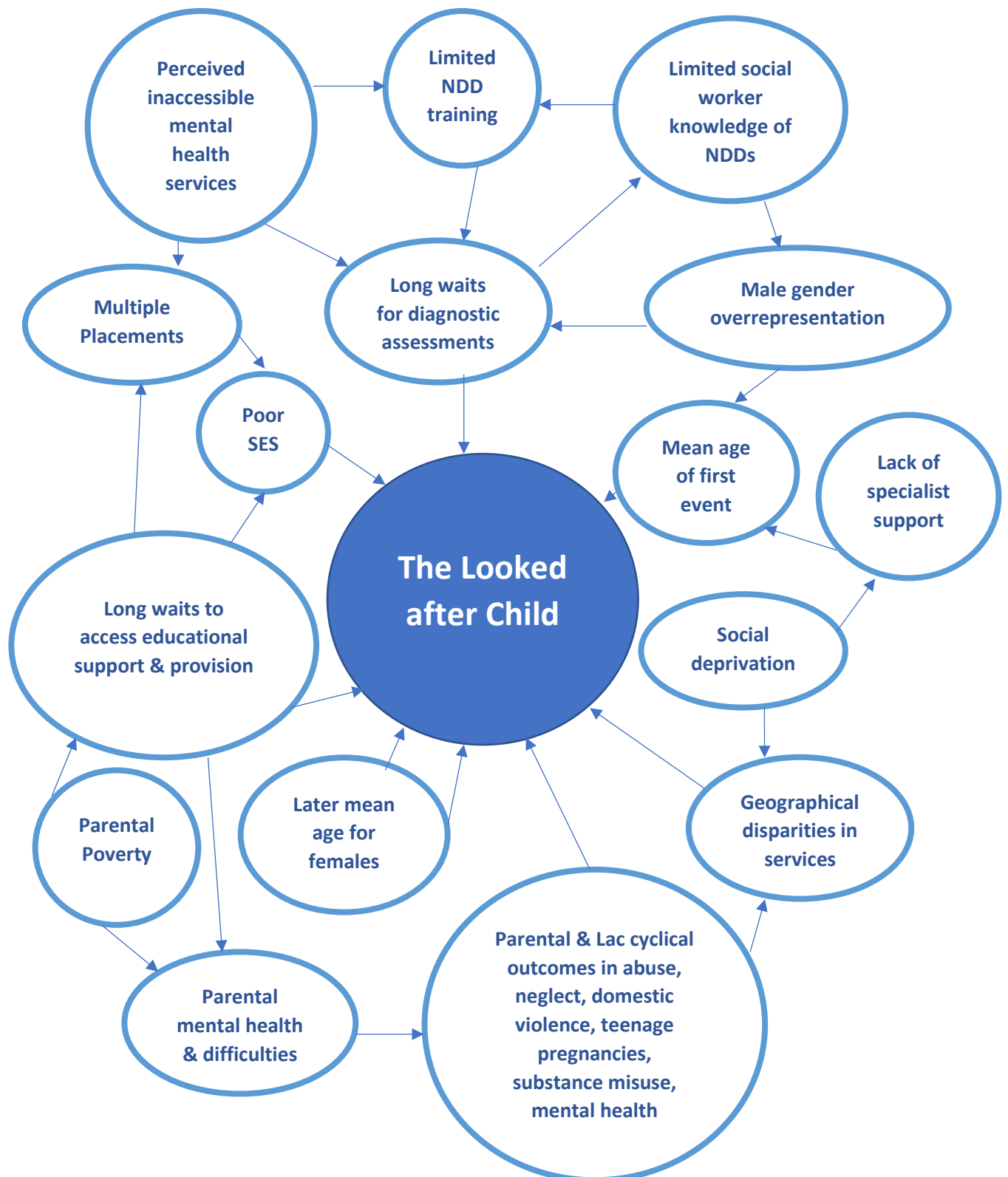
The SAIL study also found that Lac with a SEN in general between 2010 and 2015 had a significant higher prevalence in the EOTAS setting which is another novel area for Welsh policy makers to explore. It also showed that the prevalence of Lac with a SEN in the EOTAS setting has been increasing while the numbers of Acyp with a SEN is decreasing. Reasons for this should be examined in more depth as these children already have low educational attainment which is an area of high importance for Welsh government. This was also mentioned in the small q study where some participant responses based on their perceptions had seen educational attainment improving but was still an area for improvement. It will be interesting to see how this differs from 2015 onwards, particularly with the unexpected impact of the Covid pandemic.

The thesis only found one study that highlighted 'learning difficulties' for Lac with ADHD in the three key areas of learning: reading, maths and spelling. It is not new to literature that children with ADHD experience difficulties with their learning abilities, but this finding contributes to the literature on Lac with ADHD which has yet to be explored in more depth (Meltzer et al., 2003). Lac generally have been noted to have poor educational attainment and SEN compared to their non-Lac peers, which was also highlighted in the SAIL study. Having ADHD also would have a significant impact on their learning and educational attainment and would need specific provision and support. The prevalence of 'Developmental disorder of scholastic skills' (DDSS) was found to be higher in Lac within the systematic review however, this was based on only one study. The SAIL study found that Lac had a significant higher prevalence of 'Developmental disorder of scholastic skills, unspecified' compared to Acyp (4.1 versus 0.3%) which might contribute in some way to understanding why these children go on to attain such poor educational outcomes. This is an area that Welsh policy makers would benefit from further exploring to ensure that the new Additional Learning Needs (Wales) Act 2018, and Additional Learning Needs (ALN) Code 2021 meets the needs of these children (Knight & Crick, 2022).

The thesis also found impacts on the physical health of Lac with a NDD. The systematic and narrative reviews found that Lac with ASD had high levels of medication prescription, although it cannot be ascertained whether or not these children actually used this medication. Lac with ADHD were more likely to experience physical health difficulties in areas of bed wetting, eye/sight problems, speech/language problems and coordination difficulties compared to their peers with no disorder (Meltzer et al., 2003). Recent research has found that children and adolescents with both ASD and ADHD have more physical co-morbidities in areas of epilepsy, sleep disorders, encopresis, enuresis and many more, compared to those without a NDD, and this also included siblings (Ahmed et al., 2022; Buro et al., 2022; Khachadourian et al., 2023). One study also found that 25.1% of adolescents with ASD were obese (Buro et al., 2022). There could be a multitude of reasons for these physical health difficulties which might not be related to having a NDD however, this does highlight that these children may be at more risk of having problems with their physical health. Interestingly, the SAIL study found that paediatrics referrals were high for both Lac and Acyp with a NDD which may highlight some of the physical health difficulties. However, this study could not explore the reasons for these high referrals but what the findings do highlight is where the highest referrals are being made to what services which may help inform Welsh policy makers. Additionally, the tables in section 5.4.4 show similarity in the referrals being made for both Lac and Acyp with a NDD. The next section of this chapter highlights and further discusses some of the challenges, barriers and wider factors that some Lac with a NDD might encounter or experience. See figure 6.3.

6.3 Challenges, barriers and wider factors for the Lac with a NDD

Figure 6.3 Intrinsic challenges, barriers and wider factors for the Lac with a Neurodevelopmental Disorder



Finally, figure 6.3 details the challenges, barriers and wider factors for some Lac with a NDD. There is deliberately no logical flow to this figure as each factor may contribute to the next or occur as a result of the other factors detailed here. However, they are findings that some Lac with a NDD may have experienced or encountered on a local and/or national level derived from the SAIL and small q study. Although, the small q study is from a participant external perspective, many of the findings such as challenges to accessing educational provision, long delays in diagnostic assessments, lack of specialist support are representative of research conducted on children with a NDD in the general population. The wider factors such as poor SES, social deprivation and parental poverty are also not new to literature for Lac. However, the suggested inaccessibility to CAMHS is something that requires further attention as these children are already at a higher risk of developing mental disorders and having poor mental health which is reflected in the number of referrals made to CAMHS in the SAIL findings.

Sex differences are also highlighted here within the SAIL findings. Both Lac and Acyp males are significantly overrepresented in prevalence of NDDs and in the EOTAS setting which to my knowledge has not been explored before. These are novel findings as these show a more in-depth analysis of what specific disorders represent these broad NDD categories which are often not depicted in literature (Hill et al., 2017; Meltzer et al., 2003; NHS, 2018).

Furthermore, they highlight how females had a much later first event/episode than males for all NDDs in both groups (Acyp and Lac). This is a finding that will contribute to not only Lac literature but to existing literature on the general population. Females with both ASD and ADHD have been shown to be diagnosed much later than their male counterparts. Factors such as lack of awareness, training, high functioning behavioural symptomology, high cognitive ability, perceived good social communication and interaction skills, and andro-centric diagnostic assessment tools have been suggested to contribute to these late diagnoses (Cheng et al., 2022; Hull & Mandy, 2017; Lockwood et al., 2021; Lynch & Davison, 2022; McPartland et al., 2012; Tubío-Funqueiriño et al., 2021).

The lack of NDD knowledge and training for social workers should be further explored to see if this is reflective from a national context. These professionals are often the first and foremost individual that these children encounter when they have been voluntarily or involuntarily removed from the biological parent. Having a better understanding of how some of these NDDs and their behavioural symptomologies manifest in both females and males would have a significant impact on how they and other disciplines support these children.

This may not be reflective of other parts of Wales or from a national perspective. Nevertheless, a recent study examined objective and self-reported ASD knowledge in various professionals using multiple choice questionnaires. Psychology trainees answered 68% of the questions correctly compared to social work trainees who answered 46% correctly (Bono et al., 2022). This is not to suggest that social workers do not have the capacity to have a comprehensive knowledge of ASD but it does suggest that the training they had received may not have been as comprehensive as the training that had been provided to the psychology trainees. The lack of comprehensive ASD knowledge was reflected in some of the responses from the small q study. However, this is only based on one small q study conducted in this thesis. As already discussed within this thesis, each child with a NDD has individualistic needs and challenges which require an in-depth understanding and awareness, even more so for the vulnerable Lac. Providing social workers with in-depth training and appropriate interventions would help alleviate some of these challenges (Leung et al., 2022).

The parental efficacy, mental health and cyclical outcomes, although limited in evidence in this thesis is an area that is gaining interest in social work. Using family scripts or genograms are suggested to try and untangle the complexities in these families (Huss & Kapulnik, 2021; Majhi et al., 2018). As already discussed within this thesis, if we accept that NDDs may be re-occurring on a genetic or hereditary level, it could be a proactive approach and beneficial for earlier identification and intervention to reduce potential adverse outcomes in individuals with NDDs (Azeredo et al., 2018; Gialluisi et al., 2021; Grønberg et al., 2013; Kumar, et al., 2016).

The multi-directional influences of the intrinsic challenges, barriers and wider factors that encompass Lac with a NDD are complex and each challenge, barrier and wider factor could have a negative domino effect on the wellbeing of the Lac with a NDD. However, for the Lac with a NDD who reside in Wales, these findings are unique to the literature and could provide Welsh policy with areas to further explore from a safeguarding and proactive perspective.

6.3 Missing Data and Literature

While it is important to report on findings that have significance, it is also important to report on what could not be found. The lack of data on ethnicity is a significant finding which requires urgent focus from policy makers. A recent study in Ireland that examined data collection on ethnicity in health and social care data sets found similar findings. They found that only 14% (14) out of 97 data collections collated information on ethnicity (Hannigan et al., 2020). Capturing ethnicity data is crucial for varying reasons. It informs policy and practice on the burden of a disease on a population, or cultural differences that will require adaptations to service or practice, communications or language that is used. It can also provide a picture of SES, health disparities and whether services are accessible to conversely not used as a result of religious beliefs and attitudes (Armin et al., 2014; Perez et al., 2022). This also has implications for NDDs as it is already suggested that there are racial and ethnic disparities in diagnosis for ASD and ADHD as a result of varying factors such as cultural differences which have further been elaborated on within this thesis (Golson et al., 2022; Martin et al., 2022).

The limited literature on the other NDDs of interest should also be highlighted. However, the systematic review only captured articles that compared Lac to non-lac. As already detailed in the thesis, dyslexia which is a learning disorder does exist in both the general population and in Lac and this also applies to some of the other NDDs (Scaria et al., 2022; Woolgar, M., 2013; Yang et al., 2022). The recent Kent et al (2023) study found that dyslexic traits were found in Lac who were now adults but that was based on reported measures and not diagnosed. There are still very limited studies that have explored the prevalence of some of the other NDDs in the Lac population (Keefe et al., 2022). Whether or not the learning challenges associated with NDDs and which are highly prevalent in this population, are affecting educational attainment, developmental and learning difficulties, should be further explored (Eiberg & Olsen, 2022). Similar findings were identified in the SAIL data, as the study only found zero counts for NDDs such as bipolar disorder, dyslexia, dyspraxia and dyscalculia in the Lac population. However, they could be documented in the educational dataset which was not explored in this study and would be something for future research to explore.

6.4 Conclusion

This thesis explored the prevalence of NDDs in Lac, the impacts on the Lac with a NDD and the challenges, barriers and wider factors that these children may be experiencing. Although, some of these findings derive from the social worker perceptions and not from the Lac themselves, they do show similarities with wider literature. Untangling what has contributed to these prevalence rates and the adverse impacts on the child was not possible as part of this thesis and one could argue that this may never be attainable as a result of the multi-faceted, complexities that encompass these children. Nevertheless, the findings of this thesis do contribute to the limited literature on Lac with a NDD and some will inform national policy and practice of potential challenges and barriers that these children may encounter. Furthermore, it highlights some gaps in the literature that need to be explored. Recommendations for research, policy and practice are detailed in the final section of this thesis.

6.5 Recommendations

This thesis has identified several recommendations for research, policy and practice which are detailed below.

Research recommendations

- Further research into the reasons or dynamics that underpin these high prevalence rates in Lac would be beneficial to understand why they are higher in this population to ensure services meet their needs.
- Further research to understand what prominence some of the other NDDs, particularly dyslexia, dyspraxia and dyscalculia may have in the Lac population in other countries would be beneficial. These NDDs can substantially impact on the child's ability to learn within the educational setting which is an area of concern for Lac on a global level.
- Further research into the mental health service and medication usage in Lac with NDDs could provide more insight from a service, policy and economic perspective to better meet the mental health needs of these children.

- From a safeguarding perspective, more research is needed to explore the adverse impacts on Lac with a NDDs as the addition of ACEs and vulnerable environments could place these children at further risks. Urgent research is required to explore if the Lac with a NDD may be placed at further risk in areas of

- (a) Co-occurring mental disorders
- (b) Physical health
- (c) Sexual abuse
- (d) Emotional abuse
- (e) Physical or domestic abuse
- (f) Criminal justice involvement (sexual exploitation, county lines or criminal gang involvement)
- (g) Suicidal ideation
- (h) Homelessness
- (i) Sexual exploitation
- (j) Substance misuse

- ADHD and ASD prevalence rates are often depicted in literature as being higher in males compared to females. However, more research is needed to examine if male representation is higher in the other prevalence rates of DDSS, unspecified, Tic disorders, RAD and OCD as identified in the SAIL study.
- More research is needed to explore from a Lac with a NDD perspective, the suitability of residential and pupil referral unit placements.

Policy and practice recommendations

- Develop more defined and effective data collection processes for ADHD and other NDDs such as dyslexia, dyscalculia, dyspraxia that are detailed in this review.

- Capture important information related to both the Lac and Acyp populations in areas of ethnicity.
- Collate more detailed information like that captured within the CRCS dataset. This would provide a more informative dataset for exploration into the potential wider determinants associated with the Lac who has a NDD (Welsh Assembly Government, 2020).
- Explore whether the prevalence of Lac with SEN in EOTAS has increased or decreased over the last several years and the reasons associated.
- Explore the factors why females with these NDDs in Wales have a later first event/episode documented in the WLGP and PEDW datasets compared to males.
- Explore from a national context whether referrals to educational and mental health support transition with the Lac if they move out of county. This will ensure that the Lac receives the appropriate support from the very outset.
- Develop training and awareness of NDDs, in terms of how they present and what interventions can be used. This would be beneficial for all health and social care professional that support these children.
- Monitor waiting lists for diagnostic services for Lac. These waiting lists are lengthy. These children are some of the most vulnerable in society and being assessed early would ensure that their needs are met as early as possible.
- Explore the reasons for the high number of referrals to CAMHS and Paediatrics and to further explore if they are fully accessing these services to meet their emotional, mental or physical needs.
- Develop accessible screening pathways for specific learning disorders that are associated with NDDs. This should be conducted at an early age within the educational sector to provide relevant support to improve educational attainment based on the prevalence of scholastic developmental disorders, unspecified.

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Appendix

Appendix 1 Example search strategy for Systematic review.

Appendix 2 Critical Appraisal of Systematic Review

Appendix 3 Participant Information Sheet

Appendix 4 Participant Consent Form

Appendix 5 Ethical approval

Appendix 6 Semi-structured topic guide

Appendix 7 Information Governance Review Panel Protocol

Appendix 1 Example search strategy for Systematic review. Search Strategy from ProQuest 10 June 2019 10:11

Set#	Searched for	Databases	Results
S1	(((MAINSUBJECT.EXACT("Hoarding disorder") OR MAINSUBJECT.EXACT("Emotional disorders") OR MAINSUBJECT.EXACT("Obsessive compulsive disorder") OR MAINSUBJECT.EXACT("Psychosis") OR MAINSUBJECT.EXACT("Mental depression") OR MAINSUBJECT.EXACT("Bulimia") OR MAINSUBJECT.EXACT("Eating disorders") OR MAINSUBJECT.EXACT("Family medical history") OR MAINSUBJECT.EXACT("Behavior disorders") OR MAINSUBJECT.EXACT("Bipolar disorder") OR MAINSUBJECT.EXACT("Personality disorders")) OR (MAINSUBJECT.EXACT("Obsessive compulsive disorder") OR MAINSUBJECT.EXACT("Psychosis") OR MAINSUBJECT.EXACT("Mental depression") OR MAINSUBJECT.EXACT("Bulimia") OR MAINSUBJECT.EXACT("Eating disorders") OR MAINSUBJECT.EXACT("Family medical history") OR MAINSUBJECT.EXACT("Behavior disorders") OR MAINSUBJECT.EXACT("Bipolar disorder") OR MAINSUBJECT.EXACT("Personality disorders")))) AND la.exact("English")) AND PEER(yes)	International Bibliography of the Social Sciences (IBSS)	7052
S2	((ti(mental health OR mental disorder* OR mental retardation OR psychiatric disorder* OR psycholog* disorder OR psycholog* disability*) OR ab(mental health OR mental disorder* OR mental retardation OR psychiatric disorder* OR psycholog* disorder OR psycholog* disability*)) AND la.exact("English")) AND PEER(yes)	International Bibliography of the Social Sciences (IBSS)	20350

S3	((ti(development* disorder* OR development* disability* OR, neurodevelop* disorder* OR learning disability OR learning disorder) OR ab(development* disorder* OR development* disability* OR, neurodevelop* disorder* OR learning disability OR learning disorder)) AND la.exact("English")) AND PEER(yes)	International Bibliography of the Social Sciences (IBSS)	3936
S4	((ti(foetal Alcohol Spectrum Disorder* OR FASD OR Reactive Attachment Disorder OR RAD OR Attention Deficit Hyper* Disorder OR ADHD OR paediatric bipolar OR bipolar disorder OR schizophrenia OR Obsessive Compulsive Disorder OR OCD OR Eating Disorders OR Bulimia OR bulimia OR bulimic OR anorexia OR anorexic OR Autis* OR Autism Spectrum Disorder OR ASD OR Pervasive Development Disorder OR Asperger* OR Specific Language Disability OR SLD OR Speech and Language Impairment OR Mathematics Disorder OR mathematic disability OR Dyscalculia OR Intellectual Disability OR Reading disorder OR written Disorder OR Dyslexia OR Social Communication Disorder OR social pragmatic language OR Tic Disorder OR Stereotypic Movement Disorder OR Developmental coordination disorder OR Dyspraxia OR Social Anxiety OR social anxiety phobia) OR ab(foetal Alcohol Spectrum Disorder* OR FASD OR Reactive Attachment Disorder OR RAD OR Attention Deficit Hyper* Disorder OR ADHD OR paediatric bipolar OR bipolar disorder OR schizophrenia OR Obsessive Compulsive Disorder OR OCD OR Eating Disorders OR Bulimia OR bulimia OR bulimic OR anorexia OR anorexic OR Autis* OR Autism Spectrum Disorder OR ASD OR Pervasive Development Disorder OR Asperger* OR Specific Language Disability OR SLD OR Speech and Language Impairment OR Mathematics Disorder OR mathematic disability OR Dyscalculia OR Intellectual Disability OR Reading disorder OR written Disorder OR Dyslexia OR Social Communication Disorder OR social pragmatic language OR Tic Disorder OR Stereotypic Movement Disorder OR Developmental coordination disorder OR Dyspraxia OR Social Anxiety OR social anxiety phobia)) AND la.exact("English")) AND PEER(yes)	International Bibliography of the Social Sciences (IBSS)	10122
S5	S1 OR S2 OR S3 OR S4	International Bibliography of the Social Sciences (IBSS)	34993

		These databases are searched for part of your query.	
S6	((ti(Looked after child* OR LAC OR foster child* OR foster care OR out of home care OR out-of-home care OR residential care OR kinship care OR adopt* OR child* in secure unit OR child* in welfare OR child* in protection) OR ab(Looked after child* OR LAC OR foster child* OR foster care OR out of home care OR out-of-home care OR residential care OR kinship care OR adopt* OR child* in secure unit OR child* in welfare OR child* in protection)) AND la.exact("English")) AND PEER(yes)	International Bibliography of the Social Sciences (IBSS)	88130
S7	S5 AND S6	International Bibliography of the Social Sciences (IBSS) These databases are searched for part of your query.	1649
S8	((ti(prevalence OR incidence OR occurrence* OR rate* OR frequency) OR ab(prevalence OR incidence OR occurrence* OR rate* OR frequency)) AND la.exact("English")) AND PEER(yes)	International Bibliography of the Social Sciences (IBSS)	187899
S9	S7 AND S8	International Bibliography of the Social	278

		Sciences (IBSS) These databases are searched for part of your query.	
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Appendix 2 Critical Appraisal Results 01/07/20

A systematic review protocol to explore the prevalence and impacts of neurodevelopmental disorders in the care experienced by the looked after population

Analytical Cross-Sectional Studies (n=1), Case Control Study (n=1), Cohort Studies (1), Prevalence Studies (n=9)

Total number of studies (n=12)

Keys: Y = Yes, N = No, U = Unclear, N/A = Not applicable

Table: Analytical Cross-Sectional Study

Citation	Review	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Comments
Mandell et al. 2008	1	Y	Y	Y	Y	Y	U	Y	Y	Seems pretty robust but no explicit detail about confounding but may not be relevant due to the study design. Adjustments were made for clustering and multiple testing. This is a cross sectional study that explored the use of psychotropic medication in children who had ASD. The study explored all children who were in the Medicaid database who had an ASD diagnosis. They also coded other disorders of interest in this review; schizophrenia (295), bipolar disorder (296.00–296.10 and 296.36–296.89), attention-deficit disorder (314), and mental retardation (317–319). Mental retardation was further classified as mild (317), moderate (318), or severe (319) on the basis of the most common ICD-9 code associated with each child’s claims. The inclusion of this study is important to the review as the high medication use of these children in foster care could have potentially detrimental impacts on their future health and social wellbeing. The results of this review are concerning on many levels. There is still very limited literature on the benefits or positives of taking medication for these disorders. For example, we now know that ASD and ADHD have genetic similarities; they are both suggested to be nervous system disorders. If we are prescribing these children with stimulants, are we possibly exasperating the biological responses in these children; increasing challenging behaviours. Or are we dulling the biological responses with antidepressants or
	2	Y	Y	Y	Y	Y	U	Y	Y	

													neuroleptics so that the behaviours can be managed. Unfortunately, what we do know is that there is no literature yet to provide us with a definitive answer; therefore, there are ethical issues that need to be addressed here. Medication seems to be the quickest route to managing these behaviours however, we do know that more therapeutic therapies and programs can achieve the same result however, time is the key here. The results are yet again reflective of other studies in this review is that foster care children had a higher use of medication. Among all Medicaid-eligibility categories, children who were eligible through foster care had the highest use of psychotropic drugs (71%). Foster care children had the highest prescribed medication of antidepressants, neuroleptics, mood stabilizers and stimulants. Although the sample looked at all children and not just foster care in the Medicaid database with an ASD diagnosis yet again the sample was predominantly aged 6 to 11 years (45%) mostly male (78%) and white (50%). More worrying was that medication was also common even in children aged 0 to 2 years (18%) and 3 to 5 years (32%). There seems to be a recurring pattern in the literature not just for foster care children but additionally the general population.
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Table 2 Case control study

Citation	Review	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Comments
Tordön et al. 2019	1	Y	Y	Y	U	U	Y	Y	Y	Y	Y	Self-reported study so could have bias in answers. Confounding factors were explored but not explicitly. The results of this study are very interesting as for various reasons. The out of home care group had more often an immigrant background and a non-heterosexual orientation, had more often experienced physical and penetrative sexual abuse, and more often sought healthcare for mental problems. Disclosure of sexual abuse was less common, and acts of persuasion or adults' use of their social position was more common among students in out-of-home care. The higher non-disclosure of abuse by the child from the
	2	Y	Y	Y	U	U	Y	Y	Y	Y	Y	

																			<p>out of home care sample is not expected as the study suggests as they are embedded in social services. Exploration into what profession or relationship these adults had what social position they had would help further research into this area of abuse. Furthermore, even having a good educational attainment had no bearing or protective factor in this study. Although an interesting study, it does have some limitations. A small sample size, all information associated with mental health disorders and outcomes of interest were self-reported by an online questionnaire although response rate was good. Yet, it does show a higher prevalence of ADHD, eating disorders and ASD rate that supports other studies. Additionally, the association with child abuse, sexual abuse and mental health problems are reflective of other studies. Furthermore, the sexuality is also of an interest as although many studies suggest that this can be a result of their adverse experiences. Many studies are now emerging that suggest that children with ASD and ADHD have problems in this area due to their inability to understand emotions and feelings; particularly in the puberty period.</p>
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Table 3 Cohort Studies

Citation	Review	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Comments
Côté et al. 2018	1	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Rigorous well conducted study. Cote found that children in welfare had greater odds of having higher substance related disorders, psychotic or bipolar disorders, depression or anxiety, neurodevelopmental disorders, other disorders. They also had higher prescription usage for psychotropic medication and higher rates of criminal
	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	

											<p>convictions in violent offences and property offences. This is an interesting article as in Finland; more children are placed in CW due to parent's physical or mental illness or because of the child's special care or educational needs. Abuse and neglect are the less common referrals. This is complete contrast to other countries such as UK where it is the primary referral need. Strength - The study used ICD coding and not self-reported. It matched each child with a control using appropriate methodology (propensity scoring). Although, the study does not detail individually the specific disorders; it supports this SR by detailing the codes of the disorders being explored and providing prevalence of diagnosed mental disorders compared with children who have not placed. With regards to the prevalence, although the study explores a combination of disorders; the study includes 5 of the ICD-10 codes being explored in this review; therefore, providing a good rationale for including the article. Again, although the disorders are combined in prevalence rates; the comparison with non-LAC reflects the results of the SR. This study raised many questions for further research. 128 children in the out of home care compared to 67 children in the control group had been treated in specialised inpatient or outpatient hospital units for psychiatric or neurodevelopmental disorders. Most concerning was that 36% of 386 had a criminal conviction compared with 21% of control (aged 18-25). This does not associate these disorders with being in the criminal system as there are too many cofounders that could have contributed to this outcome. However, this is interesting as there is emerging research to suggest that many of these children with these</p>
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													disorders are often misunderstood and extremely vulnerable in the criminal justice system; due to their cognitive impairments; making them vulnerable to peer led pressures in a social situation (Mogavero (2018). What is important to note is that many of these disorders were not diagnosed until adulthood, one third of placed children compared to one tenth of the cohort. This has significant implications for the health and social wellbeing of these individuals as early identification and support is integral to improving their future overall wellbeing. Unmanaged and unsupported can cause detrimental impact on health and social outcomes as depicted in much research with regards to these disorders (Mogavero, M. C. (2018). What Do Criminal Justice Students Know About Autism? An Exploratory Study Among Future Professionals. Journal of Police and Criminal Psychology, 1-11.
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Table 4 Prevalence studies

Citation	Review	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Comments
Harman et al. 2000	1	Y	Y	Y	Y	Y	Y	Y	Y	Y	Good quality study. Harman follows a similar protocol to dosReis analysing Medicaid claims and eligibility records to determine the prevalence of mental health diagnoses and use of services from an expenditure perspective. This time the study analyses data derived from the Pennsylvania state. A total of 39500 children aged between 5 and 17. Although similar, the population study is much higher than dosReis and it's aim is to seek a comparison. For the purpose of this review, this study finds similar results in that mental health is once again higher in
	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	

											the foster care population (3-10 times higher) and were 7.5 times more likely to be hospitalised for the condition. Children with disabilities were defined as comparable in terms of prevalence of psychiatric conditions. Several questions arise here; are the children accessing services much quicker; attaining a diagnosis because they are in the care system or are mental health disorders higher in this population. What is interesting to note and definitely something to explore in future research is how many of these children with disabilities eventually end up in the care system and at what point. Note that ADHD is a qualifying condition for SSI. Results were that children in foster care were more likely to have a higher prevalence of these disorders compared to those on AFDC or SSI. Children in foster care and children with disabilities (SSI) were comparable. Foster care compared to AFDC was ADHD (14.7% vs 3.9), Bipolar (1.0% vs 0.1%). Foster care compared with SSI was the other way for ADHD (19.8% vs 14.7%) and bipolar (1.4 vs 1.0%). However, when adjusted, rates for ADHD and bipolar were just as large on diagnostic rates.
dosReis et al. 2001	1	Y	Y	Y	Y	Y	Y	Y	Y	N/A	Good quality study. This study explored mental health services and how did they compare to other groups who utilise the medical assistance aid services. There are several questions to this article, one is that is heavily biased to youths (the sample) in a poorer socioeconomic background. The comparison does not include all other youths who are not in the care setting. The study was only a one-year cross sectional analysis. Nevertheless, the prevalence numbers for the disorders reflect the other studies that have better comparisons. The sample frame derived from computerised claims for 15507 youths, under the age of 20, over a 1 year cross sectional analysis who
	2	Y	Y	Y	Y	Y	Y	Y	Y	N/A	

											<p>lived in one county in the mid-Atlantic state who had claimed medical or prescription claims associated with a mental disorder or psychotherapeutic medication. Limitations to this is that it is one county only. A third of this population were also excluded as paid claims for medical and prescription services was not in the database. This is a limitation for the study as this focuses on those youths that maybe in a poor socioeconomic area, managed care is health insurance. The three groups explored were categorised into foster care, supplementary security income and other types of aid. Foster care comprised of those placed out of home by juvenile services plus state adoption agencies, SSI and the other aid category comprised AFDC (60%); the pregnant women and children program (32%), which included coverage for various groups of infants, children aged 1 through 5 years, and youths 6 years or older; non-AFDC primary care and preventive services (2%); programs for the medically needy (3%); the family planning program (2%); and the pharmacy assistance program (0.3%). For the purpose of this study, the sample size was adequate. As data was population based inferential statistics were not required. The study uses diagnosed disorders according to the ICD-9 codes, 290-319. They were then categorised into 15 subcategories. Bipolar, tic disorders, mental retardation and all other mental disorders were not included due to small numbers. Additionally, another imitation to this for the purpose of this review is that subcategories such as developmental disorder and learning disorder were not further classified even though they were relatively high numbers. Data analysis addressed the prevalence rates of mental disorders and were measured by number of cases plus number of prevalence cases per 100. These youths were enrolled in the Medicaid service but additionally had a</p>
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											diagnosed disorder. Table 2 illustrates those rates of mental health disorders in foster care are 2.2 times higher than youths in SSI and 16 times higher than other aid. ADHD, depression and developmental disorders were the most frequent diagnoses. Learning disorders were higher in the SSI group.
Ford et al. 2007	1	Y	Y	Y	Y	Y	Y	Y	Y	Y	Good quality study. This comparative study has been used in many other systematic reviews and therefore has been included in this review. The sample derived from four surveys that were nationally representative and same instruments were used. Three surveys derived from looked after British children and one survey from British children in private households. The study was one of the first to use a random sample which strengthens the validity of the results. The sample groups were categorised as looked after, deprived or non-deprived children living in private households. It is important to note that the ineligibility section defines why some participants did not participate. Future research would benefit from exploring those reasons. The sample frame, although only derived from England, Wales and Scotland data sources, was appropriate to address the target population. Data sources such as local authority boards and the child benefit register were used defined by postal sector; enabling a wide range of participants to be sampled to be conducted to address the research question. All four surveys used same process and screening tools; however age range differed between private household and looked after children but was adjusted for during analysis. All participants were randomly sampled; children looked after by local authorities were randomly sampled from a range of placements that children who are cared for can be positioned in such as kinship care, residential and so forth. Additionally, using
	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	

											<p>the child benefit register and defining by postal sector; allowed the study to also sample a wide range of children living within a private household; disadvantaged children for this study were classified by parental employment status. This is an important classification as education is also often used to determine disadvantaged households and research ascertains that there are many parents who are highly educated are still in low skilled jobs due to carer responsibilities or poor physical and mental health. The sampling method used in this study represented as much as is feasibly possible a representation of the population being explored. However, for future research the child benefit register could potentially exclude many participants due to the changes in wages threshold implemented by recent government policy. The study did not require a sample size calculation due to it being a national survey. Therefore, the sample size was adequate. All study subjects were classified and categorised into several settings. Both looked after children and children from private households were classified into distinct measurable categories; gender, age, ethnicity etc enabling a comprehensive report to be produced. The response rate for all groups was sufficient for this study however, there was an overall lower response rate for the looked after population. The reasons for ineligibility are interesting to note and would be worth exploring in future research. The methods used to identify the psychiatric disorder; involved two gold standard screening tools; including both the parental or carer observations, the child themselves if they were 11 years of age or over and the teacher responsible in the educational setting. The results were then discussed by experienced clinicians and combined to attain a diagnosis as classified by the ICD-10 criteria. There are limitations to these methods; possible recall</p>
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											<p>bias by the parent or carer; particularly if the child had just entered the care placement as they would have very limited history on the child's behaviour beforehand. Over and under reporting bias could have occurred within this sample as all screening tools used were observer reported or self-reported. Both the Development and Well-being Assessment (DAWBA) and Strength and Difficulties questionnaire (SDQ) were used which are two well recognised screening tools that are regularly used in assessing psychiatric disorders. Additionally, research suggests that these two comprehensive tools do not always detect the child that masks their behaviours; particularly higher functioning disorders such as Autism or Asperger's; especially girls; which could have further increased prevalence. Additionally, it does not state in the study what clinicians were used in the multi-disciplinary team to assess a psychiatric disorder as that stated in the NICE guidelines, particularly for more complex disorders. Nevertheless, they are standardised tools that are still recognised as gold standard. Both numerator and denominator and percentages were clearly reported and both confidence intervals and p values were used to determine statistical significance. The methods section clearly outlined the analytical techniques used and how the variables were measured. The analytical techniques used were appropriate for this study. Overall, the response rate was adequate but as mentioned beforehand, the lower response rate for looked after children is something to be further explored. However, the study clearly outlines all reasons for ineligibility.</p>
Keefe et al. 2020	1	Y	Y	Y	Y	Y	Y	Y	Y	Y	<p>Large sample size of foster vs non-foster children. In terms of demographics Hispanics were underrepresented. Well conducted study utilising anonymised Medicaid records. A</p>
	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	

											really good recent comparative study that explored prevalence of mental disorders and primary care utilisation in both foster and non-foster care children from the age of 1 to 18. All data originated from electronic records therefore contributing to increased validity in the results. Overall, the results demonstrated that children not in foster care had a greater number of primary care visits and the odds of having >3 visits were significantly lower for children in foster care with a mental health disorder diagnosis. More than a quarter of children in foster care had a diagnosis of a mental health disorder, compared with 15% of children not in foster care. The study provided data on ADHD and ASD (code 299.0 developmental disorder which is now ASD). Learning disorders were also detailed but not as dyslexia or dyspraxia.
Vanderwerker et al. 2014	1	Y	Y	Y	Y	Y	Y	Y	Y	Y	Good quality study. This is a very good study but unfortunately those who had schizophrenia, bipolar, autism and major depressive disorder were excluded. An email has been sent to relevant authors but no responses as yet. Nevertheless, ADHD remains a consistent higher prevalent disorder in this population. The study explored whether the prevalence of externalising disorders would contribute to the higher use of antipsychotics foster care children. What is more concerning is that yet again a high percentage of medication is prescribed at a very young age, significantly higher in the foster care setting.
	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	
González et al. 2019	1`	Y	Y	Y	Y	Y	Y	Y	Y	Y	Good quality study. An interesting study that explores ADHD and the effects of exposure on ADHD, adjusted by age, sex, income, household education, parental psychopathology, comorbidity and ADHD medication status. The results showed maltreatment and adverse experiences including emotional
	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	

											abuse, physical abuse and foster placement were significantly associated with ADHD diagnosis. Emotional abuse and foster placement had robust associations with ADHD diagnosis. Girls who had experienced physical abuse had a threefold increase in the odds of having ADHD diagnosis; for boys, associations were observed only for emotional abuse. What was interesting so that emotional abuse was significant with boys and ADHD. This could be suggested to be as a result of breakdowns in relationships between parent/carer and the child. Boys additionally very often externalise their behaviours and challenges whereas girls with ADHD can often internalise their challenges. Therefore, this could provide some reasoning for this result. A limitation to this is that the participants were compensated to be part of this study. However, this does not always impact the validity of the interviews and results (Bentley & Thacker, 2004). Other limitations were that recall and self-report bias could have occurred and was not taken into account. Furthermore, a multidisciplinary approach was not used to diagnose the condition.
Turney et al. 2016.	1	Y	Y	Y	Y	Y	Y	Y	Y	Y	Good quality study. This study found that children in foster care have poor mental and physical health to those children in the general population, children from specific family types and children in economically disadvantaged households. The sample frame derived from the 2011-2012 National Survey of Children's Health, a national representative sample of non-institutionalised children in the USA. Limitations are that this is based on parent reporting so could potentially be biased. Additionally, the diagnostic tools or processes has not been detailed. Therefore, this could be a parent assuming that his or her child has these outcomes without an official diagnosis.
	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	

											Conversely, the child in question may be going through the diagnostic process which can often take up to ten years for many of these disorders. The strength to this is that all participants have followed the exact same process within this study. Therefore, strengthening the validity somewhat to include in the systematic review. Another limitation to this study that might impact the results of this review is that the analytical sample excluded 2443 to missing household data. Additionally, more importantly, 1075 children who had been adopted from foster care were excluded in the Table 2.
Egelund & Lausten, 2009	1	Y	Y	Y	Y	Y	Y	Y	Y	U	Generally good paper with large sample. No confidence intervals presented for the Odds ratios. The results tables could have been improved by inclusion of reference category. This comparative study aims were to explore the prevalence of mental health problems in 'out of home care', in home care and children who were not child protection clients. Strengths to the diagnoses was that the study used national administrative data which had pre-existing diagnoses. Additionally, the diagnoses were made by highly qualified medical professionals. Limitations were that the prevalence was estimated at a given point so therefore, the children could have lost their original diagnosis. Conversely, they could have attained a diagnosis later in life as is often the case with these disorders being explored. Limitations were that the SDQ was utilised and therefore, this tool has been suggested to not be subtle or comprehensive enough to capture many mental or developmental disorders. One screening tool is not sufficient to detect disorders such as high functioning ASD, particularly girls. It is important to note that it takes 10 years for an update to the DSM and even longer for the ICD; therefore, it would be interesting to see if the
	2	Y	Y	Y	Y	Y	Y	Y	U	U	

										<p>results would have changed if conducted in this period with new awareness of these disorders plus more up to date screening tools. There is also an element of possible recall bias that might affect the results of the survey questionnaires that were sent to the carers, social workers etc. The carer, social worker might not have had the child for very long in their care; and have very limited knowledge of the child's past behaviours or developmental challenges. This would have an impact on the criteria needed to diagnose or raise concerns for the child. Additionally, the terminology also used in lots of screening tools can be difficult to understand for the individual who has no experience in this area or has lower educational attainment which is the case for many parents who live in a deprived area (elaborate language). This would support previous research which suggests that many of these children might have been missed again as suggested by McCann et al (2006). Another important note is that 'not otherwise specified disorder' is often documented within prevalence studies. This is an area to explore, and it would be interesting to go back and do a revise and new up dated screening on these children to see if they now do pass the criteria for disorders such as Bipolar, ADHD or ASD.</p> <p>This study addresses the lack of children receiving mental health services, even in Denmark itself. Considering the rates are so high; policy holders need to ensure that the services are provided for these vulnerable children. Other research suggests that services are provided however the child will not engage or disengages before the therapeutic sessions finish. Several reasons for this could be that the child has moved to a different health board and has to begin the process again for referral; the</p>
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											<p>child has to repeat their ordeals to yet another professional; the child has reached crisis and is therefore unable to attend the sessions due to debilitating anxiety. Factors related to child: Boys again are overrepresented in this group. This could suggest that these disorders are higher in boys like many articles suggest. Conversely, boys are renowned in research and on a biological level to externalise their behaviours and needs whereas girls internalise more and feelings are expressed in anxiety or depressive behaviours. This is reflected often in LAC literature where girls score much higher than boys in this area. They both have the disorders but the behavioural symptomology manifests in a different and more societally acceptable way. If a child plays up in class, he is much more noticeable than the child who is quieter and conforms. An interesting note is that children in care had fewer full and more half siblings suggesting that family life was more unstable and more dynamic in family settings. Characteristics related to parents: Demographically, mothers of children in care were much younger having the children, 10% higher being teenage mums compared to the other two groups. 57% were single mums, 50% for IHC and 18% for NIHC. Mortality is also mentioned here as the parents are more deceased in comparison. Mothers and fathers with a psychiatric diagnosis were much higher. Additionally, there was a higher percentage for the mothers and fathers who had been in care previously. All these demographics and characteristics suggest a cycle of care. Higher substance misuse and higher imprisonment. Mental Health: Children in care had significantly higher mental health disorders compared to NIC. 5 % of both care groups had mental retardation, 8% of IHC had pervasive developmental disorder, especially childhood autism. Hyperkinetic disorders</p>
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											were similar for care groups but not for NIC group. It acknowledges that single mums, parents who have psychiatric diagnosis is suggested to be more vulnerable to having a disorder.
Zill et al. 2014	1	Y	Y	Y	Y	Y	Y	U	Y	U	Identification of condition from responses to survey questions. May not be based on definitive medical diagnosis. Specific tool used to collect data so probably consistently applied. Response rate low (~23%)- non-response bias discussed. A national survey was used as the sample to conduct a study that explored the health and wellbeing of children who were in foster care, children who had been adopted from foster care and used two other comparison groups (children living with both biological parents and children living with biological single parents). Results suggested that being adopted was associated with a high SES but did not impact on developmental, academic or wellbeing outcomes. 'More than a third of adopted children (36%) had been diagnosed at some point in their childhood as having ADHD. This was significantly more than the 22% of foster-care children who had received a similar diagnosis. Both groups were more likely to be diagnosed ADHD than children with never-married mothers (11%) or children with both birth parents (5%'. Yet again, ADHD is a primary neurodevelopmental disorder that is suggested to be higher in this population. Even higher than depression. What is interesting is that this survey does not include children who are in group homes or institutions. The reasoning for that should be explored in future research. They would have no parental reporting which would be a good reason for excluding them
	2	Y	Y	Y	Y	Y	Y	U	Y	U	

												from this particular study but it is important to know what their health and wellbeing outcomes are also.
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Participant Information Sheet

Project Title: Exploring the challenges of neurodevelopmental disorders in the care experienced by looked after population; examining the impact on health and social outcomes.

Dear Participant

You have been cordially invited to participate in this exciting study. However, before you decide to partake; it is imperative that you first understand what the objectives of the research are and what commitment it entails. Please read the following information carefully, before agreeing to participate in the study. The study has been approved by the 'Swansea University Medical School Research Ethics Sub-Committee' and is being supervised by Professor Hayley Hutchings, Professor Alan Watkins and Professor Ann John.

Purpose of the Research

Poor mental health in children has become a priority objective for the Welsh government. However, research proposes that care experienced children are four times more likely to have a mental health disorder compared to those not in the care setting and nine times more likely to have a special educational need due to emotional, behavioural, developmental and learning difficulties.

Therefore, this study aims to explore some of the complexities that encompass neurodevelopmental disorders; in relation to care experienced children and how they might impact on their overall future health and social wellbeing.

Why have social workers been invited to participate?

The social worker role is the primary, frontline professional who has to continuously address an exhaustive myriad of challenges and adapt a holistic approach to bridge services between health and social sectors; to meet the needs of these children. Therefore, the unique perspective, opinions and thoughts of these individuals could provide real 'lived' experiences and insight into the complexities of these disorders and the expected health, social outcomes associated with these children.

What will happen if I take part?

A recruitment letter will be sent to you requesting your participation. Once, you have agreed to participate in principle; you will receive an email confirming your interest in the study. Attached to the email will be the participation information sheet and consent form for you to make your final decision whether to be part of this study. If you consent to being part of the study; an interview date, time and place will be scheduled at your convenience. The interview will be guided by a semi-structured questionnaire, recorded for transcription purposes and will last between 40 and 60 minutes.

Participants' Rights

It is important to note that participation is on a voluntary basis; you have the right to omit or refuse to answer any of the questions that are asked of you. You have the right to stop or withdraw from the study at any point prior, during or after the study is completed without an explanation. The researcher will then assume responsibility for deleting all data collated

immediately. The researcher requests that you contact her directly to address any concerns that you may have prior to the interview.

You have the right to access, object, rectify, erase or restrict any of your personal information by writing to the University Compliance Officer. **Contact details are:**

University Compliance Officer, Vice Chancellor's Office, Swansea University, Singleton Park, Swansea, SA2 8PP.

Email: dataprotection@swansea.ac.uk

The University is required to keep a record of its processing activities which must be made available to the Information Commissioner upon request. Should you have any complaints with regards to the processing of the data. You can make a complaint to the Information Commissioner's Office. **Contact details are:**

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Email: www.ico.org.uk

Data Protection Privacy Notice and Confidentiality

The data controller will be Swansea University who will adhere to all seven data protection principles outlined in Swansea University's 'Data Protection Policy' document; in accordance with the General Data Protection Regulation (GDPR) and the new Data Protection Act 2018 (DPA 2018).

A third party will be utilised to transcribe the interview data which has a full SSL certificate; has a GDPR and CyberEssentials accreditation <https://www.universitytranscriptions.co.uk/>

All data will be stored in both a locked, secure cabinet file and on a password protected computer file. When the interviews have been conducted; all data will be anonymised to protect the identity of the participant. There will be no record that links the collated data to your personal information. Participation and consent information will be stored in a separate, locked, secure location to minimise the event of a data breach. All personal data will be deleted after the PhD has been submitted in June 2021.

It is important to note that once the data has been anonymised; this unidentifiable data will become available to other academic avenues in the form of publication or presentation at conferences. A copy of the findings will be made available to you, at your request.

Further information

Should you have any questions about your rights, concerns or suggestions please contact:

Nicola Heady, Current PhD Student, MSc Autism and Related Conditions, BA Hons Social Inclusion, Swansea University Medical School, Swansea University, Singleton Park, Swansea, SA2 8PP

Contact: [REDACTED] / Email: [REDACTED]

Professor Hayley Hutchings, Professor of Health Services Research, Co-Director, Swansea Trials Unit (STU), Patient and Population Health and Informatics Research, Swansea University Medical School, Swansea University, Singleton Park, Swansea, SA2 8PP

Contact: [REDACTED] / Email: [REDACTED]

If, however you feel that your questions have been unanswered to your satisfaction; please contact the 'Swansea University Medical School Research Ethics Sub-Committee' at: researchintegrity@swansea.ac.uk

Appendix 4

PARTICIPANT CONSENT FORM

Participant Identification Number for this study:

Title of Project: Exploring the challenges of neurodevelopmental disorders in the care experienced by looked after population; examining the impact on health and social outcomes.

Name of Researcher: Nicola Heady

Please
initial box

1. I confirm that I have read the information sheet dated (...) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary (without coercion) and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I understand that the information collected will be used to support other research in the future and may be shared anonymously with other researchers.

4. I agree to having the interview recorded and transcribed by a third party as outlined in the participation information sheet.

5. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person

Date

Signature

Appendix 5 Application for Standard Ethical Approval

Application for Standard Ethical Approval

CHECKLIST

Please note that we are able to review an application only when all documentation is submitted alongside this application form. Should any necessary appendices not be attached, this could delay the submission until the following month. Please use this checklist below to ensure that the application is complete. Many thanks.

	Attached Yes / No / N/A	Comment
Recruitment advertisement or email(s)	Yes	Attached as appendix 1
Participant information sheet(s)	Yes	Attached as appendix 2
Consent form(s)	Yes	Attached as appendix 3
Debrief sheet(s)	N/A	
Questionnaire(s)	N/A	
Interview or Focus Group schedule(s)/questions	Yes	Attached as appendix 4
Workshop schedule(s)/questions	N/A	
Written consent from public or private body	No	
Supervisor signature	Yes	

PLEASE COMPLETE THE FORM USING TYPESCRIPT
(hand-written applications will not be considered)

Principal Investigator	Nicola Heady
Date	14/11/2019
School	School of Medicine
E-mail address	██████████
Title of Proposed Research	Exploring the challenges of mental, neurodevelopmental and behavioural disorders in the care experienced by looked after population; examining the impact on health and social outcomes.
Type of Researcher	Postgraduate student
Name of course & supervisor	PhD Professor Hayley Hutchings
Supervisor e-mail address	██████████
Qualifications and professional background	MSc Autism and Related Conditions (Distinction); BA Hons Social Inclusion (First)

1. Briefly describe the rationale and the main aims of the research you wish to undertake, including a statement of the intended benefits of the research. Please use non-

technical language wherever possible.

Research continues to depict a bleak future for looked after children; predicting inauspicious health and social outcomes. Yet despite, being categorised as a high-risk group and embedded within service position; varying contributing factors such as multiple placements and residential moves, poor screening in development and education, delays in service provision, poor data collation, consent and segregated service sectors often prohibit early identification and intervention for the looked after child. With rates of children entering the care system, increasing on a global level; demands on services are placing immense pressures on government funding, front line services, families and more importantly, on the children themselves.

Situated within these poor health and social outcomes and currently, major priority objectives for government; are the areas of mental health and educational attainment. Both factors are suggested to be intrinsically linked; forming and underpinning the fundamental building blocks to achieving subjective wellbeing and increasing social mobility. Although major priorities for all children in the UK; research proposes that LAC are four times more likely to have a mental health disorder compared to those not in the care setting and nine times more likely to have a special educational need due to emotional, behavioural, developmental and learning difficulties.

The social worker role is the primary, frontline professional who continuously addresses an exhaustive myriad of challenges on a daily basis and has to adapt a holistic approach to bridge services between health and social sectors; to meet the needs of these children. Therefore, the unique perspective, opinions and thoughts of these individuals could provide real 'lived' experiences and insight into the complexities, the service provision and the expected health, social outcomes associated with these children; as a result of having these disorders.

2. Briefly describe the overall design of the project including dates and/or the proposed period of investigation

Using grounded theory; an interpretive descriptive approach will be utilised to undertake this qualitative work. This approach is proposed to be logical, robust, reflective process. through the use of coding. Non-probability sampling has been selected as the most appropriate sampling methodology; as it is suggested that this technique uses smaller samples to explore perceptions to conduct an in-depth analysis of a specific issue; which fits the aims of this study. Furthermore, it does not require a complex sampling frame or calculation to determine sample size. It is the researcher that decides on the number of participants to be interviewed; considering factors such as time restraints; for both the researcher and role of the participant; allocation of resources, quality of data and time for analysis. However, it is acknowledged that this technique can be subjective and does not represent the views of the wider population.

Due to the overall design of the study; purposeful sampling has been deemed the most appropriate technique, to attain an extensive insight into the outcomes of interest to yield a more succinct and valid interpretation of the data required. Therefore, it is proposed that a sample of 10 will enable the study to attain an enriched qualitative dataset. Although, this technique can be subjective and not representative of the wider population; it has the capacity to yield important insights that can be further explored in future research.

Although not representative of the UK; due to the locality of the study; local authority boards from South Wales have been chosen as participants. It is anticipated that the study

will be completed within a period of seven months, after attaining ethical approval. This will enable ample time to arrange and conduct the interviews; analyse the data and address any unforeseen issues that might possibly arise within the time frame.

3. Briefly describe the methods of data collection and analysis. Please describe all measures to be employed. If questionnaire or interviews are to be used, please provide the questionnaire / interview questions and schedule.

Face to face interviews using a semi-structured interview schedule will be conducted with ten social workers from five local authority boards (2 social workers per board) to attain a rich data set. As the study is using non-probability sampling as a methodology; calculations to determine sample size is not required. Therefore, the number of participants to be interviewed has been based on important factors such as time restraints; heavy workloads, allocation of resources, quality of data and time for analysis. Prior to interviews, a pilot test interview will be conducted on a retired social worker to ensure that the semi-structured schedule is fit for purpose. Subsequently, interviews will then be arranged, conducted, recorded, transcribed verbatim and NVivo used to code, identify and analyse patterns of data that will contribute to the aims of the project. Please find attached interview schedule questions.

4. Location of the proposed research (i.e., Departmental labs, schools, etc)

Issues such as privacy, confidentiality, safety and disabled access or needs will be considered. It is anticipated that the interviews will be held in the local authority board's premises where they reside in their role. A safe, secure place to address confidentiality purposes; which is convenient for the participant; due to their limited free time and nature of the role will be pre-booked for the interview.

5. Describe the participants: give the age range, gender, inclusion and exclusion criteria, and any particular characteristics pertinent to the research project.

There will be no exclusion criteria such as age and sex. However, the inclusion criteria will be that the social worker will need to have at least five years of experience working with both young children and adolescents in the looked after care setting. The rationale for this, originates from the study's outcomes of interest. The social worker will need a longitudinal experience and knowledge of the health, social outcomes and service needs associated with these children. This will enable the study to capture an 'information rich' dataset that reflects the 'real lived' experiences of both the younger child, adolescent and front-line insights of the social worker.

6. How will the participants be selected and recruited? Please describe in detail the process of recruitment, including how and by whom initial contact is made with participants (e.g. advertisement, e-mail).

An email detailing the study has been sent to all of the heads of the 'Chair of All Wales Heads of Children's Services' (AWHOCS) to gain initial interest prior to submitting for ethics approval. To date; Swansea, Cardiff and Carmarthenshire local authority boards have already agreed in principle by e-mail to take part in the study. After ethics is approved; a recruitment letter detailing the inclusion criteria will be sent by e-mail to the heads of the department. They will then email their associates with the information provided, to initiate interest in the study. They will have the final say on who participates as there will be a need to consider allocation of resources and time and they will have the knowledge of who they think will fit the inclusion criteria and provide the study with best information rich data.

After, the associate has agreed in principle to participate; they will receive an email confirming their interest in the study. Attached to the email will be the participation

information sheet and the consent form; enabling them more time to make their final decision on whether to be part of this study. If they agree to take part; an interview date, time and place will be scheduled at their convenience.

7. What procedures (e.g., interviews, computer-based learning tasks, etc.) will be used to gather information from participants?

A room will first be allocated and booked prior to the interview. A few minutes will be allocated to 'break the ice' with the participant and a refreshment drink offered to relax the surroundings prior to the interview being conducted. The researcher will then begin to record the interview on two digital voice recorders to prevent missing data due to technical issues. The interview will begin with a short introduction, explaining the aims and objectives of the study, how the interview will be conducted (semi-structured questionnaire consisting of 33 questions) and guided. It is anticipated that the interview will last anything between 40 to 60 minutes. However, the participant will be asked prior to the interview; if they are happy to continue; should it take longer than 60 minutes. The researcher will read out the introductory statement and consent form; both the participant and researcher will sign the document; providing the participant is still happy to proceed. The interview will close with a statement thanking them for their participation in the study.

8. What potential risks to the participants do you foresee and how do you propose to ameliorate/deal with potential risks? Declare any relationship with the participants.

The study does not anticipate any physical, psychological, social, economic or legal risks for the participant. However, the participant will be advised that data protection and confidentiality will adhere to all seven data protection principles outlined in Swansea University's 'Data Protection Policy' document; in accordance with the General Data Protection Regulation (GDPR) and the new Data Protection Act 2018 (DPA 2018). All data will be anonymised to protect the identity of the participant and there will be no electronic records that links the collated data to the personal information. Hard copy data will be stored in a separate, locked, secure location in the supervisor's office and all electronic data will be stored on a personal computer and external drive, password protected; to minimise the event of a data breach. Additionally he/she will be provided with all relevant contacts and procedures should he/she not be happy with the interview.

To reduce the risk of case discussion, no personal names of the children will be included in the interview. The participant will be asked to refer to the child as he/she. Additionally, the allocated interview room will a safe and secure place where case discussion cannot be overheard. In the event of the participant becoming upset during the interview; he/she will be asked if they would like a break, resume the interview to another scheduled time or cancel the interview.

If the participant has concerns about anonymity; the participant will be reassured that the data will be anonymised, however it will be stated that the unidentifiable data will become available to other academic avenues in the form of publication or presentation at conferences. A copy of the findings will be made available to the participant at his/her request.

9. What potential risks to the interests of the researchers do you foresee and how will you ameliorate/deal with potential risks?

The study does not anticipate any physical, psychological, social, economic or legal risks for the researcher. However, the researcher will adhere to the 'Lone Working Policy Arrangements'. particularly the 'lone worker working off site' section; created by Swansea

University to address any potential physical safety issues. The researcher will have contact with the supervisor and will make the supervisor aware of all scheduled interviews, dates and times.

10. How will you brief and debrief participants?

The briefing will involve a short introduction made by the researcher; providing details of the study title, the aims and objectives of the study, the reason why they have been selected as a participant; how the interview will be conducted and the purpose for using a digital voice recorder. The researcher's name and contact information will also be provided again and the researcher will re-iterate their rights to withdraw from the study at any point, during the interview and after.

The debriefing will involve a final note to thank the participant for their involvement, an explanation of how the data will be anonymised and used and offer them the option to view the results; at their request.

11. Will informed consent be sought from participants?

Yes Please find attached a copy of the consent form.

If no, please explain below:

12. If there are doubts about participants' abilities to give informed consent, what steps have you taken to ensure that they are willing/competent to participate?

There are no anticipated doubts about participants' abilities to provide informed consent due to the nature of the participant job role. However, the researcher will make it clear from the outset; that he/she has every right to withdraw from the interview or study; with no explanation at any point.

13. If participants are under 18 years of age, please describe how you will seek informed consent.

N/A

14. How will consent be recorded?

Consent will be sought from the participant from the outset of the interview; during the briefing statement. It will be recorded using the digital voice recorder and additionally the researcher will read the five statements documented on the hard copy consent form and ask the participant to agree by signing the form in their presence.

15. Will participants be informed of the right to withdraw from your study without penalty? If no, please explain why.

Yes, as detailed throughout the application and re-enforced in the participation sheet and consent form; the participant will be informed that they have a right to withdraw at any point before, during the interview or after the interview; without any explanation and all data will be deleted.

16. How do you propose to ensure participants' confidentiality and anonymity?

The participants personal data such as the consent form and questionnaire (hard copies) and recordings will be stored in the supervisor's safe, secure and locked room and shredded or deleted when the PhD is concluded. The data will be anonymised for transcription purposes and all electronic data will be held on the researcher's university computer and external drive. Both of which will be password protected. The researcher will also provide the participant with details, contacts and processes that will safeguard the rights of the participant.

17. Please describe the arrangements for storing and disposal of data:

a). Please describe the arrangements for storing and disposal of data:

All hard copy data (participant information, consent forms, recordings and transcripts) will be stored safely in the supervisor's office. After the interviews have been conducted; one of the recorded interviews will be transcribed verbatim and the other recording will be deleted as soon as the transcript is received.

All electronic data (analysed data) will be stored on the researcher's university computer and an external drive for back up. Once the PhD has been submitted in 2020; all hard copy data will be shredded and disposed of and all electronic data will be deleted.

Should the participant withdraw from the study at any point; all data will immediately be deleted and an e-mail sent to the participant confirming the deletion of the hard copies and electronic files.

b). Please explain, for each of the above, the arrangements you will make for the security of the data

All hard copy data (participant information, consent forms and transcripts) will be stored safely in a locked, secure cabinet file in the supervisor's office to minimise the event of a data breach. Participant information will be anonymised to protect the identity of the participant and location of the local authority board. There will be no record that links the collated data to the personal information of the participant. All electronic data will be stored on the researcher's university computer and password protected. In the event of a data breach, both the participant and 'International Commissioner's Office' will be informed with 72 hours.

18. Does your research require the written consent of a public or private body, e.g. school, local authority or company? If so, please attach letter of consent.

No

19. If your proposed research is with 'vulnerable' groups (e.g., children, people with a disability etc.), has an up-to-date Disclosure and Barring Service (DBS) check (previously CRB check) if UK, or equivalent non-UK clearance been requested and/or obtained for all researchers?

N/A

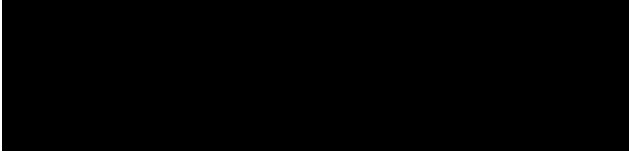
20. Does your research involve the collection of Human Tissue? E.g. saliva, urine	Yes	
	No	x

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Padgett, D. K. (2016). Qualitative methods in social work research (Vol. 36). Sage Publications.

Applicant's signature: _____

Date: __15/11/19_____



Supervisor's signature: _____
(if appropriate)

27/11/2019
Date: _____

Appendix 6 Semi-structured topic guide

Interview Questionnaire

Project Title: Exploring the challenges of neurodevelopmental disorders in the care experienced by looked after population; examining the impact on health and social outcomes.

Candidate name:

Date:

Time:

Introductory statement

Thank you firstly for giving up your valuable time to be part of this much needed research. My name is Nicola Heady and I am currently a second year PhD student being funded by the ESRC and Health and Care Research Wales; who is exploring the prevalence of neurodevelopmental disorders in the care experienced by looked after population; their service needs and the associated impacts on health and social outcomes. The aim of this research is to attain a broad understanding of the intricacies and challenges these disorders pose for the child, family and services. Furthermore, how do they impact on future health and social outcomes. The interview will be guided by this semi-structured topic guide and will be recorded and transcribed verbatim to be able to analyse the data. You are within your rights to stop the interview or withdraw at any point, should you feel the need to do so. Before we start the interview, I am going to read the five statements outlined in the consent form. Once you have agreed to these statements; we will both sign and date. I would like to note that we are only focusing on the child with a looked after status (fostered or adopted) and not a child in protection or child in need. Are you still happy to continue?

Drivers for services

1. Could you tell me briefly a little about yourself; your role and experience with fostered and adopted children?
2. Why do you think referrals to social services have increased on a national and global level?
3. What other factors initiate referral other than abuse and neglect? Have these factors become more prevalent in reasons for referral over time?
4. Do referrals increase at different periods of the year; impacting service delivery? If so why?

Neurodevelopmental disorders

5. Do you think neurodevelopmental disorders are so high in these children? Why?
6. Are there any trends in specific disorders that appear to be increasing in prevalence for these children? What are your thoughts on this?
7. Based on your experience; are these children diagnosed prior to being looked after or after they enter the care system?
8. What are your thoughts on diagnosing a child with a neurodevelopmental disorder? Do you think additional labelling might have a positive or detrimental impact on becoming (a) fostered or adopted and (B) their overall future wellbeing?
9. Are there any other wider social factors that might exacerbate or contribute to a child having these disorders?
10. In your opinion, does parental mental health or disability have an impact on children entering the care system? In what way?

Service provision

11. Early identification and intervention are significant factors in improving overall future wellbeing. What is your opinion on the amount of time it takes for a child with a neurodevelopmental difficulty; to be referred, screened and referred to the appropriate services?
12. Can you tell me your experience and thoughts on the referral process and criteria needed to access CAHMS? (Probing questions) In your opinion, does CAHMS improve their mental health? Does the child engage in these services and if not why? Do you think age has an impact on their ability to engage with these services?
13. What specialised services are available to the parent and child enabling access to help and support; prior to becoming looked after? (Probing question) What are your opinions on the quality of these services?
14. What key (a) strengths and (b) challenges in services enable or prohibit you to providing help and specialised support for these children with neurodevelopmental disorders?
15. How would you enhance or improve these services?

Educational attainment

16. Based on your experience; why do you think educational attainment is so low and special educational needs so high in these children?

17. Are there any trends in specific learning disorders that might impact on their educational learning? What are your thoughts on this?
18. What are your thoughts on diagnosing a child with a special educational need? Do you think additional labelling might have a detrimental or positive impact on (a) being fostered or adopted (B) their overall future wellbeing?
19. Are these children identified as having a special educational need prior to being looked after or after they enter the care system? Does entering the care system provide access to educational support?
20. In your opinion, does parental educational attainment have an impact on the educational attainment of these children? In what way?
21. Are there any other wider social factors that might contribute to a child struggling with his or her education?

Service provision

22. What is your opinion on the amount of time it takes for a child with a learning difficulty; to be referred, screened and referred to the appropriate services?
23. Are their special educational needs addressed in the educational setting and how? Are schools equipped with the necessary resources to help and support these children?
24. Have the children access to these services prior to being looked after?
25. What key (a) strengths and (b) challenges in services enable or prohibit you to providing help and specialised support for these children with learning difficulties?
26. How would you improve these services?

Health and Social

27. Based on your experience and knowledge of these children; what are the reoccurring health and social outcomes for many of these children?
28. What resources and support networks are there for you as a professional, to help these children fulfil their potential?
29. I know that we have only focused on children with a looked after status but from a preventative perspective; how often does a (A) 'child in protection' or (B) child in need' with neurodevelopment disorders become LAC?
30. Again, from a preventative perspective; are there any re-occurring wider social determinants that you can think of that could potentially exasperate or contribute to a child

becoming looked after?

31. What are your thoughts on the data being collated at present? Is it effective enough to inform stakeholders where to direct relevant resources and services to alleviate pressures on you, the child and family?

32. All cases are individual but based on the data that you have to input on the child and family; are there any consistent risk factors that repeatedly emerge which might potentially flag when a child is likely to become looked after?

33. If you could enhance and improve any of the services in any way to help these children and families and alleviate pressures on your service; what would you do?

Closing Statement

Thank you so much again for taking part and providing this study with a unique insight into the complexities and challenges that evolve around these children. As stated in the participation information sheet; you still have the right to withdraw from the study at any point in the future, should you wish to do so. The data will be anonymised and analysed for research purposes. The data will be kept in a safe and secure location. A copy of the findings can be made available to you, at your request.

Appendix 7 Information Governance Review Panel (IGRP) Protocol

Primary Investigator: Nicola Heady (██████)

Research Supervisors: Professor Hayley Hutchings; Professor Alan Watkins; Professor Ann John.

Aim: To increase knowledge and understanding of mental, health and social care needs in the care experienced by looked after population.

Objectives: To utilise and link health, educational and social datasets held within SAIL to estimate and compare lifetime prevalence of mental, neurodevelopmental and behavioural disorders in the care experienced by looked after population with children who have no care experience; their unique service needs and impact on health and social outcomes.

Background: Looked after children are suggested to experience poorer health and social outcomes; compared to those who do not go into the care setting [1-4]. Situated within these outcomes and currently, major priority objectives for government; are the areas of mental health and educational attainment [5, 6]. Although major priorities for all children in the UK; research proposes that LAC are four times more likely to have a mental health disorder compared to those not in the care setting and nine times more likely to have a special educational need due to emotional, behavioural, developmental and learning difficulties [7-9].

Methodology: Accessing anonymised data from the SAIL databank will enable the study to further develop understanding of the mental health outcomes, prescription rates; educational attainment and type of provision, referrals to secondary services; demographic (sex, ethnicity) and wider social determinants (postcode, number of residential and educational moves, etc) for this vulnerable group. The study has the capacity to potentially identify patterns of service need and other social determinants that might flag when a child might be in need of earlier intervention from services. Pre-defined search scripts utilised in previous studies; using R programming software and pre-defined confounding variables, will be adapted to address the research question. Following coding and encryption the data will be linked to explore the outcomes of interest. Multi-regression analyses and adjusted odds ratio will be utilised to determine if there is any disparity between the outcomes of interest.

To address the research questions being explored; the study aims to attain data from specific datasets such as Welsh Demographic Service, Primary Care GP, Educational Attainment, National Community Child Health Database (NCCHD), Outpatient Referral, Patient Episode Database for Wales (PEDW) and the Looked After Children Wales (LACW) dataset between

the period 2005 to 2018. The rationale for this period is that legislation such as the Disability Act (2005) and subsequently, the Equality Act 2010 enforced and defined mental disability as a ‘mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities’. These key legislative Acts had a significant impact on data collation during this period [10, 11]. Furthermore, research, understanding and awareness of these disorders have advanced dramatically over the last several years [12, 13]. Therefore, attaining data up to 2018 would enable the study to attain a more reliable estimate of the lifetime prevalence of these disorders and outcomes of interest.

A further aim of the study is to attain data on individuals from the age of 3 to the age of 21. The rationale for this derives from further important legislation, section 98 of the Children’s and Families Act’ which placed duty and responsibilities on local authorities; allowing young people in foster care to remain in their placement until they turn 21[14]. Subsequently, from April 2016; the Social Services and Wellbeing Act 2014, adopted this guidance as documented in part 6 of the act [15]. Furthermore, some of these disorders can be diagnosed as early as two years of age; however, many can take up to ten years to be diagnosed due to the complexity in behavioural symptomology [12, 13]. Therefore, as the study is exploring lifetime prevalence and outcomes; attaining data up to the age of 21 would enable a more reliable estimate to be calculated.

Impact: This study has the capacity to produce new findings or identify gaps in research that could inform policy and services with important information to target appropriate research or services; aid in early identification and intervention for these children; reduce social care needs and improve their overall future wellbeing.

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