

Written evidence submitted by a parent of a child in care with Asperger Syndrome/ASC (CSWB 01)

Children with Autism, ADHD, Fetal Alcohol Spectrum in Care by a parent of a child in Care with Asperger Syndrome/ASC

When we think of disabled children in Care, the picture that springs to mind may be that of a child with multiple and visible impairments with high support needs that birth families cannot meet, possibly when the child enters adolescence and all begin to plan for their long term future.

The reality is very different. Most children in Care with a disability are likely to have a neurodisability.

These include children with foetal alcohol spectrum disorder, autism, learning disabilities, attention deficit hyperactivity disorder and learning difficulties such as dyslexia and dyspraxia. Neurodisabilities are often co-morbid with each other and sometimes co-morbid with other conditions. People can be neurodisabled to varying degrees so, as an example, a child could have a 'severe' or 'mild' learning disability although the effect on the child may be anything but mild if it means they are easily bullied, exploited or have little sense of danger. This is why it is very important that a child with neurodisabilities receives an accurate and differentiated diagnosis and all understand how their disability affects them when they interact with the world.

Most children become looked after as a result of abuse and neglect. It is well known that delays in identifying and meeting their emotional well-being and mental health needs can have far reaching effects on all aspects of their lives. Delays in identifying a child's neurodisabilities can be equally damaging and indeed compound mental health problems. Given that neurodisabilities are life-long and poor understanding can lead to long-term harm, it is especially important that these too are identified when children enter Care.

"Research undertaken highlights that a significant number of young people who become known to CSE services have moderate or mild learning disabilities or learning difficulties – and, in particular, autistic spectrum conditions (ASC) and attention deficit hyperactivity disorder (ADHD). The evidence suggests that many of these young people who have moderate learning disabilities or learning difficulties, or are possibly on the autistic spectrum, have never had a formal diagnosis or assessment of need. Young people clearly articulated how the lack of recognition that they have a learning disability can be problematic, leading to frustration at school and exhibiting behaviour described by others as 'challenging'. For some, problems at school led them to cease engaging in education or being excluded, which further increases their vulnerability to CSE. Evidence gathered also suggests that some professionals may have a propensity to focus on 'challenging behaviour' and miss indicators of a potential learning disability and CSE. There appears to be a clear pattern across the UK of CSE professionals working with young people for whom there is no formal or informal identification of a learning disability or specific learning need. Although this warrants further investigation, it appears that a lack of knowledge around learning disabilities, lack of information-sharing and multi-agency working and lack of available services to meet this group of young people's needs exacerbates these issues.

Specialist CSE professionals' articulation of a desire for a formal diagnosis reflects their search for information that can provide them with an improved understanding of how they can work with a young person to meet their needs. Many also identified that a formal diagnosis is particularly crucial to meeting young people's needs because, in many instances, it is the only route to accessing additional specialist support.

Anita Franklin, Phil Raws and Emilie Smeaton (2015) **Unprotected, overprotected: meeting the needs of young people with learning disabilities who experience, or are at risk of, sexual exploitation**

There is increasing evidence from a wide range of sources including birth families, adoptive families, foster carers, those working with victims of child sexual exploitation and young people in secure settings that the support neurodisabled children in Care are given, is falling well short of meeting their needs. Reasons for this are varied and complex so what needs to change within the care system?

The Care System

When a child with neurodisabilities enters Care, possibly because the risks they pose to family members cannot be managed safely or because the family home is not a safe and nurturing environment or parents/carer(s) cannot meet their child's needs for another reason, then the Care system must be able to consistently improve outcomes for the child and support them around their disability as necessary to achieve this.

For this to be a realistic prospect there needs to be :-

- new statutory and practice guidance that places a requirement on local authorities to provide appropriate support to children in Care with neurodisabilities and gives practical guidance on how to do this using evidence from a range of sources including independent research, the Innovation Programme and analysis of practices in local authorities that receive good Ofsted and/or CQC ratings.
- an enhanced screening programme for children entering Care that flags up indicators that a child may have autism, intellectual impairments and other neurodisabilities. This screening programme could be combined with assessments for speech and language difficulties, often (but not always) an indicator that a child has a neurodisability such as autism. Where professionals are relying on a screening programme rather than assessments to detect neurodisabilities, they must have training in its use and the potential and reasons for false negatives and false positives and there should be a path to specialist assessment and diagnosis irrespective of placement stability.
- new communication standards such as <http://www.england.nhs.uk/accessibleinfo> appropriate for children. A common standard should also be used to consistently and uniformly record looked-after children's neurodisabilities whether for example, flagged up in school by a SEND team, diagnosed before entering Care, detected in looked-after children's health assessments by health professionals, known to children's services disability teams or diagnosed within Care irrespective of the setting. Health and social care commissioners should have access to information on numbers and needs of children in Care with neurodisabilities so that they can accurately commission health and social care for this cohort and outcomes for looked-after children with neurodisabilities should be monitored.
- enhanced training so all social care professionals from social workers to Independent Reviewing Officers know how to support a child with neurodisabilities including training in how, in their practice, to take account of cognitive or processing deficits and to address sensory needs.
- new care pathways that meet the needs of children in Care with neurodisabilities. All must understand that a looked-after neurodisabled child's strengths and vulnerabilities will be different to both their non-neurodisabled and non-looked-after peers and the support each child receives within and beyond Care must take account of this.
- a requirement for carers to be trained in ways to support children with neurodisabilities including, where appropriate, training that helps them to understand the reasons for and ways to reduce a child's 'challenging behaviour' that results from their neurodisability. This applies to all carers whether foster carers, adoptive parents, staff in children's homes and in residential settings for children with 'emotional and behavioural' difficulties or equivalent.

- a requirement for LA's to signpost looked-after children and their carers to mainstream services for children with neurodisabilities including the Local Offer and to address the needs of neurodisabled looked-after and former looked-after children when preparing the Local Offer.
- a concerted focus on ensuring neurodisabled children's wishes, strengths and vulnerabilities are taken into account in decision making about them. There should be new practice guidance that shows how to do this. One model could be the Practice Toolkits developed by the Law Society for autistic and learning disabled witnesses.
<http://www.theadvocatesgateway.org/images/toolkits/3AUTISM211013.pdf>
- embedding practice that support disabled children's rights to good social and health care.
http://cdn.basw.co.uk/upload/basw_30635-1.pdf Adult rights based health and social care practice for people with neurodisabilities should be integrated with and inform statutory and practice guidance particularly affecting looked-after children with neurodisabilities in adolescence and former looked-after children.

Finally

Children in Care with neurodisabilities can present with the most difficulties and are often the most challenging of our young people to support. If we do not identify their disabilities and support them and the people who care for them appropriately, what does it mean for the child if not a lifetime of extreme vulnerability on the margins of society?

What does it tell us about the Care system itself, if it fails these children? Many committed people work within it but failure to identify and support children with neurodisabilities means that for a significant number of children in Care, the Care system itself is failing.

Read debates in the House of Lords on a proposed amendment (57c, Amendments 4 and 5) to the Corporate Parenting Principles within the Children and Social Work Bill to place a requirement on Corporate parents to screen children in the first health assessments for neurodisabilities here:-
[https://hansard.parliament.uk/lords/2016-10-18/debates/F87D90E7-21C7-4F40-A6A9-63D754DB02AE/ChildrenAndSocialWorkBill\(HL\)](https://hansard.parliament.uk/lords/2016-10-18/debates/F87D90E7-21C7-4F40-A6A9-63D754DB02AE/ChildrenAndSocialWorkBill(HL))

BMA, 2007 (updated February 2016) Alcohol and pregnancy Preventing and managing fetal alcohol spectrum disorders

"The management of FASD incorporates the identification, referral, diagnosis and treatment of individuals affected by prenatal exposure to alcohol. Early diagnosis is vital to ensure appropriate treatment and support systems are implemented at the earliest stage. The lack of knowledge and understanding of FASD among healthcare professionals means they often do not feel competent to make a diagnosis. This is compounded by the absence of validated diagnostic or screening tools, the under-reporting of maternal alcohol consumption, the difficulty in detecting the defining features of FASD, and the similarity between the characteristic features of FASD and other genetic and malformation syndromes. As a consequence, FASD is rarely diagnosed at birth or in infancy. There is a lack of specific guidance on diagnosis, referral and treatment in the UK, although clinical care pathways from antenatal care to diagnosis have been proposed by a forum of UK health and medical professionals. Several sets of diagnostic criteria have been developed to assist in the evaluation and categorisation of the effects of PAE. Clear guidance on the diagnosis of the full range of fetal alcohol spectrum disorders, for all healthcare professionals in the UK, is required."

It is known that looked after children are at high risk of FASD yet there is no Care Pathway for early diagnosis.

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