

# The challenges that social care services face in relation to looked after children with neurodevelopmental disorders: A unique insight from a social worker perspective

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**Abstract**

Looked after children (LAC) continue to be one of the most vulnerable groups in society with numbers and rates in care increasing year-on-year. The aim of this study was to explore the unique perspectives, perceptions and opinions of experienced social workers on the little explored subject of neurodevelopmental disorders (NDDs) in this population. Using purposeful sampling, 10 social work professionals with extensive experience of working with these children were interviewed using a semi-structured interview. A thematic analysis using NVivo software was utilised to analyse, code and identify themes that contributed to the aims of the study. Four overarching themes and sub-themes emerged from the findings: perceptions of NDDs,

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perceptions of diagnosis, access to service provision and the impact on care settings. Attention deficit hyperactivity disorder, autism spectrum disorder, dyslexia and dyspraxia were the more prominent conditions discussed. Even though these children are embedded in service provision, the findings raise important questions for both health and social care policy. There is a pressing need for research from a nationwide context to further explore areas of prevalence, training, resources, access to relevant specialist support services and the impacts on the already vulnerable LAC with an NDD.

### **Keywords**

Looked after children, neurodevelopmental disorders, attention deficit hyperactivity disorder, autism, social care services, qualitative analysis

## **Introduction**

Behavioural, mental and developmental disorders are noted to be highly prevalent in looked after children (LAC; Ford, et al., 2007; McAuley and Davis, 2009). These conditions are often attributed to complex adverse childhood experiences (ACEs), stress and/or poor socioeconomic environments and can manifest at any point in childhood or adulthood (Simkiss, 2019).

Relatively new to the field of psychiatry is the area of neuropsychology and the identification of neurodevelopmental disorders (NDDs) that are solely diagnosed based on behaviours, such as attention deficit hyperactivity disorder (ADHD) or autism spectrum disorder (ASD). These lifelong conditions can significantly affect the child on a biological and physiological level, impacting both the brain and the nervous system (Thapar, Cooper and Rutter, 2017). As a result, many children who have NDDs suffer from poor mental health, learning difficulties and emotional dysregulation or struggle to form interpersonal relationships (Ghirardi, et al., 2020; Saito, et al., 2020).

The field of neuroscience and our understanding of NDDs have dramatically evolved over time. There has been a notable progression from earlier, detrimental theoretical influences that suggested that the 'refrigerator mother' caused a child to be autistic or that all children with ADHD were just 'naughty' to the now current, more informed biological understanding of both these conditions and other NDDs (Joseph, 2018; O'Reilly, 2007; Thapar, Cooper and Rutter, 2017). There is still no definitive biological explanation for the causation of these disorders. However, research strongly points in the direction of possible genetic predisposition or hereditary origins given the fact that they can manifest in any child regardless of environment (Ozawa, Takahashi and Harizuka, 2018; Thapar, Cooper and Rutter, 2017).

Irrespective of the aetiology, the prevalence of some NDDs is increasing on a global level. This trend is often attributed to varying factors such as improved diagnostic assessment tools and increased awareness and understanding of the conditions (Elsabbagh, et al., 2012; Song, et al., 2021a). Similarly, emerging research proposes that the prevalence of NDDs has increased in the LAC population but with higher prevalence rates compared with their peers (Parsons, et al., 2019; Willis, Dhakras and Cortese, 2017). Disconcertingly, higher rates of maltreatment have also been suggested to occur in children with an NDD (McDonnell, et al., 2019; Stern, et al., 2018).

Considering that these children's needs cannot be met using standardised support and intervention services, there is still a paucity of research into LAC who have an NDD (Gilbert, et al., 2021). Early identification and intervention are considered the most effective pathways for supporting and meeting the needs of these children (Pasco, 2018). The physical, social and emotional environments are important areas that need to be adapted to meet their needs (Adamou, et al., 2021; Ghazali, Sakip and Samsuddin, 2019; Li, et al., 2019). However, research has shown that this is not always attainable for many children and families in the general population. Limited access to services and resources and a lack of professional knowledge and understanding frequently place the child and family in stressful environments with no support or provision (Ring and Black, 2018; Rogers, et al., 2016; Williams, et al., 2021). If not supported correctly, many children with an NDD can develop debilitating co-occurring conditions, such as anxiety, depression and eating disorders, and can be more at risk of sexual abuse, early mortality and exclusion from education, employment and society (Bargiela, Steward and Mandy, 2016; Hirvikoski, et al., 2016; Sayal, et al., 2018; Wei, et al., 2015).

Social workers have to adapt and undertake an array of multifaceted responsibilities when supporting LAC in the 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 interdisciplinary roles, ranging from counsellor, therapist, case manager, educator, facilitator and mediator to advocate (Education Department, Scotland, et al., 2005).

This study aimed to explore the opinions, experiences and perceptions of social workers, who are often the first frontline professionals involved with these children. Their unique perspectives were sought to provide real 'lived' experiences and insights into the complexities, service provision and impacts on well-being for LAC with NDDs.

The study aimed to explore the following research questions:

- What is the professional understanding and perception of NDDs in the LAC population?
- What service provisions are available to meet the needs of the child, carer/parent and social worker?
- What are the impacts on care settings?

## Methods

Grounded theory – an interpretive, phenomenological approach that explores individuals, experiences and interactions – was used to undertake this qualitative work to address the research questions (Reiners, 2012).

## Sample

The participants were nine social workers and one social work professional with extensive experience (over five years) of working with LAC, all recruited from two Welsh local authority boards. A purposeful, non-probability sampling approach was used as this does not require calculations to determine sample size (Guest, Namey and McKenna, 2017). Due to the nature of the social worker role and the unforeseen impact on social services, the number of participants interviewed was based on important factors such as time constraints, heavy workloads, allocation of resources, quality of data and time for analysis.

Participants were recruited by means of an email which was sent to the heads of children's services to gain initial interest prior to submitting the research for ethical approval. Subsequently, a recruitment letter was emailed to prospective participants which outlined the criteria for inclusion. The only exclusion criteria applied was that the participant was required to have a minimum of five years' experience of working with both young children and adolescents in the looked after care setting. Interviewing social workers with a wealth of experience and knowledge would enable the study to capture a more information-rich data-set 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 take part in the study. An interview date and time was then scheduled at their convenience.

### *Protection of human subjects*

Ethical approval was granted by the Swansea University Medical School Research Ethics and Governance Committee prior to conducting the interviews. Participants were provided with an information sheet that detailed policies and procedures for participants' rights, safety, disability, data protection and confidentiality.

Data protection and confidentiality were guided by and adhered to all seven data protection principles outlined in the University's *Data protection policy* document, in accordance with the General Data Protection Regulation (GDPR) and the new Data Protection Act 2018 (UK Government, 2018).

All data were anonymised to protect the identities of the local authorities, participants and population of interest. To reduce the risk of case discussion, no personal names of any children were included in the interviews; they were only referred to as s/he. No electronic records that linked the collated data to the personal information of the participant were 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 the International Commissioner's Office would be informed within 72 hours and the appropriate action would be followed. Consent was sought from the participant and verbally recorded at the beginning of the interview during the briefing statement. The participant was advised that s/he could withdraw from the study at any point.

### *Data collection*

Interviews were conducted using a semi-structured interview style, which asked open questions that had been developed from the existing literature and some findings from a systematic review that the authors had conducted previously. Three of the authors (NH, HH and AJ) reviewed the questions to enhance content validity (May, 1997; Pope and Mays, 1999). Questions included:

- Are there any trends in specific disorders that appear to be increasing in prevalence for these children? What are your thoughts on this?
- What are your thoughts on diagnosing a child with a neurodevelopmental disorder?
- Early identification and intervention are significant factors in improving overall future well-being. What is your opinion on the amount of time it takes for a child with a neurodevelopmental difficulty to be screened and referred to the appropriate services?

- What specialised services are available to the parent and child enabling access to help and support prior to becoming looked after? What are your opinions on the quality of these services?
- What resources and support networks are there for you, as a professional, to help these children fulfil their potential?

Interviews were scheduled to last approximately one hour and were recorded digitally and transcribed verbatim for analysis.

### *Data analysis*

A thematic analysis using NVivo software was utilised to analyse, code and identify thematic patterns or similar text or data that contributed to the aims of the study. As validity and reliability in qualitative research are often perceived to be subjective and prone to bias, each transcribed interview was read several times over a period of six months (Toews, et al., 2016).

As professionals in only two local authorities were interviewed, no demographic information or participant identifiers were recorded to maintain the anonymity of the social workers and LAC. Several quotations and extracts were edited to protect the identities of the social worker, child and family.

Firstly, the researcher assigned a code to each line of interest as a summary marker. Each code was then subsequently analysed in further detail and double-checked to ensure correct coding and to explore any other thematic relationships with other codes. Word text search and word frequency queries enabled the study to further explore content and ensure no important data or themes had been missed during the coding process (Feng and Behar-Horenstein, 2019).

## **Results**

Ten interviews were conducted with nine social workers with extensive experience and one frontline professional who formed part of the social services multidisciplinary team and worked closely with LAC. The overall findings raised four overarching themes which shall be discussed in further detail below:

- perceptions of NDDs;
- perceptions of diagnosis;
- access to service provision;
- impacts on care setting placements.

### *Perceptions of NDDs*

As the study set out to explore the understanding and knowledge of NDDs from a social worker perspective, it was important to primarily investigate what NDDs existed in this population. This enabled the study to narrow the focus on the specific NDDs of interest.

*Perceived prevalence.* There was a general consensus in the participants' responses that NDDs were increasing in prevalence in the LAC population. ADHD was perceived to be the most prominent disorder, followed by ASD, dyslexia and dyspraxia:

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. (Participant 1)

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. (Participant 3)

... Unfortunately. Autism is what I hear all the time. (Participant 9)

*Professional knowledge of NDDs.* Having an in-depth knowledge of how the child with an NDD presents in their behaviours is essential to providing the correct provision and support that is individual 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 existing literature (Chasoff, Wells and King, 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 present similar traits. (Participant 7)

... 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 ... giving those labels then without that. We know that attachment difficulties and things like ADHD and autism can mirror each other. (Participant 1)

Limited training in the behavioural symptomatology 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. (Participant 3)

So, we get sent to 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? (Participant 4)

These findings were not surprising as social workers already have to attain a wide breadth of knowledge and understanding of a multitude of varying needs. This, coupled with a frequent lack of resources and time for in-depth training, would inevitably prohibit a deeper understanding of NDDs and their associated complexities.

### *Perceptions of diagnosis*

Diagnosis is considered to be 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 a condition is incorrectly diagnosed or missed altogether (Langenfeld, et al., 2021; Pinto, 2019). As NDDs are such complex conditions, it was important for this study to explore whether attaining an NDD diagnosis improved the well-being of the LAC or not. This topic provoked an array of conflicting thoughts and opinions from participants. Misdiagnosis and overdiagnosis, the benefits and disadvantages of diagnostic labelling and the prescription of medication are discussed further below.

*Misdiagnosis and overdiagnosis.* Several participants expressed concerns about the misdiagnosis and overdiagnosis of NDDs which placed a seed of doubt in perceptions of clinicians' 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. (Participant 1)

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 overdiagnosis of ADHD-type symptoms. (Participant 8)

Conversely, several participants expressed their concerns that some disorders such as autism, dyslexia and dyspraxia were being overlooked. This is reflected in the literature which proposes that many children with fewer behavioural problems are frequently missed (Hull and 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. (Participant 1)

And I think to be honest, dyslexia is missed quite a bit 'cause 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. [We would be told] 'No, they're just clumsy'. (Participant 2)

*Benefits and disadvantages of diagnostic labelling.* From a sociological perspective, diagnosis is often associated with labelling and categorising a child and so has always been a controversial area of research (Mannay, et al., 2017). For the LAC who has often already acquired a wide array of labels, this was felt to be an important area to explore in our study and raised mixed responses from participants.

Several participants viewed a diagnostic label as a protective factor for the child's future well-being, 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 staff 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. (Participant 2)

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. (Participant 1)

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

. . . 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. (Participant 9)

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. (Participant 7)

*NDD diagnostic intervention: Medication prescription and usage.* Medication usage in the LAC population has been suggested to be higher compared to that of their peers (Mandell, et al., 2008; Raghavan, et al., 2005; Willis, et al., 2017). It was an important area to explore in this study as for many children with an NDD, medication is often a pre- or post-diagnostic intervention used to reduce challenging behaviours or to assist in the areas of sleep, concentration and regulation of emotional responses. There were a lot of mixed opinions and perspectives on the subject of medication among participants. ADHD was the predominant disorder raised during discussions on the subject of medicating children and adolescents.

Some participants found that medication had helped to stabilise the care placement and educational setting and had a positive impact on the child. However, many participants felt that it should only be used as a last resort:

As it goes, well, they're increasing her medication and she's quite stable now. (Participant 10)

. . . 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. (Participant 7)

Conversely, some expressed concerns about medication of LAC with NDDs. Some participants had found that the prescribed drugs had exacerbated the child's behaviours and were eventually not required:

...with ADHD...medication and labels are an easy way of dealing with it. I think that's a common factor. (Participant 1)

...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 10 times worse and he was irritated... I feel like you need to try...exhaust all options and medication should be the last option. (Participant 4)

### *Access to service provision*

Early identification and intervention are integral to improving the life chances for children with an NDD, and a diagnosis is usually associated with a direct means to accessing specialist service provision (Hutchon, et al., 2019; Manolova, 2017). However, the literature on studies conducted on the general population in this area suggests that this does not reflect lived reality (Crane, et al., 2018; Legg and Tickle, 2019; Sayal, et al., 2018). It was important for our study to explore whether the LAC had swift access to assessment and specialist provision.

This area of discussion raised varying concerns for many of the participants and, unfortunately, reflected the challenges that many children and families experience in the general population. Access to diagnostic assessment, mental health services, specialist educational provision and pre- and post-diagnostic support services was a lengthy and often unattainable process. Frequent moves in residential and educational settings, a lack of resources, complexities in attaining diagnostic evidence and living in rural areas further contributed to the complexities.

*Times from referral to diagnosis.* Many participants encountered long delays in reaching the actual diagnostic assessment. Referral to diagnostic assessment appeared to be straightforward and to present realistic timeframes. However, accessing the actual assessment took years in some cases, particularly for those children with suspected ASD:

... we have got children in the looked after population that have been waiting a long time for an autism diagnosis. (Participant 1)

What I find is that they do the assessments and then they'll say 'We think that they may have ADHD, ODD [oppositional defiant disorder], be on the spectrum, we're referring to neurological department', and then they're on an 18 months/two year waiting list. (Participant 5)

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. (Participant 8)

The difficulty of accessing an educational psychologist was noted, but this differed for one local authority as they had a practitioner in this role embedded in their working model. This enabled the social worker to have direct access to knowledge which provided them with a positive support network before referring the child for a diagnostic assessment:

... And if it's along the EP [educational psychologist] 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. (Participant 7)

... but I do feel there's a lot of batting back and forth about who provides the support, waiting lists for Ed Psychs [educational psychologists] 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. (Participant 4)

*Child and Adolescent Mental Health Services.* Children with NDDs are extremely vulnerable to experiencing poor mental health and frequently suffer from debilitating co-occurring mental disorders (Petrou, et al., 2018; Reale, et al., 2017). It was important to investigate how mental health services supported the vulnerable LAC.

This service generated a lot of emotive responses from the participants interviewed. Very few found using Child and Adolescent Mental Health Services (CAMHS) a positive experience and the majority of participants expressed significant concern with regards to accessing the service due to unattainable thresholds for criteria. A lack of resources was perceived to be a significant barrier to accessing services.

Referral was noted to be a straightforward process with realistic timeframes. However, the inaccessibility of the service was concerning. Meeting the criteria to access CAMHS and obtain intervention was unattainable for many:

I've never got to the actual point of CAMHS, I've made lots of referrals [laughs] but I've never met threshold with the children that I've referred. I've spoken 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. (Participant 4)

I've got children that are probably still waiting two years down the line. (Participant 1)

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. (Participant 9)

We've got access to... 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. (Participant 10)

Several participants stated that the child 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. (Participant 10)

...maybe they're struggling with resources and stuff as well, but I struggle to know what you need to do 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. (Participant 4)

A lack of resources was also noted as a reason for inaccessible mental health services by another participant:

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. (Participant 8)

When CAMHS was accessed, it was frequently observed that if the child did not meet the diagnostic criteria for a mental disorder, they would be referred on to 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 in. (Participant 1)

Yeah, very often we get a response of 'They don't have... we've assessed it, we've had a multi-agency, or multidisciplinary 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... 'cause what they're saying to us almost on each occasion: 'They haven't got a mental health diagnosis'. (Participant 9)

**Access to NDD specialist services.** Access to specialised NDD services and educational provision was noted to be a challenge for many participants both pre- and post-diagnosis. Limited professional knowledge of NDDs and a lack of resources were noted as potential barriers to accessing specific, specialised therapeutic interventions and services in both healthcare and educational settings:

...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. (Participant 4)

. . . I think on the ones where there's practical stuff, like the dyslexia and dyspraxia, where they know that they've got to do, 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 there's more cognitive and neuro[logical] stuff I think it's more difficult for them. (Participant 1)

However, some participants found that having access to an educational psychologist on a regular basis provided them with an additional objective viewpoint and well-received knowledge that enabled them to better support the child:

. . . 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 [educational psychologist] can kind of suggest some interventions which is really helpful. (Participant 4)

*Frequent residential and educational moves.* Frequent educational and residential moves were observed as prominent barriers prohibiting LAC from accessing timely services and support. Moves to rural areas were noted as particularly challenging. However, many participants conveyed more concern for children who had undergone multiple residential and educational moves, particularly when placed in another 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 . . . [there is] definitely [a] disparity between the east of the county and the rural bit of it in terms of access to services. (Participant 1)

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. (Participant 5)

### *Impacts on care placement settings*

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: multiple placements, residential care placements and the perceived barriers to being fostered or adopted.

*Multiple care placements.* Several participants noted that children with NDDs such as ADHD 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 parents/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 13 foster care homes until he's 14 [years old]. (Participant 3)

Well, you know, I've had an 11-year-old come in a month ago, and there's been a lot of service provision 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 'cause they couldn't keep him safe because of his behaviour which was crazy . . . [it] was [directed] against them [but] 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. (Participant 6)

**Residential care.** Participants viewed residential care as a more positive, protective setting for the child with an NDD and for those with severe behavioural problems. Safeguarding them was a priority for many participants but only after attempting multiple placement settings. One child was stated as being as young as seven years old:

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. (Participant 10)

I'd say the majority of our kids in residential care 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 [residential care homes or units where some children are placed as they cannot be supported in any other available care setting] we've got, different ages . . . But I know of a boy who is seven who's in residential. (Participant 2)

One participant noted that the behaviours associated with these conditions and the lack of support services contributed to a child being placed in residential care:

. . . 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. (Participant 2)

Having a stable, safe and caring environment was suggested to be the most effective approach for the child, with positive outcomes:

. . . 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? (Participant 4)

**Foster placement or adoption.** If a LAC is unable to be returned to their biological parent, the next step is to ensure that they are placed in a safe long-term caring environment. Some participants expressed concerns that having a diagnosed NDD might hinder or prohibit the child from being fostered or, especially, adopted:

I do think it could be detrimental, because you see that label ADHD and the first thing you think of [is] 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 [for] adopters I would say that that's a problem. (Participant 4)

If they were given a choice between a child without a label and one with a label then they probably would want without label. (Participant 7)

Yeah, it makes them more difficult to match [to] a foster carer. (Participant 8)

## Discussion

This is the first qualitative study to the authors' knowledge that has explored the perceptions, awareness and experiences of social workers in the UK on the subject of LAC and NDDs. This study found that social workers experience challenges in the understanding of NDDs, further impeded by inaccessible services and a lack of professional knowledge and resources, which present barriers to providing full support for these children. Of equal if not more importance are the detrimental impacts on the LAC who have an NDD, particularly in the suitability and stability of care settings.

Firstly, while the prevalence of NDDs was not our main focus, it is important to note that ADHD was perceived to be the most prominent NDD in this study's population followed by ASD, dyslexia and dyspraxia. However, the authors could only find ASD statistics in Welsh governmental LAC publications (Welsh Assembly Government, 2020). This highlights a significant gap in the data for policies to explore to ensure suitable service provision is provided for LAC who have ADHD.

While prevalence rates are needed, even more important is the need to have a social care service that has been trained and supported to understand the complexity of these conditions to meet the individual needs of children with NDDs. Several important sub-themes emerged from the social workers' perceptions and knowledge of NDDs, raising important questions for future research.

Limited knowledge and a lack of in-depth training was a major concern which had a negative impact on the well-being of the social workers. Their feelings of ineptitude in their knowledge and understanding of NDDs caused them a lot of apprehension, confusion, frustration and stress as they were primarily responsible for the overall well-being of these children. The majority of participants expressed their desire to attain more in-depth training so that they could better meet the needs of the LAC with an NDD and support the parent/carer to develop a relevant and appropriate care plan.

Although attachment was not explored as an NDD, the term frequently arose in participant responses. The similarity in behaviours associated with trauma, attachment or an NDD was confusing for these participants; this was attributed to a lack of in-depth training and other professional understanding of NDDs in this study. Bowlby's theory of attachment is very influential in social work training, since understanding the impacts on the biological, neurological and psychological needs of the child who has experienced high-level, stress-related ACEs is paramount for these professionals (Harlow, 2021). However, more limited in social worker education and training is an understanding of the biological, neurological and psychological needs associated with developmental disorders and mental health (Kourgiantakis, et al., 2020). This paucity of training could unconsciously prohibit the

social worker's understanding and exploration of an NDD or other mental disorder and encourage them to attribute the behaviours to attachment only. More training in the disorders outlined by the International Classification of Diseases (ICD) manual would enhance the knowledge of social workers and provide them with alternative and varying evidence-based interventions that could be utilised to help these children.

Diagnosing or labelling a child with any social or clinical term can be controversial and generate different emotive responses; it can also often be influenced by conflicting ideologies about whether behaviours are induced by biological or psychological environments (Ahmedani, 2011; Hinshaw and Scheffler, 2014). However, diagnoses of NDDs are not based on ideologies but derived from a multidisciplinary professional approach and input which is underpinned by evidence-based research. Several participants found the diagnosis of an NDD to be positive for accessing educational provision. However, some expressed concerns over misdiagnosis and overdiagnosis, prohibiting any further exploration into underlying trauma-related conditions; this is reflective of other research (Kentrou et al., 2019; Rodriguez et al., 2018). Conversely, research has found that LAC who present with trauma-related conditions may prohibit clinicians from exploring underlying behaviours that suggest an NDD (DeJong, 2010; Parsons, et al., 2019; Pinto, 2019). Placing the child's needs at the centre of services was at the core of each participant's response. However, it is important to note that supporting the child with an NDD would differ in a care plan. A correct diagnosis is paramount to providing the correct specialist support for the LAC with an NDD, but it is equally important for the social worker to explore the behavioural symptoms of trauma or attachment as a LAC may present with both.

As anticipated, the topic of prescribed medication elicited conflicting thoughts and opinions. Some participants viewed a marked improvement in behaviours with medication, while others found it to exacerbate behaviours, which is again reflective of research (Alfageh, et al., 2019; Cortese, et al., 2018). Medication was seen as a last resort, while stability in a care placement was viewed as more effective. Since medication usage is thought to be high in the LAC population, this should be explored further with other social work professionals. The National Institute for Health and Care Excellence (NICE) guidelines on ADHD management suggest that children with this condition should only be prescribed medication if they have severe impairments that have adverse impacts on their daily lives (NICE, 2019). The social worker should play a key role in this area as they are the ones who work closely with LAC and have a unique, privileged insight into their individual daily needs (Karlsson and Lundström, 2021).

As noted previously, early identification and intervention of NDDs are an essential part of accessing timely services, which will empower the child to thrive in society. A surprising finding was that LAC who are embedded in services and prioritised in policy had to wait a long time to access specialist services. Diagnostic assessment and attainment for NDDs, particularly ASD, worryingly ranged into periods of years and was noted as a lengthy, complex process. Even when the child had attained a diagnosis, they were discharged and referred on to third-sector services which were already overwhelmed with requests. This raises further questions for policy as to what support is available for LAC who have an NDD.

Particularly disconcerting in our findings was the inaccessibility of CAMHS. Poor mental health and co-occurring mental disorders are particularly prevalent in the LAC population and in children with an NDD (Ford, et al., 2007; Hansen, et al., 2018; Petrou, et al., 2018; Reale, et al., 2017). Several participants noted that the LAC was only able to access CAMHS if she or he had transitioned into a crisis situation. Even when a child accessed

CAMHS, they were frequently discharged as their behaviours did not equate to a classified mental disorder. This denial of services was a major concern for all social workers as they felt ineffectual in their ability to support the mental health of vulnerable children. From a preventative perspective, if CAMHS are not funded or equipped to deal with the mental health needs of these children, policy should further explore what other mental health service provision is available (UK Government, 2020).

Accessing support services was also impeded by geographical location and moving between multiple residential and educational placements. There were disparities in service provision between counties, particularly for children who lived in more rural areas. Support services should be accessible to all as they are integral to the future overall well-being of these children and should be made available for all LAC. Social workers reported that when a child moved placement, particularly to another county, the whole diagnostic, educational or CAMHS process would have to restart, further adding to already lengthy processes. Information on the child was exchanged between counties and local authorities in a paper file format. Although this finding cannot be generalised to a national level, it should be explored further as there are implications for data protection. This process could also hinder a child's timely access to a service provision. A more technological, effective and efficient process for the transfer of sensitive information should be explored, therefore.

The stability and suitability of care settings for children with NDDs were also of some concern. Several participants noted that LAC with ADHD 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 parents had voluntarily placed these children in care as they found this to be the safest option for the child. This reflects other research, which has shown that children with ADHD and ASD are over-represented in residential care (Buescher, et al., 2014; Dein, et al., 2021; Karlsson and Lundström, 2021). There are some protective factors to these placements. However, more research is needed to explore whether specialist foster care or kinship care might better meet the needs of these children (Osborne, et al., 2021). Conversely, it could be suggested that a lack of early identification, intervention and specialist support could be contributory factors to the manifestation of challenging behaviours and breakdowns in care settings, resulting in residential placement.

Finally, an unexpected finding was that many participants conveyed concern that diagnosing children with NDDs would reduce their chances of being fostered or adopted, attributing this to the perceived behavioural challenges associated with these conditions. Although only perceptions, the professional responses described are important to note and explore further. Children with NDDs are frequently stigmatised in societal perceptions as they are associated with significant behavioural, psychological and social challenges (Swaab, et al., 2021). However, with the correct support, many are able to lead a fulfilling life and function extremely well on a daily basis (Gunty, 2021). An in-depth understanding and awareness of these conditions is 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 to reduce the need to access health and social care services (Gunty, 2021; Song, et al., 2021b).

## **Strengths and limitations**

A key strength of this 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 settings. Their perspectives are unique but integral to research as they are able to provide insights from the



real, lived experience of working with these children. They additionally have a unique insight into the wider family challenges and social determinants that 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 and reflective practice 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 and Noble, 2014). To further address personal bias, a conscious but not documented reflective practice was used when analysing the data. Using a thematic analysis approach further strengthened the study by using a framework that facilitated the analysis of the data in a systematic approach.

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 (Smith and Noble, 2014). 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 sample size was small, and the findings were derived from only two local authorities so cannot be generalised to the rest of Wales or the UK.

## **Conclusion**

This study highlights some important areas for the stakeholders responsible for supporting LAC, their parents/carers and social workers to explore further in a national context. For the social worker, the lack of in-depth knowledge of NDDs, not only in social care but also in the healthcare sector, the scarcity of specialist training and resources and the difficulty of accessing specialist health and educational service provision all raise concerns. For the parent/carer, the lengthy waiting times for access to the specialist provision required to support vulnerable children require further investigation. The behavioural responses that are associated with a child with an NDD can often create challenging environments for the parent/carer and wider family (Harold, et al., 2013; Olatunji and Idemudia, 2021). Lastly, but more importantly, the study highlights significant questions for further exploration into the future overall well-being of the LAC who has been diagnosed with an NDD or has a suspected NDD. Early identification appears to lead to an unwarranted lengthy process ranging into periods of years, and early intervention from both health and social care sectors, particularly CAMHS, is unattainable for many children. Equally important is the impact on the stability and suitability of the care settings in which these children are placed as a result of their challenging behaviours and responses, which is reflective of the challenges associated with some of these conditions. Children's services would benefit from more support in early identification, understanding and access to timely intervention. This would have a direct and indirect impact on the social, emotional and mental health of LAC with NDDs, enhancing their educational attainment while stabilising their care placement and reducing the need for them to access health and social care services in future.

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