Draft Guidance

Assessing the Needs of Disabled Children and their Families

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Introduction

This guidance applies in situations where a Children's Services authority is undertaking a disabled children's needs assessment and the authority has no cogent evidence that the child is at risk of neglect or abuse.

In this guidance references to a disabled child or to disabled children includes references to all disabled young people (or persons) under 18 years and references to parents include (where the context permits) references to other significant adult family adult carers.[1]

This guidance is aimed at everyone involved in assessments, not just at those who have a specialist role with disabled children. An assessment should be a positive opportunity to identify and respond to the needs of children and families. Serious concerns have been raised about the quality of assessments of disabled children. The process of assessment and the likelihood of multiple assessment arrangements may compound the difficulties facing disabled children and their families and result in conflicting messages about the needs and the most effective types of intervention/ or support. Since discrimination of all kinds is an everyday reality in many children's lives, every effort must be made to ensure that agencies responses do not reflect or reinforce that experience and indeed, should counteract it.

In the past, disabled children have often been excluded from or marginalised within mainstream services, and many standard assessment frameworks and approaches have been developed with only non-disabled children in mind. Disabled children are 'children first' and this guidance is based on this principle of inclusion. However, recognising disabled children as children first does not imply denial of a child's particular needs: 'Ensuring equality of opportunity does not mean that all children are treated the same. It does mean understanding and working sensitively and knowledgeably with diversity…'.

This guidance aims to assist those undertaking assessments of need, by enabling social care practitioners to understand and work more sensitively with disabled children and their families.

Extracted from Department of Health Assessing Children in Need and their Families: Practice Guidance (Stationery Office 2000) paras 3.1 – 3.4.

Overarching Assessment Principles

1. Appreciating that an assessment of a disabled child's needs (in a situation where there is no cogent evidence of neglect or abuse) requires social care professionals to think and act differently compared to when they are undertaking an assessment in the context of a 'safeguarding' investigation.

2. The importance of beginning with the assumption that parents are best-placed to judge the well-being of their disabled child:[2] that as a result of their daily experience and special bond they have a 'sense of knowing'[3] of their child's condition and needs.[4]

3. Appreciating that many parents of disabled children feel that their expertise regarding their children's wellbeing is not always recognised or taken seriously.[5]

4. Appreciating that many disabled children and their families find assessments to be highly stressful, undignified, and traumatic experiences:[6] that the experiences of parents who find themselves subject 'to child protection investigations as a result of seeking help' has the effect of stopping them asking for support.[7]

5. Appreciating that the presence of an assessor causes anxiety: that Children's Services officers have enormous power to interfere in family life. In consequence assessors must appreciate that insensitive or inappropriately managed assessments can materially aggravate the everyday stress and cognitive overload (having to deal with too much information / tasks at once) experienced by many parents of disabled children.

6. Appreciating that assessments of disabled children and their families should be 'needs based' and should focus on the supports that the child and their family need in order to enjoy 'a quality of life comparable to that enjoyed by others who do not live with disability'.[8] Assessments should not therefore be used as an opportunity for 'family surveillance' or to 'judge parenting capacity through a child protection lens'.[9]

7. Local authorities must ensure that assessors have the necessary skills, knowledge and competence to carry out needs assessments concerning the entitlement of disabled children and their families to social care support services. This means ensuring that assessors undergo regular, up-to-date and in-depth training:

   - concerning the nature and the legal purpose of the assessment and care planning process, and the relevant statutory obligations that are engaged under the Chronically Sick and Disabled Persons Act 1970 and the Children Act 1989;

   - concerning the vital importance of disability awareness and of understanding the social causes / social impacts of disability and of the nature of impairments / conditions which are appropriate to the assessor's role,[10] including (for example) children who may be neurodiverse[11] or have a sensory impairment, a learning disability or a mental health need.

8. Where an assessor does not have the necessary understanding or experience of assessing the needs that arise from a particular condition, they must consult someone who does. Consultation, in such cases, is essential to ensure, among other things, that the person being assessed is involved throughout the process, that the full range of their needs are captured and that the social care support services required as a result are all accurately identified.[12]

9. Appreciating the need to understand the deep-seated structural inequalities that lead to adverse outcomes – for instance disabled parents and children who are also part of Black, Asian and Minority Ethnic groups will experience even more impeded accesses to social care support services. Assessors need to understand these persistent inequalities and through advocacy, interagency working, and co-production, assist families to challenge and shift these barriers.[13]

Parent and child centred practice

10. Good practice is when a social care professional commences an assessment with no preconceived views about the strengths and weaknesses of a family. This means that wherever possible the assessment should commence with the 'family first': with a detailed meeting with the family – and not, for example, after discussions with the child's school or healthcare and / or other professionals. Good practice is when a social care professional appreciates that in general 'the best source of information will be the child and their family'.[14]

11. Many families with disabled children live with significant disadvantage and experience what has been described as 'clustered injustice'[15] – as having multiple synchronous difficulties in accessing basic entitlements such as their child's right to appropriate education, healthcare, decent (suitably adapted) housing, transport and social care support. Many parents have legitimate concerns about their child's health, their own health, their other children's well-being, their financial difficulties and much else. Many families describe their experience of being assessed as adding stress to an already challenging situation[16] and the difficulties and exhaustion of having to attend a myriad of meetings with professionals where the same information must be repeated over and over again.[17]

12. Not infrequently the cumulative impact of these multiple challenges is experienced by parents of disabled children in terms of trauma and cognitive overload.[18] This can result in parents being perceived to be, for example, 'difficult', combative or over anxious: a form of labelling that many disabled parents with a wide range of conditions have also experienced, including, for example, parents with sensory impairments, chronic fatigue, autistic and neurodivergent parents.[19] Good practice is when a social care professional demonstrates empathy and understanding of these challenges during the assessment process and makes plain that their role is to endeavour to alleviate the pressures families experience: that every effort will be made to ensure that the process will be the least disruptive, least intrusive and as painless as is possible.[20]

13. Good assessment practice also involves:

    - adopting a 'person centred' approach: an open and honest approach based on active listening, on open discussion and the avoidance of stereotyping – both in relation to those being assessed and in relation to the way that their decisions are made concerning how support needs can be addressed;
    - asking a disabled child and their parent(s) their preferred name within the written assessment e.g., rather than writing 'mum' throughout, would they prefer their first name?;
    - appreciating that families will need time to build trust and that they will almost inevitably lack the necessary trust when they experience a high-turnover of assessors;
    - that the purpose of the assessment process is for the authority to learn about the issues that are of importance to the family – a process that requires a focus on the needs of the child and the family, rather than on what are perceived to be the child's 'problems'.

Trauma-informed practice

14. Trauma[21] awareness and trauma-informed practice are critical aspects of social care professionals' roles when assessing a disabled child and working with their families.

    - Disabled children and their parents can experience trauma when their needs are not recognised, are misunderstood, are negated and / or are unmet by statutory services;
    - In this context, good practice requires that social care professionals remind themselves of their responsibility to be curious and to exercise judgement within the boundaries of their individual expertise – and in consequence to appreciate the limits of their expertise. It follows that where, for example, the assessor is not a clinician or diagnostician they should be particularly mindful of their professional limitations;
    - Many parents of disabled children describe the trauma they experience when they believe that their alleged 'poor parenting skills' are blamed for their child's difficulties. Many have also identified the trauma that they and their families experience when inappropriate suggestions have been made that they are responsible for their child's difficulties – for example, their child's absences from mainstream schooling or that they have fabricated or induced their child's illness / impairments (FII). In this respect it is essential that social care professionals are fully aware of the relevant guidance concerning such difficulties.[22]

Hearing the child's voice

15. The assessment process should ensure, so far as is reasonably practicable, that the disabled child is encouraged to express their views freely on all matters affecting them.

16. There are many ways of communicating with a child and of ensuring that their 'voice' can be heard. The mere fact that a child is non-verbal doesn't mean that they cannot communicate their views and local authorities should ensure that assessors are appropriately trained and have the necessary communication skills to effectively engage with a disabled child. In this context, good assessment practice requires:

    - that assessors discuss and agree with the family the process for facilitating the child's right to have their 'voice' heard: appreciating that some disabled children need time to build trust and how traumatising it can be for them to be confronted by a stranger and told that they have to speak with that person – regardless of their wishes;

    - that local authorities ensure that assessors have strong legal[23] (and human rights) literacy and confidence[24] to make proportionate decisions as to when it might be appropriate to ask to speak with a child in the absence of their parents and the reasons for making such a request;

    - that the aim of the assessment process is to understand the disabled child as a unique person with unique views and needs, and not simply as a 'diagnosis'.

Non-discriminatory practice

17. Good practice and domestic law require that people who are different should (where this difference is relevant) be treated differently.[25] It is for this reason that local authorities should respond differently to situations where support is sought to address the disability related needs of a child and their family, compared to situations where there is cogent evidence that a child is at risk of neglect or abuse.

18. 'Responding differently' requires (among many things): that there be no 'one-size-fits all' approach to the assessment process, that there be distinct administrative forms, distinct guidance and training for assessors, and distinct eligibility criteria.

19. The requirement to respect and accommodate 'difference', requires that those involved in the assessment and care planning process:

    - ensure that the disability related accessibility needs of families are addressed, which will require a genuine awareness of the different ways that some disabled people receive information and communicate – for example neurodivergent parents, those with sensory impairments and disabled children;

- understand that because a neurodivergent parent may not appear to have emotional reactions (that would ‘normally’ be deemed ‘appropriate’) this is not necessarily an accurate reflection of how they actually feel. Some autistic parents, for example, take longer to process information and in consequence their reaction may come later – possibly when the assessor is no longer present;

- understand that not all neurodiverse parents may be aware of their neurodiversity, may not have had a formal diagnosis, or may not wish to disclose any such information to an assessor – and that they are under no obligation to do so;

- ensure that all relevant accessibility issues (for example in relation to the communication needs of the child and parents) and reasonable adjustments are made so that assessment meetings are as inclusive, effective and stress free as is feasible. Reasonable adjustments may, for example, include (in the case of autistic children / parents) having a clear structure for the assessment meeting.

Human rights

20. Social care professionals involved in the process of assessing the needs of disabled children and their families have a duty to promote their human rights, including a duty to facilitate their access to the right services.[26] In consequence there is a duty on local authorities to ensure that assessors are aware of their responsibilities under relevant human rights provisions and are also equipped with the skills to make proportionate decisions when the qualified rights of families are engaged.

21. The Human Rights Act 1998 requires that state officials demonstrate respect for the private and family lives, and the homes of those with whom they interact on a professional basis. In fulfilment of this obligation, the Act places severe restrictions on the rights of state officials to interfere with individuals’ private and family lives and their homes. Inherent within this obligation is an understanding of the power imbalance between the state and the individual and an appreciation that the mere fact that an assessor has been ‘invited’ into a person’s home does not give them the right to ask (for example) to examine a child’s bedroom, or to inspect a family’s kitchen, or bathroom or to interview a child alone: that simply asking for permission to do these things does not render lawful the invasion of privacy, family life and the home. Families consistently report that in such situations, they feel they have no choice[27] but to agree – that any refusal would be recorded on the assessment paperwork and then used as evidence that they have something to hide – notwithstanding that they find such intrusions to be deeply humiliating and inappropriate.

22. It follows, that unless there are credible ‘family specific’ reasons for believing that action of this kind is necessary, requests of this nature should not be made. Good practice requires that where a rights interference is considered necessary, the reasons should be explained (together with the evidence base for these reasons) in advance to the family. The reasons should be confirmed in writing together with details as to what the consequences would be if the family refuses and their rights to challenge any such consequences.

The social model of disability

This guidance is informed by an understanding of the 'social model' of disability, which uses the term disability not to refer to impairment (functional limitations) but rather to describe the effects of prejudice and discrimination: the social factors which create barriers, deny opportunities, and thereby dis-able people. Children's impairments can of course create genuine difficulties in their lives. However, many of the problems faced by disabled children are not caused by their conditions or impairments, but by societal values, service structures, or adult behaviour:

a major problem for disabled children is that they live in a society which views childhood impairment as deeply problematic (p.20).

Extracted from Department of Health Assessing Children in Need and their Families: Practice Guidance (Stationery Office 2000)

23. Social care professionals involved in the assessment of the needs of disabled children and their families must be able to demonstrate a deep and reflective understanding of the 'social model' of disability and of the importance of not locating the 'problem' of impairment within the child or their family. Such an understanding requires that assessors approach their practice:

- with the assumption that parents are best placed to identify the societal barriers they encounter as a result of their child's impairment and the support that their family needs to overcome these barriers;
- with an emphatic and thoughtful appreciation that the barriers 'to inclusion' that disabled people encounter are generally long term and that institutional policies that mandate short term support responses are generally inappropriate. Policies of this kind suggest a medicalised conception of disability – as something 'curable' by time-limited interventions designed to make the disabled person and their families 'independent' – in the sense of not requiring further social supports;
- by appreciating that the legal duties on Children's Services departments, relating to the support needs of disabled children and their families, exist in order to address the many disability-related disadvantages that they experience. That in consequence the presumption should be that disabled children are in need of societal care and support in addition to, or instead of, the care and support provided by their family;[28]
- with an understanding that everyday tasks that are straight forward for people who do not live with disability are often very challenging (sometimes impossible) for disabled people and their families: tasks such as work, travel, leisure and accessing basic necessities;

- with an understanding that for families in this position, many of the major problems they encounter are due to the inappropriate way that individuals and their institutions respond to 'disability': responses that can directly or subliminally attribute blame to disabled children's parents – categorising their needs and their behaviour as 'problematic';

- with an awareness that generalisations such as 'even non-disabled children struggle with that' are to be avoided: that every child and family are unique in need or presentation;

- by understanding the importance of counteracting the 'cognitive overload' experienced by parents when having to deal with multiple departmental silos – each with different forms and procedures. This requires reducing / simplifying – so far as is appropriate – administrative procedures, avoiding families having to repeat information they have already provided and creating family specific solutions to help ameliorate the institutional / administrative barriers families encounter.

Conceptualising neglect

24. Disabled children and their families are one of the most severely disadvantaged groups in the UK[29] and assessors must be acutely aware that social disadvantage or advantage (perceived) is not synonymous with parental neglect.

25. It is well established that parents of disabled children 'are at increased risk of poorer mental and physical health'[30] and as a group experience consistently low wellbeing indices measures. Disadvantage attributable to their anxieties about their children's health, the clusters of problems that they experience due to the impersonal siloed[31] administrative systems they encounter and their dissatisfaction[32] with 'a costly and intrusive' social care system characterised by its rationing of services: a system that's energy 'appears to be disproportionately spent on assessing and investigating families instead of providing support'.[33]

26. The fact that research suggests that disabled children are at a greater risk of abuse[34] does not mean that this provides a lawful justification for assessing all disabled children through the 'safeguarding lens' – anymore than it would be lawful for the police to undertake stop and searches based on racial profiling. In the absence of 'child specific evidence' action of this kind could amount to unlawful direct discrimination.[35]

27. Given the clusters of chronic difficulties that disabled children and their families encounter, good practice requires that social care professionals do not make assumptions (for example):

    - that a disabled child's poor attendance at school constitutes 'neglect'. Many families experience severe challenges in identifying and / or securing access to suitably inclusive educational settings for their disabled children;[36]

- that because a parent's description of a disabled child's behaviour at home is at odds with their reported behaviour in other settings, the parent is over anxious or an unreliable witness, or is a parent who lacks appropriate parenting skills or is neglectful;[37]

- that a parent who is emotional during the assessment or care planning process has in consequence a mental health difficulty: crying or other examples of emotional distress are normal and healthy human responses to stress;[38]

- that because they consider a home to be 'untidy' (or 'overly tidy') it does not, in itself, equate to 'neglect'. Untidiness may well be evidence of a lack of essential statutory support to which the family should be entitled or a result of a disabled child's behaviour or a consequence of the family's social disadvantage or a myriad of other reasons. Tidiness may be due to the parent feeling 'under immense pressure to make the house look immaculate', believing that it is likely to be judged by the visiting assessor;[39]

- that because a parent fails to attend several appointments this amounts to neglect: it may well be due to the challenges that the parent is experiencing in juggling their many other appointments, other commitments, the clusters of difficulties the family is experiencing including their (consequent) depleted reserves of mental effort;[40]

- that unusual behaviour or parenting practices do not necessarily constitute harmful behaviour: there are often logical reasons for such behaviours. Assessors must be open minded to different priorities or ways of parenting and the fact that there are multiple ways of parenting a child and the most appropriate one for the specific child will depend on their specific needs. It is not one size fits all. Assessors should also be mindful that some parents may not know that they have an impairment. In the case of neurodivergent parents, for example, they may be very capable parents, but nevertheless struggle with planning, talking on the phone, emailing and attending appointments on time. Reasonable adjustments for these impairment related difficulties may require, for example, the use of different forms of communication such as text reminders and copying another person in the communications (for support), the provision of good directions and so on.

Before the assessment visit

28. Except in cases of urgency, the assessors must have been allotted sufficient time to ensure that they have familiarised themselves with all the relevant documentation relating to the needs of the disabled child and their family.

29. Assessors, when making arrangements to meet a family in order to undertake a disabled children needs assessment, or a parent carer needs assessment, should bear in mind the importance of:

    - clarifying how the family wants to be addressed;

- identifying any accessibility issues (eg disability or language related needs) that the family may have in order to enable them to be fully involved in the assessment process;
- identifying the child's interests in order to aid (among other things) relationship / trust building;
- finding a time that is convenient for the family and also one that occurs at a 'good time' for the child;
- ensuring that there should be no unannounced or 'short notice' visits;
- ensuring that appointments are kept as arranged with the family;
- appreciating that many families find meetings of this kind stressful:
  - in order to attend the meeting, families often have to (for example) cancel work and important social commitments, rearrange medical / school and other appointments relating to their disabled child, make other caring arrangements for their other children – and so on;
  - that many families have to spend considerable time preparing their child(ren) for the arrival of a stranger;
  - that many families find it extremely stressful coping with appointments that have been cancelled at short notice.

30. At the first point of contact or at a time before the initial visit, families should be invited to provide information they consider relevant to the assessment. It should be made clear at that stage that the family has a free choice as to whether they do this.

31. The information that they provide at this stage might include, for example: family details (names and ages etc), previous assessments, copies of previous DWP disability forms, relevant medical reports, EHC Plans, significant incidents in the family's history and so on. Where families are willing and able to provide some information of this nature, they should have the choice of doing this in a format of their preference, including the option of uploading the information electronically onto the local authority's template assessment form.

32. Assessors should identify relevant information that the authority already holds (for example earlier Social Care, Occupational Therapy, Speech and Language Assessments etc) – and this information should be shared with the family before the assessment.

33. Parents should be given the opportunity to arrange a time before the first meeting with the assessor (including a first meeting with a new assessor) when they are able to speak privately – ie in the absence of their children.

34. Before the assessment commences families should be provided with sufficient information to ensure they have a good understanding of the nature and purpose of the assessment process. This information should be available in a variety of accessible formats.

35. It is important to bear in mind that the prior provision of accessible information does not absolve the authority from ensuring that the family understand the essential information detailed below and the assessor must check (and confirm) that the family has the necessary understanding of the nature and purpose of the assessment process.

36. Before an assessment meeting takes place, families must be:

- given the assessor's full name and ideally a picture, together with details as to their experience (ie confirmation that they have attended relevant training courses – eg legal, disability awareness and impairment specific training);
- given clear contact details including a reachable telephone so that they can contact the assessor if needed;
- made aware of their relevant rights, for example:
    - their rights to other assessments – such as a Parent Carer's Needs Assessment and/or to a Young Carer's Needs Assessment and/or an assessment under the Care Act 2014 (for disabled parents and for parents who are also caring for an 'adult in need');
    - their right to have a friend / advocate present at the meeting;
- provided with details of a local parent carer support group/ forum;
- A clear explanation of the process of assessment – for example – clarifying the assessor's role and emphasising that the purpose of an assessment is the provision of appropriate support (and not a safeguarding / surveillance / box ticking opportunity), how many visits are anticipated, the questions to be asked, how long the meeting is expected to last, how long the whole process is expected to last (from first contact to the provision of any support identified as needed);
- provided with an explanation as to what documents they will be asked to sign at the meeting and subsequently (eg consent forms, CiN Plans) and what happens if the family is not prepared to sign them;
- encouraged to prepare a daily diary of their disabled child's care and support needs;
- provided with full details (including relevant evidence) of any concerns that have been raised by third parties;

- given the opportunity to choose the setting for the meeting. For example, families may be living in an accommodation they have not chosen / that they consider unsuitable for a meeting, or they may prefer to have the meeting in a particular room of their accommodation. It is crucial that the assessment happens in a place that is comfortable for the family;

- where appropriate, less intrusive alternatives to host a meeting could be discussed, such as on-line meetings eg via Zoom / MS Teams etc;

- given full details of whether the assessor might wish to see other parts of the home, or to interview a child alone, together with a family specific explanation as to the reasons in writing why this is being requested;

- details of which other people the authority may wish to consult as part of the assessment process and the family's right to withhold their consent to this. Families must also be informed as to what happens if they have concerns about the nature or extent of this consultation (for example as to how such concerns can be addressed);

- made aware of what support may be available as a result of the assessment as well as (in simple / comprehensible language) what the local eligibility rules are (for accessing this support), what the consequences are of accepting such support, what the waiting times are, and so on.

37. Families must be provided with copies of relevant materials (electronic or if not suitable, hard copies) prior to the meeting (and hard copies provided at the meeting) including:

- all the form(s) that the assessor will be using for the assessment;[41]

- any form that has been partially completed in advance (either by the family or by the assessor), using material provided by the family – see para 31 above).

Assessment meetings

38. If there has been significant delay in arranging the appointment or if appointments have been cancelled by the authority, or if the assessor is late in arriving at the meeting, the authority / assessor should make a serious and meaningful apology for this.

39. Before the meeting the assessor must remind themselves that:

- parents may be more 'lenient' when a social care professional is there, in order to try to regulate their child, and that this is not evidence of a lack of boundaries / poor parenting;

- the assessment meeting should not be rushed nor be overly long;

- they must be realistic / truthful about what the family should expect and should be empathic when responding to any statements made by a parent as to negative past experiences with Children's Services (eg having had to tell their story several times before).

40. The assessor should explain at the outset that:

    - the assessment can be postponed if a child becomes distressed and – in any event – that the child is able to leave the room if they are in any way troubled by the assessment process;

    - it is 'OK' if one parent is more present than the other;

    - it is appreciated that parents / children are likely to be anxious and that presentations at meetings with strangers / 'professionals with power' can change behaviours. That in consequence the assessor appreciates that this snapshot of their 'family life' that she / he witnesses may not be indicative of what 'regular' life looks like;

    - they will be using a standardised form to ensure relevant issues are covered in their discussion, but they will do everything they can to personalise the process;

    - the family can contact the assessor – for example, in case they remember any information after the assessment – and reminding the family how they can do this;

    - what will happen after the meeting – that the family will be sent a draft copy of the assessment documentation (and any care plan), together with details of other follow up action and timescales.

41. The assessor should ensure that the family is asked what care and support they believe that they need and the assessor should verify that this has been correctly understood.

Follow up action

42. Immediately after the assessment meeting (and in any event within 48 hours) assessors should provide families with:

    - their note of the meeting which will include a clear written statement confirming what they have agreed (with the family) to do;

- details of what urgent support has been identified as required and when (and how) this will be provided;
- a timeframe as to when they will receive a copy of the relevant documentation – for example the draft / completed assessment(s) for agreement (ie providing the family with an opportunity to correct any errors / misunderstandings);
- a copy of their recommendations in terms of support provision / follow up action and their evidence-based reasoning for their recommendations;
- details as to what will happen in consequence of their recommendations – for example, when (and how) the family will receive the care and support services for which they are eligible (including interim services) and whether a decision on the provision of support services will depend upon approval by a senior officer / a scrutiny panel (etc) and, if so, the timeframe for this process, the names and qualifications of the relevant senior officer / scrutiny panel members.

43. If the care and support that the family believe they need is agreed(via the assessment) to be an eligible need, the family will be provided promptly with a care plan that specifies in full detail the care and support services required, what actions are to be undertaken in its delivery, by whom and the authority's reasons as to why the specified care and support will meet the disabled child's and the family's needs.[42]

44. If the care and support that the family believe they need is not approved (or is delayed) then the family will be provided promptly with cogent reasons for the decision / delay, together with details of the process by which the 'non-approval' can be challenged.

Endnotes

1 Being carers for whom local authorities have responsibilities under section 1(2) The Carers (Recognition and Services) Act 1995

2 Care Act 2014, section 1(3); Social Services and Well-being (Wales) Act 2014 section 6(3).

3 B Carter and others, 'Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives ' [2017] Pain Research and Management 1-11 at 9.

4 K Kruithof and others, 'Parents' knowledge of their child with profound intellectual and multiple disabilities: An interpretative synthesis' [2020] 33(6)(Nov) Applied Research in Intellectual Disability 1141–1150.

5 H Charnock and others, ''We shouldn't have to shout to be heard'' Valuing Parents as Experts' (University of Bristol, Policy Report 75 Oct 2022) at **http://www.bristol.ac.uk/media-library/sites/policybristol/briefings-and-reports-pdfs/2022/PolicyBristol_PolicyReport75_Charnock_valuing-parents-experts.pdf** accessed 28 April 2023.

6 Department of Health, Assessing the needs of disabled children and their families: Practice Guidance (Stationary Office 2000) at 3.16 and see also J MacAlister, The Case for Change. The independent review of children's social care (2021) 30 at **https://webarchive.nationalarchives.gov.uk/ukgwa/20230308122442mp_/https://childrenssocialcare.independent-review.uk/wp-content/uploads/2021/06/case-for-change.pdf** accessed 30 April 2023.

7 MacAlister (n 6) at 30 and see also K Morris and others, Stepping Up, Stepping Down (BASW 2018) at **https://www.basw.co.uk/system/files/resources/Stepping-Up-Stepping-Down-Report.pdf** accessed 30 April 2023.

8 J Read, L Clements and D Ruebain, Disabled Children and the Law (2nd edn, Jessica Kingsley Publishers 2006) at 17.

9 I Trowler and others, Research and analysis: A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families (Department of Health and Social Care 2021) at **https://www.gov.uk/government/publications/social-work-and-autistic-young-people-an-exploratory-study/a-spectrum-of-opportunity-an-exploratory-study-of-social-work-practice-with-autistic-young-adults-and-their-families** accessed 30 April 2023 and see also Department of Health (n 6) at 3.21.

10 Health and Social Care Act 2008 sections 20(5ZA) and 21A

11 The national strategy for autistic children, young people and adults: 2021 to 2026: Policy Paper (Department for Education and Department of Health and Social Care 2021) and Capabilities Statement for Social Work with Autistic Adults (Department of Health and Social Care and The British Association of Social Workers (BASW) 2019).

12 Department of Health and Social Care, Care and support statutory guidance to the Care Act 2014 (June 2014) at paras 6.85 – 6.97 at **https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance** accessed 2 May 2023; Department of Health (n 6) at 3.30; Department for Education and Department of Health and Social Care (n 11); and see also The Care and Support (Assessment) Regulations 2014 No. 2827 regulations 5 and 6.

13 BASW (n 11).

14 Department of Health (n 6) at 3.30.

15 L Clements, Clustered injustice and the level green (Legal Action Group 2020).

16 MacAlister (n 6) at 30.

17 Department of Health (n 6) at 3.21. J Read, L Clements and D Ruebain (n 8) at 102 noted that 'many families have to attend frequent appointments with a range of unfamiliar specialists in different settings … [and that] arrangements may be particularly demanding if the child has quite complex impairments. Citing a 2003 Department for Education and Skills (DfES) report, which referred to the experience of a family of a 13-month-old child who had, over a nine-month period, attended a total of 315 service-based appointments in 12 different locations – see Department for Education and Skills and the Department of Health, Together from the Start- Practical guidance for professionals working with disabled children (birth to third birthday) and their families (2003).

18 P Baker, 'A survey of complex trauma in families who have children and adults who have a learning disability and/or autism' [2021] 15(5) Advances in Mental Health and Intellectual Disabilities 222-239; Challenging Behaviour Foundation (CBF), Broken. The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support

required (CBF 2021) at **https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/brokencbffinalreportstrand1jan21.pdf** accessed 23 April 2023; and L Clements (n 15) chapter 6.

19 See for example C Long and others, Fabricated or Induced Illness and Perplexing Presentations. Abbreviated Practice Guide for Social Work Practitioners (BASW 2022) at 2, 8; and see also E Cage and Z Troxell-Whitman 'Understanding the Reasons, Contexts and Costs of Camouflaging for Autistic Adults' [2019] 49(5) Journal of Autism and Developmental Disorders 1899–1911 at 1900. Appreciating too that many neurodivergent people have co-occurring physical conditions, many of which are invisible such as chronic pain, chronic fatigue, joint hypermobility, epilepsy and believing them about their symptoms – see for example, E Rydzewska, 'Umbrella systematic review of systematic reviews and meta-analyses on comorbid physical conditions in people with autism spectrum disorder' [2021] 218(1) The British Journal of Psychiatry at 10-19 and B Donaghy, D Moore and J Green 'Co-Occurring Physical Health Challenges in Neurodivergent Children and Young People: A Topical Review and Recommendation' [2023] 29(1) Child Care in Practice 3-21.

20 In this context the MacAlister review (MacAlister (n 6) at 30) cite K Morris and others (n 7) who referred to 'cold hearted encounters with professionals which damages the relationship, leading to resistance from families which then inform judgements about risk and family capacity to care for their children'.

21 Trauma has been described as 'what happens to a person where there is either too much too soon, too much for too long, or not enough for too long' (P Duros and D Crowley 'The Body Comes to Therapy Too' [2014] 42 Clinical Social Work Journal 237–246 at 238).

22 See for example, Department for Education, Working together to improve school attendance Guidance for maintained schools, academies, independent schools, and local authorities (September 2022) and C Long and others (n 19).

23 Including – for example – an understanding of mental capacity law as it applies to children and young people in relation to both their powers to make decisions (including to consent and to refuse) and the making of 'best interests' decisions.

24 I Trowler and others (n 9).

25 See for example Gorry v. Wiltshire Council and others [2012] EWCA Civ 629 (concerning Article 14 European Convention on Human Rights in combination with Article 8) and Thlimmenos v Greece (2001) 31 EHRR 15; Application No. 34369/9731 6 April 2000.

26 I Trowler and others (n 9).

27 Department of Health (n 6) at 3.31.

28 See for example, Social Services and Well-being (Wales) Act 2014 (n 2) section 21(7).

29 See for example, S Broach and L Clements, Disabled Children: a legal handbook (3rd edn, Legal Action Group 2020) at paras 1.31 – 1.36; C Murphy and others, 'Epidemiology of mental retardation in children' [1998] 4 Mental Retardation and Developmental Disabilities Research Reviews 6–13; and B Dobson and S Middleton, Paying to Care: The Cost of Childhood Disability (York Publishing Services 1999).

30 See, for example, J Lloyd, G Bjornstad, A Borek and others, 'Healthy Parent Carers programme: mixed methods process evaluation and refinement of a health promotion intervention' [2021] 11 BMJ Open at **https://bmjopen.bmj.com/content/bmjopen/11/8/e045570.full.pdf** accessed 30 March 2023.

31 K Morris and others (n 7) at 5.

32 D Wilkins and D Forrester, 'What do parents think about statutory child and family social work services in the UK?' [2020] 51(6) British Journal of Social Work 2210-2227.

33 MacAlister (n 6) at 30.

34 The leading paper on this issue (L Jones, M A Bellis, S Wood and others, 'Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies' [2012] 380(September 8) The Lancet at 899) is a meta-analysis of a number of studies – only two of which were UK based. The paper explains that the data does not identify where the abuse comes from – ie whether it is internal (family generated) or external (school bullying / hate crimes / institutional abuse etc) and concludes that there was a vital need for methodologically rigorous research.

35 See in this respect, European Roma Rights Centre & Others v. The Immigration Officer at Prague Airport & the Secretary of State for the Home Department, and The United Nations' High Commissioner for Refugees [2003] EWCA Civ 666 at para 108.

36 B Bodycote, 'School Attendance Problems and Barriers Square Pegs' in I Gilbert, F Morgan and E Costello (eds), Square Pegs: Inclusivity, compassion and fitting in – a guide for schools (Crown House Publishing 2023) and see also Not fine in school, 'Forcing an Anxious Child to Attend School' (2019) at **https://blobby.wsimg.com/go/a41082e1-5561-438b-a6a2-16176f7570e9/FORCED%20ATTENDANCE%20Oct%202020.pdf** accessed 2 April 2023.

37 As C Long and others (n 19) at 8 note 'that an assertion by a schoolteacher, or teaching assistant, that the child is 'fine in school' is taken as evidence that the parent is either overanxious or exaggerating the difficulties they experience once the child is home from school … . There is a growing evidence base to support the concept of social 'camouflaging' in Autistic individuals, which is often motivated by a 'sense

of alienation and threat' and an attempt to avoid social ostracization' citing (L Hull, W Mandy, M Lai and others, 'Development and Validation of the Camouflaging Autistic Traits Questionnaire' [2019] 49 Journal of Autism and Developmental Disorders 819–833 and E Cage and Z Troxell-Whitman (n 19); and see also A Pearson and K Rose 'A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice' [2021] 3(1) Autism in Adulthood 52-60.

38 L Fullard, A different world: A Parent Carer's perspective (The Parent and Carer Alliance 2023) at **https://www.parentandcareralliance.org.uk/wp-content/uploads/2023/06/A-different-world-L-Fullard-statement-.pdf** accessed 29 June 2023.

39 Ibid.

40 L Clements (n 15) chapter 6.

41 The Parent and Carer Alliance is working on a 'Draft Disability Needs Assessment Form' (see L Arnold and L Fullard, Draft Disability Needs Assessment Form (The Parent and Carer Alliance 2023) at **https://www.parentandcareralliance.org.uk/wp-content/uploads/2023/06/Draft-Disability-Needs-Assessment-form-v2.pdf** (accessed 29 June 2023).

42 See for example, complaint no 17 012 586 against Wirral Metropolitan Borough Council, 22 March 2018.

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