A systematic review protocol to explore the prevalence and impacts of neurodevelopmental disorders in the care experienced by looked after population

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Protocol

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Abstract

Background: Looked after children (LAC) placed in either a foster care, kinship, residential or adoption care settings continue to develop debilitating disorders that significantly impact their future overall wellbeing. Prevalence of these disorders are often depicted under broad categories such as mental, behavioural or neurodevelopmental disorders (NDDs). Limited in research, is the prevalence of specific disorders that fall under these broad categories.

NDDs such as autism or attention deficit hyperactivity disorder which cannot be medically tested for and fall under an umbrella group in the current, expert field of genetics and neuropsychiatry will be explored. Unsupported, these disorders can lead to suboptimal health and social outcomes for both the child and family. In the general population, prevalence of these NDDs and impacts on health and social wellbeing are relatively well documented but for minority groups such as LAC; research is extremely limited. This review will aim to estimate the prevalence of NDDs in LAC and compare to those children who are not looked after. Additionally, it will identify if NDDs have any impact on the health and social wellbeing of this vulnerable group.

Methods: This review will report in accordance with the guidelines outlined in the Preferred Reporting items for Systematic Reviews and Meta-Analyses. PubMed, ASSIA, IBSS, Web of Science, PsychINFO, Scopus, Psych articles, Social Care Online, secondary, grey literature and government publications will be searched to identify any eligible studies. No restrictions will be placed on age or design of publication. Eligible studies must include participants, 25 years of age or under and have confirmed diagnoses using standardised international diagnostic codes or tools. Odds ratio and 95% confidence intervals using the random-effects model will be utilised to analyse the data. The Joanna Briggs Institute critical appraisal tools will be utilised to assess quality and bias.

Discussion: Attaining an estimated prevalence of these NDDs in the LAC group and identifying any impacts on health and social wellbeing will contribute to the existing but limited LAC literature. From a preventative perspective, the results will inform key stakeholders in health, educational and social sectors with important information to aid in safeguarding and meeting the unique needs of these vulnerable children.

Systematic review registration: PROSPERO Registration number: CRD4201913103

Background

The high prevalence of psychiatric disorders in LAC, is well documented in research; often suggested to be as a result of adverse childhood experiences or poor socio-economic environments [1 - 4]. However, these prevalence studies are often depicted and categorised under broad headings; such as mental, behavioural or neurodevelopmental [2, 4, 5]. Although, significant findings; limited within secondary literature is a more in-depth, individual analysis of what specific disorders represent these broad categories.
Mental and behavioural disorders can significantly affect an individuals’ mental health, emotions, memory, ability to learn and socialize at some point in their life [6, 7]. Some may affect the individual on an intermittent basis or manifest during periods of immense stressful or challenging life events [6, 7]. However, NDDs are disorders that are proposed to be life-long which affect the biological processes associated with both the brain and/or nervous system [8-13].

NDDs are a complex, multifaceted subject area of which we are only at the tip of exploration; however, they cross a wide clinical spectrum and many are suggested to have genetic and hereditary origins [8-13]. Some disorders such as Prader-Willi Syndrome or Fragile X Syndrome can be diagnosed with a medical test [14-15]. Many NDDs such as ASD or ADHD can only be diagnosed solely based on behaviour [16, 17]. Emerging research ascertains that these particular NDDs frequently co-occur and co-exist but can take years to diagnose as they display similar behavioural symptomology in areas such as impaired social communication and interaction skills, similar sensory and motor dysfunctions, sleeping and eating difficulties, attachment issues and attention problems [18 -21]. As a result, these similarities make early diagnosis of these NDDs even more challenging for the professional and many do not attain a diagnosis until they reach adolescent or adult age [17, 22 -24]. This lack of early diagnosis and intervention can leave the child struggling in the home, school and social setting with no support or understanding; attempting to navigate a world that makes no sense to them. Unfortunately, unsupported many children 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, low educational attainment and potential exclusion from education, employment and society [22 – 32].

Rationale

This review will explore the prevalence and impact of NDDs that affect the brain and/or nervous system but cannot be medically tested for [8-13]. The disorders of interest for this review are Foetal Alcohol Spectrum Disorder (FASD), Reactive Attachment Disorder (RAD), Attention Deficit Hyper Disorder (ADHD), Bipolar, Schizophrenia, Obsessive Compulsive Disorder (OCD), Eating Disorders, Autism Spectrum Disorder (ASD) (Pervasive Development Disorder, Asperger), Mathematics Disorder (Dyscalculia), Intellectual Disability, Reading and written Disorder (Dyslexia), Speech and Language Impairment, Social (Pragmatic) Communication Disorder, Tic Disorder, Stereotypic Movement Disorder (Dyspraxia) [33].

Although, some of these NDDs are not categorized as NDDs in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) manuals; they all share commonality as they affect the biological processes that control the brain and/or nervous system recognized and labelled as such in current, up to date literature by leading experts [8-13]. These manuals which significantly influence the clinical sector, are the most up to date and authoritative guideline for professionals and research. Yet, it is also common knowledge that the DSM and ICD manuals can take over ten years to be updated; in that time, research can develop very quickly [34]. Therefore, the review was concerned it might under-identify the prevalence of NDDs. As an example, ADHD has only recently
been classified as an NDD in both the DSM and ICD; however, it was classified as a disruptive, behavioural disorder for decades in previous manuals [35, 36]. ASD which is classified as an NDD was first classified as ‘childhood schizophrenia’ in the first DSM [37]. If this review had been conducted prior to these updates, research might have missed important information and not included these NDDs in the inclusion criteria.

To date, there has been limited research applied to NDDs in respect of the looked after child. They have often been noted in LAC research as important but under researched and omitted from results or not elaborated upon for varying reasons; such as low sample numbers [38-40]. Nevertheless, new increased awareness of the diversity of how these disorders manifest in the child is rapidly increasing in the psychiatric field with diagnostic assessments and accuracy improving [15-17]. Willis et al (2017) recently conducted a systematic review on the prevalence of ADHD in LAC and proposed that this NDD was higher in in the LAC population compared to non-LAC [41]. Although, a significant finding, the review only explored ADHD and used a national prevalence from each country of study to compare rates [42]. This review will extract the true prevalence rates from the included studies to compare the prevalence of NDDs between LAC and non-LAC. Two further ‘looked after’ groups of interest; children who have been adopted and children who have been placed in a kinship care setting will be included in this review as these children fit the inclusion criteria as they would also have been removed from the biological home and placed in a care setting [41].

Impacts on health and social wellbeing associated with having an NDD in the general population are still limited but relatively well documented. Many individuals with these NDDs are often excluded from society, attain a poor socioeconomic status, become socially isolated and develop debilitating mental health problems [22-32]. Extremely limited in research, are the impacts on the health and social wellbeing associated with having an NDD in the looked after population.

Objectives

Rates of children entering the care system are increasing on a global level; demands on services are placing immense pressures on government funding, third sectors, front line services, families and more importantly, on the children themselves [42, 43]. The review proposes it is an appropriate time to estimate the prevalence of NDDs in the LAC population and investigate the impacts on the health and social wellbeing of these children. The review objectives are to:

1. Estimate the prevalence of NDDs in looked after children and compare with those children who are not-looked after.
2. Identify what impacts NDDs may have on the health and social wellbeing of the Looked after child.

Methods

This protocol has been registered with the PROSPERO database for systematic reviews (Registration number: CRD4201913103) and will be reported in accordance with the guidelines outlined in the Preferred
Reporting items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P) [44]. The review will follow the PRISMA-P guidance and all processes will be clearly defined in the review [44].

**Search Strategy**

The PICO approach has been used to help define the primary research question and formulate the search strategy.

Does the child (P) who is in a looked after care setting (I) compared to those children that are not placed in the care setting (C) have a higher prevalence (O) of these neurodevelopmental disorders?

As observational and descriptive studies draw inference from a sample to a population; where there are limits in logistics and ethical considerations; it is anticipated that these studies will be the most prevalent in this review. However, all designs will be included providing they meet the inclusion and quality criteria [45].

The following databases will be searched to identify relevant primary literature for the review: PubMed, ASSIA, IBSS, Web of Science, PsychINFO, Scopus, Psych articles, Social Care Online. The proposed databases were selected based on those identified in other peer reviewed studies that explored similar outcomes of interest and were agreed and deemed appropriate by all authors [46, 47].

The review will additionally systematically hand search published and unpublished secondary, grey and governmental literature as they can be a rich information source for exploring citations and reference lists to further identify any new primary articles. Furthermore, exploring unpublished literature will contribute to alleviating potential publication bias [48].

Due to the breadth of the research questions; there will be two stages to the search strategy. The first stage will explore the prevalence of these neurodevelopmental disorders in the LAC population and if feasible compare to non-LAC. The second stage will explore any impacts on health and social wellbeing as a result of having these disorders.

**Eligibility Criteria**

No restriction will be placed on the age of publication. Publications in the English language and international literature will be included; however, it is recognised that there are limitations to this approach.

The legal definition for a ‘Looked After Child’ varies on an international level, however the review will be guided by the legal definitions underpinning the United Kingdom (UK), derived from both the Children Act 1989 and the Children Act 1995, Scotland (RCPCH, 2015). There will be a broad restriction on the terminology used to identify a child in care (adoption, residential, LAC, out of home care, foster child, kinship care) to ensure the review encapsulates the majority of children who are or have been in care;
which coincides with governmental legislation, policy and third sector terminology for the definition of the population (RCPCH, 2015).

There will be no restriction on the care setting or time placed in a care as many of these children transition into different care settings such as adoption; residential or group care; reside with close family members or re-enter the care system [49]. The only restriction is that the child will have been placed in a care setting for over 24 hours which coincides with UK legislation. Non-LAC will be defined as children or young adults that are not in a care setting or have never been in the care setting. There are limitations to this, as a child may have re-entered the care setting pre or prior to when the study collated the data [49]. However, this will be acknowledged as a limitation in the review.

As there is a duty of care to support some of these children up to the age of 25 in the UK; this will be the upper limit to the restriction. This will enable the review to capture those individuals who might have been diagnosed later in their life with these neurodevelopmental disorders. Additionally, this time period will enable the review to explore the earlier impacts on the health and social wellbeing of these children, as a result of having these neurodevelopmental disorders; for earlier intervention purposes. Additional adverse life experiences after leaving the care setting are often associated with this population; therefore, going any higher in age although a significant knowledge gap in research; could confound the results of the review [49].

Synonyms associated with the neurodevelopmental disorders being explored as detailed in Table 1 which is attached as a supplementary file will be included in the search strategy. As these neurodevelopmental disorders are life-long; this review aims to attain a life-time prevalence and compare prevalence between the LAC population and their non-LAC peers. Only comparative studies that explore prevalence of these neurodevelopmental disorders between these two groups will be used to conduct a meta-analysis. With the introduction of the new International Classification of Diseases 11th Revision (ICD-11) guidelines which acknowledge that many of these neurodevelopmental disorders now co-exist; this review will include studies that have prevalence rates for children who have more than one diagnosis [50].

Only studies that have confirmed diagnoses, or have used diagnostic codes defined by the diagnostic statistical manuals such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) or standardised diagnostic assessment tools which are guided by the DSM and ICD will be included in the review. It is accepted that there are limitations to this approach as coding of disorders can be often be applied without clinician interviews [51]. It is also important to note that there will be limitations to what diagnostic manual was used at the time of diagnosis as the diagnostic criteria would have changed over time for some of these disorders [51]. Furthermore, there are standardised diagnostic assessment tools which have been suggested to be male biased or thresholds of criteria too low to attain a diagnosis for varying reasons [52]. The review will follow other studies of similar methodology and include in the characteristics the description of the tools, codes and diagnostic manual used for transparency purposes. The review will acknowledge any limitations and address them in the review.
There will be no predefined health and social impacts or outcomes; due to the anticipated, limited studies in this area with regards to these vulnerable children and the specific associated disorders being explored. Predetermining these might prohibit or exclude any important impacts or outcomes that might be affecting these children as a result of having these disorders.

**Study Selection**

The review will be undertaken by three reviewers. Two reviewers will critically analyse, code and appraise the selected studies. The third reviewer will be assigned as mediator; should the review need to reach consensus on any final selected studies.

Initially, all studies will be screened by review of title, followed by review of abstract as demonstrated by the search strategy already conducted (see Appendix 1).

The next stage will be to apply the exclusion and inclusion criteria and remove studies that do not fit the specified criterion. Following this, all remaining papers will be fully screened. As the study is exploring two areas of interest; the study selection will be divided into two stages. The first stage will select and appraise the selected studies that meet the inclusion criteria for the prevalence of these disorders and the second stage will appraise the selected studies that meet the inclusion criteria for impacts on health and social wellbeing.

The review will also ensure that the studies captured by the systematic reviews are not duplicated and that no significant or new literature has been missed during, preceding or proceeding when the systematic reviews were conducted. Intermittent searches will also be conducted while the review is being undertaken to ensure that new literature is not missed [53].

After the searches are conducted; a reviewer's meeting will be 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.

**Data collection and extraction**

An extraction form will be designed to collate the information related to the areas of interest. Characteristics such as study name, country, total sample size, age, gender (% male), type of placement, case ascertainment method, disorder, diagnostic system used, diagnostic instrument, number of cases of neurodevelopmental disorders and any impacts on health and social wellbeing. The form will systematically provide clear and unambiguous results to enable further analysis to occur [53].

**Quality and Bias assessment**

To screen and assess the quality of the literature in this review; the Joanna Briggs Institute (JBI) critical appraisal tools will be utilised [54]. These are appropriate tools that have been used in other reviews and suggested to be applicable due to the diversity of the designs normally anticipated in a systematic review. All appraisal tools will address the bias in design, conduct and analysis [54]. For consistency purposes,
two reviewers will independently assess and appraise the studies [53]. If there is a divergence in assessment, a review meeting will be arranged and the third reviewer will become mediator to reach consensus. This will be documented within the review as a narrative summary, to provide clarity and transparency.

**Data Synthesis and Analysis**

Data synthesis and analysis will be guided by the studies that are selected for review. If feasible, a meta-analysis will be conducted. The first stage will aim to estimate a pooled prevalence of the specific disorders in the LAC population versus the non-LAC population [53]. If sample sizes are too small the review will also transform the data into number of cases per population to enable an effect size to be calculated. [53].

It is anticipated that there may be high heterogeneity between studies, therefore, the random effect model will be used to estimate a mean of a distribution of effects [53, 55]. Using this model should provide a more balanced weight to smaller and larger studies to estimate a more standardised mean effect. [53, 55]. Effect will be expressed as odds ratio with a proportion of 95% confidence intervals around the summary estimates. Forest plots will be used to provide a graphical representation of the results. To address publication bias, the funnel plot or trim and fill method will be used; although it is anticipated that the trim and fill method will be more appropriate due to the smaller studies associated with the care experienced population [53, 55, 56].

Subsequently, where statistical analysis is not possible; a descriptive analysis will be provided detailing the prevalence ranges of the NDD (eg, ADHD ranged from 2% to 16% in six of the studies) and characteristics of the studies.

A thematic analysis will be used to enable a framework and narrative synthesis to occur. All information relating to the impacts on the health and social wellbeing of this population; as a result of having these neurodevelopmental disorders will be double coded by two reviewers. In the final stage, all analyses will be amalgamated to provide a discussion of the results attained.

**Software considerations**

The SUMARI software package, a comprehensive review management system that has been designed to assist researchers in the health and social sciences to conduct and support systematic reviews will be utilised to extract, critically appraise and part analyse the data [57]. To conduct the meta-analysis; the RevMan 5.0 software package will be used to meet the needs of the research design [57].

**Dissemination and Research Integrity**

The findings will be disseminated through various pathways, such as peer review journals, public and third sector organisations, Welsh government policy departments, the Children’s Commissioner,
appropriate paediatric National and International Conferences; using various methods such as posters, websites and presentations.

Limitations

The protocol anticipates that there will be several limitations to acknowledge, due to the complexities that surround this population. One limitation may be that there will be differences in the definition of a LAC or non-LAC; which will be noted and addressed in the review should it impact the results in any way. It is also acknowledged that diagnostic criteria will have evolved and changed; in relation to the classification of these disorders outlined in the previous and current ICD and DSM. Although, the rationale for making the upper age limit 25 is detailed, a limitation to this could be that the review excludes older individuals with or without these disorders and possibly additional information regarding health and social wellbeing. Any limitations that arise during the review process will be documented and included within the final systematic review publication.

Discussion

Research has explored the prevalence of disorders that fall under broad, umbrella categories of mental, behavioural or neurodevelopmental disorders. However, this is the first systematic review to our knowledge that has only focused on this group of specific NDDs that cannot be medically tested for. Estimating the prevalence of NDDs and understanding the impacts on the health and social wellbeing of LAC can only enhance and contribute to existing LAC literature. Attaining an estimated prevalence of specific disorders will aid future research in narrowing focus on those disorders that might be more prevalent or impede on these vulnerable children. From an economic and social mobility perspective; the results might also inform key stakeholders of where to direct earlier appropriate services that may be required in health, educational and social sectors to meet the unique needs of these children. Earlier intervention designed to improve future health and social wellbeing can only reduce future demands into these services.

From a preventative and safeguarding viewpoint, current research ascertains that detrimental impacts on health and social outcomes are often associated with these NDDs in the general population. The impacts are even worse for the vulnerable child who is already at risk of attaining poor health and social outcomes in mental health, disability, suicide, criminal system involvement, teenage parenthood, substance misuse and educational attainment [58 - 67]. It is therefore of great importance that we explore if these NDDs place these already vulnerable children at even greater risk in society.

Abbreviations

LAC: Looked after child/children, ICD: International Classification of Diseases, DSM: Diagnostic and Statistical Manual of Mental Disorders
Declarations

Ethics approval and consent to participate
Not applicable. Due to the nature of this review, no ethical approval is needed. However, ethical considerations will be acknowledged throughout the review; if deemed appropriate [41].

Consent for publication
Not applicable.

Availability of data and materials
Not applicable.

Competing interests
The authors declare there are no competing interests.

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Authors’ contributions
All authors detailed on the title page will be involved in the analysis and interpretation of results. All authors have been involved in the design of the study and will revise and approve the final manuscript.

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Table

Table 1 Neurodevelopmental Disorders and Associated Synonyms
| DISORDER                                      | OTHER 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                         | Acalculia 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                                 | Tourette’s Syndrome                                |
| Stereotyped movement disorder                |                                                    |
| Foetal alcohol syndrome                      | Foetal alcohol spectrum disorder or FASD          |