# Law Commission consultation on disabled children's social care law

## Summary of evidence from *Legal Action for Women, Disabled Mothers' RIghts Campaign and WinVisible*

Legal Action for Women co-ordinates the Support Not Separation (SNS) coalition, which includes organisations of single mothers, women of colour, women with disabilities, rape/domestic abuse survivors, breastfeeding advocates, psycho-therapists, men and social workers. We defend mothers and children against unwarranted separation and the devaluing of the mother-child relationship.

WinVisible has campaigned since 1984 for the rights of disabled women with visible and invisible disabilities, including autistic and neurodiverse women, and against institutions for disabled children or adults.

The Disabled Mothers' Rights Campaign (DMRC), co-ordinated by WinVisible, brings disabled mothers together to defend our right to have and to keep our children, and against discrimination in pregnancy and maternity care.

## Consultation Question 1.

We invite consultees' views on the provisional analysis of the costs set out in the draft impact assessment. In particular, please highlight any assumptions we have made that you consider may be incorrect and explain why.

We are not in a position to comment on the specific financial costs, except to say that year in, year out, budgets allocated to S17 of the Children Act have been reduced by 50% whilst the money for S47 has continued to increase. It was reported to The Children's Wellbeing and Schools Bill Parliamentary Committee on 22 January 2025, budgets for child protection and removal more than doubled every year while support has reduced by 50% each year. This means that very often when families ask for support, they are told no help is available for cost reasons and they are pushed into child protection rather than receiving support in the community. We challenge the following assumptions:

1. The assumption that training costs are for social workers only. There is no reference to training costs for other professionals, such as Occupational Therapists, physiotherapists, and any additional staff who may be involved in assessments.
2. The assumption that parent/carer wellbeing will increase as a consequence of service provision. This very much depends on what services are provided, by whom, and their underlying aim and quality. The assessment process itself can be extremely detrimental to children and parent/carer wellbeing, especially when the focus is on scrutinising/blaming the mother/carer rather than supporting children within the family and meeting needs arising from disability.

3. The assumption that there will be increased scope for home care and reduced reliance on residential care. This is very much contingent on HOW the assessments are completed and the ability of social workers to shift away from the child protection lens. If there continues to be an unwarranted emphasis on child protection rather than support, there is a risk that the increased number of assessments could result in even more children being taken from families instead of supported to remain safely together.

**Consultation Question 2.**

**We invite consultees' views and/or evidence as to whether our provisional proposals could result in advantages or disadvantages to particular groups or to individuals with particular characteristics?**

We welcome the Equality Impacts set out on page 22, section 2.10. We draw attention to the specific impact on disabled mothers of disabled children. We know that due to disability discrimination, disabled mothers and disabled expectant mothers are already disproportionately investigated by social services, and there is a risk that the proposals could exacerbate this unless there are additional safeguards against the misuse of assessments.

The concerns of disabled mothers (some of whom share the same disabilities as their children) are reflected in the Disabled Mother's Rights Campaign Charter of Rights which calls on Councils to ensure that:

1. Women with disabilities have a right to family life – to start a family and

keep our children.

2. We have a right not to be discriminated against

3. Support services under the Care Act and Children Act must be obligatory.

4. All meetings and hearings in 'child protection' and/or family court

proceedings must be made accessible.

5. Court hearings must be open to the public.

6. Mothers, overwhelmingly the primary carers, must never be cut off

benefits.

The industry of child-removal is resource intensive. By identifying more children as 'at risk', children's social care is driving its own demand. Too many children are needlessly taken through "child protection" – investigations have increased by 127% in the past 11 years, but the number which did not result in a "child protection plan" (i.e. proved to be unwarranted) went up by 211% over the same period. Many of these investigations are on disabled children deemed at risk.

Once they become 'looked after', disabled children are 'hard to place' and often end up miles from home in provision which doesn't meet their needs, or in the worst cases actively harms them. Disabled children are more vulnerable to abuse and neglect, a risk which can increase when they are exposed to multiple professionals and carers.

Disabled children still constitute a significant group in the looked after system. In fact, research suggests they are more likely to be "looked after" than non-disabled children: figures in Britain show 5.7% of disabled children in the general population are looked after whilst this applies to only 0.6% of the child population as a whole (Poverty & Social Exclusion in the UK, Gordon et al, 2000). Other studies also find that disabled children are more likely to be over represented within the looked after system and suggest this is because they may remain in care for longer (Permanence and Stability for Looked After Children Cleaver, 2000)

The misuse of Section 20 agreements ("voluntarily" giving up custody to Children's Services) are a matter of great concern. Disabled mothers are threatened that if they don't sign a Section 20, their children will be forcibly removed. However once they have signed and their children are in foster care, mothers are not entitled to legal aid and if they want a Section 20 to be withdrawn, they have to pay for legal representation which is costly. If Children's Services want to ask a parent to sign a Section 20 then they should pay for a lawyer of the mother's choosing so that she can be properly advised. Social workers should also never threaten a parent that if they don't sign they will take a parent to court. If a single mother signs a S20 agreement because she needs medical treatment and local help, she should not have to face battling Children's Services to get her children home for example.

When mothers ask for help we know of situations where they have been told they cannot cope with a disabled child and a non-disabled child so are asked to sign a Section 20 only for the disabled child instead of supporting the mother to meet both children's needs at home under Section 17.

## Consultation Question 3.

**We provisionally propose that there be a single express duty to assess the social care needs of disabled children.**

We agree on the basis of these assessments being separate from child protection assessments, including that they should be done by a completely separate team.

Local authorities have legal obligations under the Children Act 1989 to children in need, who fall into two broad categories: children who are at risk of abuse or neglect, and disabled children. But the problem is there is only one assessment protocol involving the same social workers. So, families who ask for support too often find themselves being investigated instead. The assumption should be that no child should suffer harm, but discriminatory assessments are encouraged on the basis that a mother's disability is seen as harmful to a child, rather than the mother being supported to keep families together.

Under the current system of a single assessment, which relies on social workers who are not qualified to assess disability/medical needs, and the fact that Section 17 money is not ring-fenced like Section 47, mothers are too often blamed for not coping with their disabled child's needs as way of cutting money spent on supporting families.

Disabled children are less likely to receive the correct support than their peers simply because Section 17 support is not mandatory. At present Councils can say they don't have the money to support a family with disabled children, which may result in the family reaching a crisis point for which the mother is much more likely to be blamed, resulting in their children being more likely to be taken away.

Social workers are not trained in disability and the complex way that each child's needs are different resulting in their failure to identify what each particular child needs. Disabled children often have disabled mothers and due to discrimination and as a way of saving money social workers often claim that the mothers are "projecting" their own disabilities onto their children, in other words, the child's needs are not genuine. This leads to child protection and/or child removal rather than assessing a child's needs.

When a mother challenges the lack of support being offered they face being accused of Fabricated Induced Illness (FII), that is, of exaggerating her child's disability/needs and being blamed instead for a child's challenging behaviour which is attributed to her lack of parenting skills rather than the child's disability. This is a common experience among mothers of autistic children (who are likely to be autistic themselves). Officially it is claimed that FII allegations are rare, but families report something very different.

Disabled Mothers' Rights Campaign and Support Not Separation worked with Channel 5 on its national news programme broadcast at 5pm, 25 January 2023. Ch5 announced their shocking findings that parents with a learning disability are 54 times more likely to have their children taken into care. This confirms our experience of the discrimination and hostility faced by disabled mothers, and other single, working class and mothers of colour who face an uphill battle to stop social workers and the family courts taking our children from us.

When assessing a child's needs, social workers often disregard that the mother might also be disabled and no reasonable adjustments are made: for example in the way that she might answer a question if she is autistic. Easy Read materials and other access adjustments are rarely seen and are not visible on Councils' websites, and mothers often do not realise what help and support they can receive either under S17 of the Children Act or S12 of the Care Act and their entitlement is rarely explained to them.

Disabled children are more likely to be taken into care than their non disabled peers and government statistics are hard to find given inconsistencies in how disability is defined across Local Authorities, with significant variation in the percentage of children in care who were recorded as having a disability - ranging from 3% in one local authority to 32% in another. The difference was even more pronounced in care leavers with 1% compared to 36%. We know disabled children placed in institutions are five times more likely to be abused than their non disabled peers and they are failed both educationally and medically. Government National Data omits data on disabled children in care at present meaning they can be left without support as there is no scrutiny or transparency.

At present local authorities are permitted to apply their own criteria when it comes to determining eligibility for support under S17 and this can amount to a way of saving costs at the expense of providing support.  This leads, inevitably, to a situation where a child may be eligible for support in one council area but not another. This is indefensible, as well as being contrary to the position in adult social care, where the same eligibility criteria must be applied everywhere.

Meanwhile parents are left traumatised and even blamed by professionals who should be supporting them.

We suggest the Law Commission must establish just how much unmet need among disabled children and their families there is and what are the effects on children and families?  It is crucial to seek answers to the following questions:

- How many requests for social care assessment for disabled children are refused
- How many disabled children are assessed and then deemed not eligible for support, How many families provide hundreds of hours of care every week of their lives without breaks,
- How many disabled children have had their care package reduced,
- How many families are given direct payments in acknowledgement of their child’s need for support but can’t spend these because there are no services or they can’t find suitable support-workers
- What is the impact on disabled children when they are removed from their mothers and placed hundreds of miles away, often at great cost to the local authority

## Consultation Question 4.

**We invite consultees’ views on the appropriate threshold for carrying out an assessment. Should an assessment be carried out where:**

**(1) the child appears to be disabled;**

**(2) it appears the child may have needs for care and support;**

**(3) it appears the child may be eligible for care and support**

**(4) the child is likely to be eligible for care and support; or**

**(5) it appears that a child may need care and support in addition to or instead of that provided by their family.**

As above, we agree on the basis of the assessment of disabled children being separate from social care assessments - see question 3

An assessment should be done on the basis that a child has the need for support; diagnosis might come much later. It can take many years to get a diagnosis for a disabled child, especially if they suffer from a rare condition. Also, diagnoses can be flawed or problematic and create a medical label for a child that will follow them through life. Social workers must pay attention to what mothers describe as the issues their child faces, rather than assuming they are exaggerating. The current process is humiliating to mothers. A mother with a child who has special needs is already under pressure trying to ensure her child has access to education, medical help, etc and to then face the additional stress of parental blame can cause anxiety, depression or other mental health issues, including symptoms of Post Traumatic Stress Disorder.

**Consultation Question 5.**

**We invite consultees' views on the extent to which, if at all, the law should facilitate the combining of assessments undertaken for other purposes? There are three main options.**

**(1) The legislation could make clear that the assessment for a disabled child should be separate and additional to other assessments.**

**(2) The legislation could remain silent and allow local authorities freedom to choose whether the assessments can or should be combined.**

**(3) The legislation could encourage or compel the assessments to be combined. This could be done in three different ways:**

**(a) by giving a power to combine assessments;**

**(b) by imposing a duty to combine assessments; or**

**(c) by a presumption of combining the assessments which can be rebutted with a good reason.**

Yes, assessments should be carried out by a separate team and should be looking at the child's needs. All assessments should take place in consultation with a child's current medical and/or therapeutic team in whom the mother has confidence. Since they are known to the family, they are best placed to document a child's needs arising from their condition.

**Consultation Question 6.**

**We invite consultees to provide their:**

**(1) experiences of the use of equivalent assessments under the Mental Capacity Act 2005; and**

**(2) views on whether this approach would be appropriate in the context of disabled children's social care.**

We have no experience of the use of equivalent assessments.

**Consultation Question 7.**

**We invite consultees to tell us about their experiences, both positive and negative, of the current process of assessing the social care needs of disabled children.**

The overwhelming response we received from mothers who have been through the process was negative. Some comments from mothers we spoke to:

- *It's been absolutely horrendous, absolutely awful.*
- *It feels punitive.*
- *Bullying is so entrenched - they come in and destroy you, then they just waltz away and you're left fragmented… it's been absolutely horrific.*
- *It's always a battle.*
- *If you speak out about your child's needs, or even your own conditions, rather than support being put in place it becomes seen as a safeguarding risk.*
- *I asked for help under section 17…It was the biggest mistake of my life. By asking for help I ended up on Child Protection and threatened with my child being taken into care … we got that ended, and the case is now closed, but because of all that [they put us through] my son is suffering and the Local Authority still aren't supporting at all.*

Mothers spoke of asking for help not only resulting in an *interrogation* but in services for their child actually being removed, where the social workers didn't believe them:

- *With my son there were some traits of autism… we asked for help with his behaviour because I was struggling to get him to school. They didn't believe me and asked for evidence, so I provided video evidence… then they used that against me because they said I was videoing when I should have been*

> *looking after my son [whereas in fact the camera was on the mantelpiece]. They took away my son.*

Disabled children are more likely to be taken into care than their non disabled peers and government statistics are hard to find given inconsistencies in how disability is defined across Local Authorities, with significant variation in the percentage of children in care who were recorded as having a disability - ranging from 3% in one local authority to 32% in another. The difference was even more pronounced in care leavers with 1% compared to 36%. We know disabled children placed in institutions are five times more likely to be abused than their non disabled peers and they are failed both educationally and medically. Government National Data omits data on disabled children in care at present meaning they can be left without support as there is no scrutiny or transparency. *'s Blue Badge, they took all the support I could get away from us.*

- *Then there was a massive data breach...they shared my data with my neighbour which led to a campaign of harassment [from the neighbour] that lasted 4 years… I wouldn't ask for help again.*

Mothers are routinely disbelieved, seemingly whatever they say. Whilst most mothers shared experiences of professionals thinking they were making up or exaggerating their child's needs, in other cases mothers were criticised when they did not wish to medicalise or label their child unnecessarily.

One mother highlighted how social workers wanted to push for her son to be diagnosed with autism to pursue their own agenda:

*We were on a Child in Need Plan… The Family Support Worker said my son [then nearly 10] should be tested for autism because he was so steadfast in not wanting to see his father… [this was] because he did not want contact with an abusive father, and was frightened. . .the father kept dragging me back into court (because he was a domestic abuser), the social services tried to get the judge to force us have our son tested… The judge said that's down to the parents, and I ignored it because I know there's nothing wrong with my son….I wouldn't mind if there was but social services were trying to deem there was something wrong with him for not agreeing with them, standing up for his rights and not wanting to see his Dad.*

**Consultation Question 8.**

**We provisionally propose a requirement that assessments are proportionate and appropriate to the circumstances of the child and their family.**

The specialists and medical teams which work with families should have the main say as they are best qualified and know the child and mother. Social workers are not medically qualified to say what support a disabled child need, they cannot possibly be expected to make medical judgements that mean a child will or will not get support in the community. If a social worker does not understand a condition, then the child is less likely to get the support they need. Social workers should not rely on their own experts who are not known to the family. Disabled people can have good and bad days, and this is often not taken into account by non-medical professionals. If a child has not yet been given an official diagnosis, their needs should still be assessed.

All assessments should consider Equality Act reasonable adjustments given the mothers might have the same condition. That means the needs of the mother should also be supported under Section 17 if she herself has a condition or disability and this should be done with compassion rather than a critical eye.

All assessments should be recorded, and the families should have an advocate to guide them through the process which is often quite hostile and critical of them and provide support to deal with the vast amount of paperwork that is created.

We agree with the definition of proportionate taken from the guidance notes to the Care Act: "proportionality means "provide[ing] the right level of response to suit the needs of the person, the situation and the level of risk".

**Consultation Question 9.**

**We provisionally propose that assessors should be required to have appropriate expertise and training.**

Yes, but we note that the Care Act which this proposal mirrors, is flawed because disabled adults' experience is that we are assessed according to **budget considerations**. In other words, the social worker will only record and recognise those needs which the council is prepared to fund.

Rather than social workers consulting a person of their choosing, the assessment should be completed by a person with expertise such as professionals who know the child well. Any and all experts who are consulted must have met the child and family - their opinion should not be based on paperwork alone.

**We invite consultees' views on whether assessors should be required to have expertise in specific conditions.**

As above - it should be the medical professionals, specialists or therapists who are already working with the child and family. We note that diagnoses for autism, Myalgic encephalomyelitis (ME), or Ehlers Danlos Syndrome for example, can take many years. Only if the family have not managed to secure a diagnosis, should another expert be called. The family should be included in this conversation and have a right to choose who assesses.

### Consultation Question 10.

**We provisionally propose that local authorities should be required to provide disabled children and their families with a copy of their assessment.**

We agree that children and families should be provided with a copy of their assessment and within a clear timescale. The family must also be entitled to check and approve the content prior to the assessment being finalised. This is based on extensive accounts of inaccurate or misleading information getting forever stuck on record because time is not taken to correct it. All records created MUST be accurate. Families have the right to record all sessions, and these recordings should be encouraged so that they can be used to correct any inaccurate or misleading information.

### Consultation Question 11.

**We provisionally propose that guidance should emphasise that assessors need to consider whether any other relevant statutory assessment duty is engaged when assessing the social care needs of a disabled child.**

Yes, this is specifically important in relation to National Health Service/continuing care assessments as well as EHCPs. However, as noted in question 9 and 10, it is important that this is not used to pass responsibility to the NHS as a way of avoiding statutory duties.

### Consultation Question 12.

**We invite consultees' views on whether it is necessary and appropriate to give local authorities the power to delegate the assessment of the social care needs of disabled children to trusted third parties, retaining ultimate responsibility for the standard of the assessment.**

We do not agree with contracting assessments to private companies. Outsourcing to other companies as happens in Personal Independence Payments (PIP) for example who use nurses and Occupational Therapists have proved very problematic and caused misery to families.

But if this becomes a power to delegate an assessment to an agency with relevant knowledge, whether a voluntary organisation, parents' organisation or the NHS, it could help families. No profit should be made by third parties from delegation of assessment. We know that contracted companies or social workers/OTs operating as a company, work to the budget targets of the council and focus on that rather than the needs of the child.

### Consultation Question 13.

**We invite consultees to tell us about their experiences, both positive and negative, of parent carers' needs assessments, or assessments for carers without parental responsibility.**

*I am part of a Parent Partnership Group (in my LA) … A lot of parents feel afraid to ask for a carers assessment because they're worried that if they actually disclose the behaviours their child shows and what support they need to be able to cope with that behaviour, that this might lead to child protection plans.*

The experience is that mothers don't ask for assessments as they know they will be judged. They are told they are projecting their disability onto their child who might happen to have the same inherited disability:

*I'm disabled. It's another weapon they use against me. I'm told that I'm putting my needs onto the child.*

When consulting with our network of mothers who have fought for support for their children, they overwhelmingly reported that they wished they had never asked for help, because of the devastating consequences for their families. Nearly all were met with child protection or family court, they have been labelled anxious, accused of FII and just wanting benefits. Consequently, their children did not receive the care or support they needed. All felt their mental health had been negatively impacted during the course of being assessed.

**Consultation Question 14.**

**We provisionally propose that there should be a single duty to assess the needs of a carer for a disabled child, which should arise upon (a) request by the carer or (b) it appearing to the local authority that the carer may have needs for support.**

Yes, on the request of a carer.

**Consultation Question 15.**

**We provisionally propose that, in assessing the needs of a carer for a disabled child, the local authority should be required to have regard to the well-being of the carer.**

The well-being of the mother/carer is absolutely crucial to the well-being of the disabled child. A mother/carer who is receiving the support they are entitled to is best placed to meet her disabled child's needs. Her ability to do so is greatly undermined when she has to fight at every step of the way, often in a climate of cuts and hostility, for the support her child needs. Support for the mother/carer should be mandatory not optional, and should include financial support. See for example our campaign for a Care Income Now for mothers and other carers which would mean mothers could be financially independent and could not be accused of “neglect” which is actually poverty. At a time when profits of millions of pounds are being made by private companies providing residential care and/or fostering services, giving money to mothers is in the best interests of children as well as being most cost effective.

**Consultation Question 16.**

**We provisionally propose that all carers should have a right to a copy of their assessment.**

As above - see answer to question 10.

**Consultation Question 17.**

**We provisionally propose a requirement that carers’ assessments are proportionate and appropriate to the circumstances of the carer.**

As above - see answer to question 8.

**Consultation Question 18.**

**We invite consultees to provide their experiences of the extent to which siblings’ needs are considered during the assessment of a disabled child.**

At present siblings are not assessed and should most definitely be included in the assessment. Instead of relying on current local offers their needs should be met according to a national standard. When, as at present, a mother is accused of not being able to cope, her other children may also be threatened with child protection or removal. Mothers who have other children have told us it is not worth risking the loss of their other children by seeking support for their disabled child.

**Consultation Question 19.**

**We invite consultees to provide their experiences of the conduct of young carers’ needs assessments.**

The experience of many mothers who ask for help with their disabled children is that there is an assumption that having a disabled mother/parent/sibling is harmful and may lead to them being a child carer, and they need to be saved from this fate. This assumption must be challenged and there should be an independent assessment of potential young carers should be carried out. While young children should not carry unfair responsibility, children of disabled parents or siblings of disabled children are often more mature, skilled and independent than their peers.

The crisis with young carers arises from a) the lack of adult social care support for disabled mothers/parents, and b) from the punitive child protection approach of social services, meaning that mothers and children are frightened that they will be separated if they ask for help for young carers.

**Consultation Question 20.**

**We provisionally propose that statutory guidance should direct local authorities to consider whether the needs of any siblings need to be taken into account as part of the assessment of the needs of a disabled child.**

See Q19

**Consultation Question 21.**

**We provisionally propose that there should be a single duty to assess the needs of all carers, whatever their age.**

The single duty to assess a carer's needs must take account of both children and mothers/adults providing care, and address their varying needs. Both adults and children should be fully involved in the assessment.

**Consultation Question 22.**

**We provisionally propose that there should be a single statutory duty to meet the social care needs of disabled children.**

We agree that there should be a single statutory duty. This should be guaranteed by funding so that rationing doesn't arise.

**Consultation Question 23.**

**We provisionally propose that the single statutory duty to meet the social care needs of disabled children should be subject to national eligibility criteria.**

There must be a national eligibility criteria to avoid the so-called postcode lottery.

**Consultation Question 24.**

**We invite consultees' views on what the essential features of any national eligibility criteria should be.**

That assessments should be based on need not availability of funding

No family should be automatically threatened with child protection if they request support either through the Children Act or the Care Act and similarly if they ask for an EHCP.

**Consultation Question 25.**

**We invite local authority consultees to provide copies of any eligibility criteria they apply to disabled children's social care.**

N/A

**Consultation Question 26.**

**We provisionally propose that the single statutory duty to meet the social care needs of disabled children should take precedence over any other powers and duties which could be used to provide the services.**

The single statutory duty taking precedence over discretionary powers would help ensure uniformity across different councils and families would not feel the need to move to get services. However, we do not agree that the statutory duty to disabled children should over-ride the statutory duty to their mothers if they are disabled and are entitled to support under the S12 of the Care Act. Bothe entitlements should be equally maintained.

**Consultation Question 27.**

**We invite consultees' views on the residence requirements that should apply to the single statutory duty to meet the social care needs of disabled children.**

Residence requirements should be residence in the borough and not discriminate against immigrant parents and children who don't yet have permanent residence in the UK.

National eligibility criteria would help ensure that parents are not forced to move boroughs to access support for their children.

**Consultation Question 28.**

**We invite consultees' views on whether disabled facilities grants should be provided under the single statutory duty to meet the social care needs of disabled children.**

Disabled facilities grants should be provided to ensure building work happens more quickly. At the moment there is a long waiting time and approval process, which is detrimental to disabled children.

**Consultation Question 29.**

**We provisionally propose that there should be powers to meet needs:**

**(1) that do not satisfy the national eligibility criteria; and**

**(2) pending an assessment of needs.**

**Do consultees agree?**

There are bound to be family needs which are not covered by national eligibility criteria but which should reasonably be met, and in some cases until an assessment has been done, a child's needs may not have been previously identified.

**Consultation Question 30.**

**We provisionally propose that there should continue to be a power to meet the needs of parents and carers.**

Meeting the needs of mothers/carers should be a statutory duty, as well as a power.

This would be beneficial financially because supporting mothers would not cost the exorbitant amounts being charged by privatised foster carers/companies running residential homes, etc

Council budgets for S17 and S12 of the Care Act should be ring-fenced and put on a statutory footing, just as budgets for S47 are.

**Consultation Question 31.**

**We invite parent and carer consultees to provide their experiences of accessing short breaks.**

Mothers find it difficult to access short breaks firstly because it requires a complicated assessment and secondly because of lack of places and resources. They also worry that asking for respite care will be used against them to say that they are unable to cope. In our experience, social services have used a request for respite in order to remove children long-term and without family court proceedings. For example, if a mother goes into hospital for treatment, she is asked to sign a S20 order. She then might have to fight to get her children returned to her care.

In our experience, disabled children have been placed in institutions for a short stay where the conditions are extremely bad. Abuse is rife in such places. Whitefield School in North London and LIFE school in the Wirral (where the company charged £50k a year per pupil) exposed by Panorama, are two recent examples.

Mothers deserve respite care but should not have to worry about whether their child will be abused in these places. It is not acceptable that a mother may feel forced to stop the respite early because their child is distressed.

**Consultation Question 32.**

**We invite local authority consultees to tell us about the short break services available in their area and any criteria which must be met to access those services.**

N/A

**Consultation Question 33.**

**We provisionally propose to define short breaks as:**

**Services to:**

**(a) provide breaks for the benefit of disabled children; and/or**

**(b) assist individuals who provide care for disabled children to continue to do so, or to do so more effectively, by giving them breaks from caring.**

**Including:**

**(a) accommodation;**

**(b) the provision of care at home or elsewhere;**

**(c) educational or leisure activities; and**

**(d) services to assist parents and carers in the evenings, at weekends and during the school holidays.**

**Do consultees agree?**

Services should respond to the needs of disabled children and their families and not depend on what different local authorities deem appropriate, or not.

**Consultation Question 34.**

**We provisionally propose that short breaks should be made available under the single statutory duty to meet the social care needs of disabled children.**

As above

**Consultation Question 35.**

**We provisionally propose that eligibility for a short break should be subject to national eligibility criteria.**

The criteria should be national to avoid variation between local councils.  But it should not promote children being placed in institutional places (whether private or council) and should not boost profiteering by private providers.

**Consultation Question 36.**

**We provisionally propose that children who are provided with a short break in the form of accommodation away from the family home should have the same benefits and safeguards as currently apply to children provided with a short break under section 20 of the Children Act 1989.**

**Do consultees agree?**

As we have said earlier, misuse of Section 20 to remove children without due legal process must be addressed as a matter of urgency to ensure that what is supposed to be a “voluntary” arrangement does not become an obstacle course to children being returned home.  The need to use respite care should never be used as an excuse to claim a mother can't cope so the state should take over.

**Consultation Question 37.**

**We invite consultees to tell us what, in their experience, are the main social services that disabled children require.**

Disabled children require social services which consider them as part of their families and wider communities rather than respond to their needs in isolation i.e. a child’s needs cannot be separated from their mothers’ needs. In our experience, services can be too narrowly focussed on a child’s disability only, rather than considering that if the mother is supported, then the child in turn is better supported. They might need services such as special equipment, special clubs, respite or money to spend on replacing things.

**Consultation Question 38.**

**We invite consultees to tell us about the main social services for disabled children that are available in their area.**

Whilst we are based in Camden, London, we work with mothers across London and the UK so unable to comment on specific areas. What we do know is that local offers at present vary council to council - effectively there is a postcode lottery.

In Westminster, for example, no services at all are provided for disabled teenagers. Younger children will be offered respite, not in the area and often told that the mother has to stay with the child as respite staff are not medically trained. This means families are not really getting any services.

**Consultation Question 39.**

**We provisionally propose that legislation should provide a non-exhaustive list of the social services that can be provided to disabled children.**

We broadly agree that a non-exhaustive list of services that CAN be provided would be helpful. However, the non-exhaustive aspect would need to be highlighted both to the families and to service providers. There is a risk that any list, while not intended to be exhaustive, is used by Local Authorities to restrict or ration what they make available.

We refer to page 126 of the consultation document and note with concern that the first item on this list is ‘2.10 (1) accommodation’. Given the concerns we highlight above about respite and conditions in institutions elsewhere in our response, as well as the current undue focus on child protection and removal, we suggest that the final proposal is more specific about what is meant by this. We agree that housing is a key issue for disabled children and their families but expect this is largely beyond the scope of the consultation.

**Consultation Question 40.**

**We invite consultees’ views on the services that should be included in the list referred to in Consultation Question 39.**

As above, any list should make it very clear that it is ‘non-exhaustive’ as set out in the proposals. We believe the services should match the needs of the child rather than being prescribed.

**Consultation Question 41.**

**We provisionally propose that local authorities should be able to provide services:**

**(1) directly;**

**(2) indirectly through third parties; and**

**(3) by means of direct payments.**

**Do consultees agree?**

Whichever way services are provided, they should be high-quality with sufficient funding. Services should be according to the child's (and their family’s) needs and should be provided by voluntary organisations, other organisations or via direct payments, according to the family’s wishes.

As stated above there should not be a list prescribed by the council but rather services should meet the needs of the children and what the families want. What works for one family and child is not always what another family wants and there needs to be flexibility to choose what would work. Current services are too limited, and this needs a national level.

The problems with direct payments include that Councils may use these as a cut, where the budget is not enough to cover employment costs, and so hours have to be cut back. (As regards direct payments for adults, Councils have also deducted care charges before issuing the payments, meaning that the disabled person has to make up the difference from their disability benefits, or cut down the number of hours of support.) Councils heavily control what the money is spent on, for example, one council refused to allow a mother to buy a cheap second-hand table tennis table for her daughter during lockdown as it was not a recognised expense. Users, whether disabled adults or parents, are bogged down in administration and worry about budgeting, and have to do quarterly accounts.

Any unused budget should not be recovered from the family; they should be able to use it for a later date.

Local organisations are often underfunded so can't provide full services or are too small to handle the level of support. Volunteers and peer supporters may not be available to the extent they are needed, e.g. they are only available two hours a week per family.

**Consultation Question 42.**

**We provisionally propose that parents, carers and children aged 16 and over should have a right to a personal budget.**

Yes - with the comments given in Q41.

**Consultation Question 43.**

**We provisionally propose that the regime for direct payments should be adapted so that:**

**(1) the amount of the payment is the amount sufficient to secure the provision needed, as opposed to an amount that is estimated to be reasonable; and**

**(2) payments should be kept under review, so that their sufficiency can be monitored and alternative arrangements made if necessary.**

**Do consultees agree?**

See answer to Q41. Direct payments should be sufficient for all reasonable costs including extra needs that arise, be unbureaucratic and be easy for a person to use without needing support from another local organisation. No charges should be deducted.

### Consultation Question 44.

**We provisionally propose that disabled children who are eligible to have their needs met by social services should have a statutory entitlement to a plan setting out what services they are to receive, and where, when and how those services will be provided.**

We agree that there should be a statutory entitlement to a plan, and when this plan shows what they need it must be actioned upon immediately and not have to wait for funding. This entitlement should extend to those services set out in the plan, so it is not just a piece of paper!

### Consultation Question 45.

**We provisionally propose that the content of the plan to meet the needs of a disabled child should be dealt with in guidance.**

We would need to see the guidance before commenting.

### Consultation Question 46.

**We provisionally propose that the plan to meet the needs of a disabled child should be combined, where appropriate, with other plans for the child such as their EHCP, care plan or pathway plan.**

This proposal is very problematic. For example, not all children with needs in school will have care needs so we do not think it should be combined. Alongside the fact that SEND tribunals can take more than a year during which time the child is not receiving support; we think that SEND needs to be sorted out before any combining of pathways. Some children do not meet the criteria for other plans such as EHCPs. And if all their plans were combined, they might miss out on vital care and support needed at home because it was felt they did not need extra support in school. This in turn might cause assessors to blame mothers and trigger the cycle of child protection/removal.

### Consultation Question 47.

**We invite consultees to provide examples of local authority charging practices.**

Generally, children’s services are free but under the Care Act which applies to adults, councils have the power, but not the duty, to charge.

In England, only Hammersmith & Fulham Council has free homecare.

If disabled mothers get increased support under s12 of the Care Act, assessing the needs of the family, we sometimes face increased care charges which are calculated from our disability benefits (ESA/UC and PIP) and are an enforceable debt with threat of being taken to court.  Wages of disabled people are exempt from charging, as charges are treated as a disincentive to work.  But for an unwaged disabled mother who is unable to take on waged work even part-time, both her money to live on (ESA/UC disability addition) and entire PIP daily living component (extra disability costs) are assessable for care charges, down to a minimum income guarantee set by the DoHSC which is low.

Services should not be means-tested and should be free at the point of use, like the NHS.

**Consultation Question 48.**

**We invite consultees' views on whether local authority charging practices would be likely to change if any of the provisional proposals in this consultation paper were implemented. In particular, is it likely that local authorities would need to charge more, or more often?**

If a council's obligations are expanded without central government funding to match, it is likely that charging would increase, despite families with disabled children already being impoverished.

We are calling for the massive spending on child protection placements to be ended and instead funds to go to supporting families and keeping children in their home.  The percentage of children removed who are actually abused is small, most removals are for poverty deemed neglect or as a result of outright discrimination.

Some local authorities are taking a different approach with good results.  For example, Neath Port Talbot had one of the highest numbers of children going into care in Wales.  But by supporting families in the community it has halved the number of children in care and now has one of the lowest rates in Wales, despite contacts to the team increasing by 53%. Helping children stay with their mothers is a priority in Neath Port Talbot and should provide a model of good practice for others to follow.

**Consultation Question 49.**

**We invite consultees' views on the extent to which disabled children's social care law can and should be aligned with SEND law.**

At present SEND law is not fit for purpose.  To avoid paying for a disabled child's needs families are threatened and reported to Children's Services which too often threatens to remove their children.  This prospect terrifies mothers into stopping seeking support or not ever applying for it.  This must be addressed.

At present parents have a right to ask for a personal budget (PB) as part of an EHCP needs assessment but we know that this either does not happen or that it can take a year to challenge it through the courts, while the child receives no support.

98% of all cases taken to EHCP Tribunals are successful in favour of the mothers/carers, meaning that councils have wasted time and a vast amount of money trying to stop children receiving care and support. The process of applying, rejection and appealing can take years during which families can be threatened and abused, and put under huge pressure to retract by social services who threaten to remove children if a mother pursues a challenge at Tribunal. Many mothers in our network have withdrawn from applying to the Tribunal under such threats which not only affect the disabled child but also their siblings.

Local authorities collectively allocated around £73m in the last few years of their resources towards defending SENDIST appeals. Since the SEND reforms became law in 2014 Councils have directed over £325m of resources to SENDIST appeal defence – with a further £100m of costs to the public purse borne by the judicial system over the same period. This is money lost to the disabled children.

In our experience, the SEND system is just another system that abuses children and blames the mothers while disabled children are left unsupported or not in school.

When disabled children are in “care”, we know from experience they are far worse off: they do not have a mother fighting for their needs, their mother is denied information by social workers and they are allowed to just stop attending school. Virtual schools are not monitored but do take money and EHCPs are abandoned. Children are abused and they are unable to tell those they love what is happening in these schools.

The government’s new Children’s Wellbeing and Schools Bill aims to make all schools into Academies, however the CEO of one such trust has openly discussed that to make savings they would.

*include cuts to pastoral and special educational needs and disabilities (Send) teaching support staff. On the grounds that a child with support staff “doesn't learn independence, they learn to become dependent upon that adult.”*

**Consultation Question 50.**

**We provisionally propose that the current dividing line between social care and health care in respect of children, based upon the scale and type of the care being provided, should be placed on a statutory footing, with a regulation-making power to enable that line to be changed in future.**

We agree that social care and health care for children should be statutory, but we oppose the merging of social care and the NHS which medicalises social support and children’s development. Disabled adults aim for support to enable independent living, not be reduced to bodily functions where these are the only recognised needs. Children's social care should have similar aims to enable the child, mother and siblings to live full lives, not be medicalised.

**Consultation Question 51.**

**We provisionally propose that there should be a single provision setting out when a local authority with responsibilities under section 117 of the Mental Health Act 1983 is required to assess a disabled child's social care needs.**

We object to detention of young disabled people in psychiatric units, often in solitary confinement where they are raped and abused. All children should be living with their families with support given to the mothers rather than privatised schools.

Disabled children in care do not receive adequate housing, education and medical treatment and they attempt to run home to their mothers. This has seen Councils misusing Deprivation of Liberty Orders which have risen by 462% since 2023. Disabled children are locked up in isolation in extreme conditions as a way of control which is neither therapeutic or humane.

We welcome any move to end this practice by means of alternative provision in the young person's interest in favour of children staying with their mothers and being supported there.

**Consultation Question 52.**

**We provisionally propose that guidance include a specific section – co-produced between local authority and NHS representatives – on the intersection between health care and social care. This should make the following clear.**

**(1) How children with health care needs are to be identified (see further in this regard our provisional proposals regarding referral for assessment at paragraph 4.41).**

**(2) Local authority responsibilities to meet the health care needs of disabled children.**

**(3) NHS responsibilities to meet the health care needs of disabled children.**

**(4) Expectations for joint working and joint accountability where local authority and NHS responsibilities overlap in the meeting of such needs.**

**(5) Mechanisms for dispute resolution, including an expectation that "internal" disputes as between local authority and NHS organisations should not affect the meeting of the needs of the child in the interim.**

We do not agree with joining up services which have their own very different ideas on the needs of children including parental blame. What a consultant sees as a need might not be seen as a need by a social worker.

We do not agree, as you suggest, that children should be ‘looked for’ and an assessment forced on them. Families should have the right to reach out for assessments if they want them, but not all families are comfortable with the intrusive nature of assessments, and it could lead to more families not reaching out for support.

Assessments on the NHS can take many years to secure, during which time it could be decided that the child does not need anything as they have not yet been seen by specialists. In our view, support should be provided on the basis of a child’s needs, even without a diagnosis.

It is unacceptable for a child to be in a position where one side is waiting for the other side to make an assessment, leaving the child caught in the middle receiving no support.

### Consultation Question 53.

**We invite consultees' views on the cause of the problems faced by disabled children receiving social care in making the transition to adult social care.**

Transition to adult social care must start as soon as a child enters secondary school. Often new assessments are needed and this can take years. Alongside these disabled children might be changing all their medical teams to adult services and this slows down progress. There should never be a break in services and the status quo must be maintained by the current team until transition is reached.

At this point the child themselves must be allowed to attend and voice what they want, and all meetings should be made accessible.

### Consultation Question 54.

**We provisionally propose that the Care Act 2014 be amended to provide a statutory age at which transition planning should be started in relation to disabled children.**

We agree.

### Consultation Question 55.

**If the Care Act 2014 were to be amended to provide a statutory age at which transition planning should be started in relation to disabled children, we invite consultees’ views as to the age at which this should start.**

Planning should start at age 11 and always include the child.

We also want to raise a problem for families with disabled children in the transition from child Disability Living Allowance (DLA) to adult Personal Independence Payments (PIP).

At the moment, the transition age for a disabled young person’s DLA ending is when they are coming up to age 16.

Not being moved over automatically to PIP, but the mother/carer having to make a fresh claim, and encountering problems, is a major disruptor of the mother/carer’s family income, which also causes hardship to disabled children. Carer’s Allowance and money for a mother/carer to live on are tied to getting DLA or PIP. The DWP stops Carer’s Allowance and connected benefits such as Income Support if there is a gap in DLA/PIP. This disrupts Council Tax Support and housing benefit as the mother/carer’s means-tested benefit has stopped. There are currently huge delays in the DWP processing PIP claims, plus the PIP test and assessments are discriminatory and carried out by Atos or Capita working to targets. For example, a girl being treated by Great Ormond St Hospital was scored 0 for PIP and WinVisible had to support her mother to challenge this successfully.

What that age should be would ultimately be a matter for Government, but we welcome the consultees' views. There are two obvious candidates.

1. The first is 14, as this is the age by which the current statutory framework provides that the assessment process should have started where the child has an Education, Health and Care Plan under the Children and Families Act 2014.
2. The second is 16, recognised as a significant age in other legislation, for instance in the Mental Capacity Act 2005.

We propose the transition should start at age 11 (at the same time as transition to secondary school), see above. However, because services for adults are more restricted than for children, starting at a younger age must not be used to restrict services from a younger age or lead to rationing of services.

**Consultation Question 56.**

**We invite local authority consultees to tell us the methods they use to:**

**(1) identify the nature and extent of social care provision required by disabled children in their area;**

**(2) ensure that sufficient services are made available to meet those needs; and**

**(3) keep the sufficiency of service provision under review.**

N/A as we work across multiple areas.

**Consultation Question 57.**

**We invite consultees' views on, and experiences of, the sufficiency of disabled children's social care provision in the local area.**

N/A as we work across multiple areas.

**Consultation Question 58.**

**We invite consultees' views on whether it should be mandatory for local authorities to have a designated social care officer.**

Yes, but this officer should never come from or have a background in child protection.

**Consultation Question 59.**

**We invite consultees to tell us about their experiences of co-operation and joint working in the social care context, or between social care, education and health.**

Experiences are very poor, families are threatened with child protection and mothers are blamed for their own children's disabilities.

**Consultation Question 60.**

**We invite consultees' views on the factors that help and hinder effective co-operation and joint working.**

See above.

**Consultation Question 61.**

**We invite consultees' views on the statutory complaint's procedure (either through making or handling a complaint).**

When a complaint is made social workers and/or doctors make it difficult and sometimes all assessments stop whilst complaints are heard. The complaints procedure is used by professionals as a diversion and distraction from taking action to remedy a problem. Complaints are rarely upheld; sometimes the Council accepts one minor detail and dismisses the rest.

**Consultation Question 62.**

**We invite consultees to tell us about experiences of complaints to the Local Government and Social Care Ombudsman. Do consultees consider that the current system enables timely and appropriate resolution of such complaints?**

Going to the Ombudsman takes stamina and determination and many full-time carers don't have the time and energy to do it, on top of daily life.

Even when complaints are upheld by the Ombudsman, it does not mean that the next family will be treated fairly. An Ealing disabled mother who joined our group had her complaint largely upheld, and secured childcare costs and some compensation. But this is very rare. And her complaint of racism was not upheld by the Ombudsman. The outcome of this was shortly after this ruling her child was removed from her care and the money she had won was "saved" as a result.

**Consultation Question 63.**

**We invite consultees' views on whether the Children's Commissioner should be given an express power to initiate legal proceedings in respect of the social care needs of disabled children.**

Yes. However, it seems unlikely that the Commissioner would have the time and resources to take action on every case where it might be needed. The most likely outcome would be to concentrate on those cases which are most newsworthy, rather than those which might be more deserving.

**Consultation Question 64.**

**We invite consultees' views on the changes necessary in order for families to have an effective and independent mechanism to challenge and rectify decisions about disabled children's social care.**

There should be a totally independent body which considers all complaints. Under the current system Councils consider complaints against them - ie mark their own homework, so there is no independent scrutiny.

**Consultation Question 65.**

**We invite consultees' views on extending the powers and jurisdiction of the SEND Tribunal as a potential option to challenge and rectify decisions about disabled children's social care.**

No - the Tribunal system is already overloaded and costly to parents.

**Consultation Question 66.**

**We provisionally propose that the Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations are amended. This amendment should make clear that the SEND Tribunal has the power on an “extended” appeal to recommend that a local authority carries out a social care assessment where one has not been carried out.**

We agree that the SEND Tribunal should have the power to recommend an assessment but given it can take a year to get to a Tribunal this should not be the sole mechanism to ensure assessments happen.

**Consultation Question 67.**

**We provisionally propose that a child should be regarded as disabled for the purposes of disabled children’s social care law if:**

**(1) they have a physical or mental impairment; and**

**(2) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.**

We agree with a definition along the lines of the Equality Act, and with the proviso that needs should be recognised even if the mother/carer does not yet have a medical diagnosis, which can take many years to establish.

**Consultation Question 68.**

**We provisionally propose that the statutory definition of disability should clarify that social care services should not be denied to a child purely on the basis that their impairment gives rise to:**

**(1) addiction;**

**(2) a tendency to set fires;**

**(3) a tendency to steal;**

**(4) a tendency to physical or sexual abuse of other persons;**

**(5) exhibitionism; and**

**(6) voyeurism.**

Children reach out and communicate in many ways and what is perceived as bad behaviour might actually be a cry for help and understanding.

**Consultation Question 69.**

**We invite consultees' views on whether the definition of "substantial and long term" requires adaptation for younger children in the context of disabled children's social care law.**

See answer to Q67.

Children's needs change as they grow and mothers should not be put through a rigorous process as their children's needs change. Assessments should not start again but rather reflect a change in a child's needs whatever that might be and it should be a matter of just talking and a very quick process not another long and drawn-out assessment. In the NHS as a disability evolves, they do not require a new assessment to give a child what they need in terms of equipment or medication for example, and this should be the same for social care.

**Consultation Question 70.**

**We provisionally propose that decision-making as to the assessment and meeting of the social care needs of disabled children should be based upon:**

**(1) an overarching principle that the best interests of the child be the primary consideration for decision-makers;**

**(2) a set of considerations to which decision-makers must have regard in applying that principle; and**

**(3) a final check that decision-makers must apply as to whether the purpose being served by the proposed decision or action can be as effectively achieved in a way which is less restrictive of the child's rights and freedom of action.**

All should apply but we would add that there should be an independent body that a mother could turn to if professionals use opinions rather than factual evidence to decide what a child needs. There should be full and open transparency and professionals should not be allowed to regulate themselves including hearing complaints.

**Consultation Question 71.**

**We are provisionally proposing the following list of considerations to which decision-makers should have regard:**

**(1) the importance of promoting the upbringing of the child by the child's family, in so far as doing so is consistent with promoting the best interests of the child;**

**(2) the importance of the child participating as fully as possible in decisions relating to the exercise of the function concerned;**

**(3) the importance of the child being provided with the information and support necessary to enable participation in those decisions, having regard to their particular needs;**

**(4) the views, wishes and feelings of the child;**

**(5) the views, wishes and feelings of the child's parents and carers and their knowledge of their child's condition and needs;**

**(6) the need to support the child and their parent carers in order to facilitate the development of the child and to help them achieve the best possible outcomes at each stage of their life;**

**(7) the importance of preventing or delaying the development of the needs for care and support;**

**(8) the need to prepare the child for adulthood and independent living; and**

**(9) the characteristics, culture and beliefs of the child (including, for example, language).**

We would strongly add to all these points that professionals must STOP using parental blame as a way of not supporting families. Start listening to the mothers and work with them rather than judge them. What works for one disabled child might not work for another family so there MUST be an individual approach.

**Consultation Question 72.**

**We invite consultees' views on the operation and practical effect of the list in section 1(3) of the Care Act 2014.**

See our other comments on Care Act assessments in questions 54 and 55.

**Consultation Question 73.**

**If the approach that we have set out in Consultation Questions 70-71 to participation were to be adopted, we invite consultees' views as to whether and how it should vary according to the age of the child.**

Please see our answer to question 76

**Consultation Question 74.**

**We provisionally propose that legislation should provide that children (of any age) who have the ability to do so, can:**

**(1) request an assessment of social care needs (see further Chapter 3);**

**(2) make representations in the course of the assessment of those needs (see further Chapter 4);**

**(3) make representations about the content of any plan developed to meet those needs (see further Chapter 11);**

**(4) opt-out of advocacy support where a duty to provide such advocacy is engaged (see further Chapter 22);**

**(5) request that services are provided by way of direct payments (see further Chapter 10); and**

**(6) make use of the relevant remedies that are available where a local authority has failed to assess or meet their needs appropriately (see further Chapter 18).**

We agree that children should be fully involved in all decision-making about their needs. However this should not be used to exclude a mother/carer's point of view, particularly as she will be concerned about the needs of the whole family.

**Consultation Question 75.**

**We provisionally propose that the test for whether a child aged 16 or 17 is able to make the decisions set out in Consultation Question 74 should be the test contained in the Mental Capacity Act 2005.**

N/A

**Consultation Question 76.**

**We invite consultees' views as to whether legislation should provide that the test for whether a child aged under 16 is able to make the decisions set out in Consultation Question 75 is:**

**(1) competence (and not provide any further definition of the term); or**

**(2) the child's ability to understand, retain, use and weigh the relevant information, and to communicate their decision.**

See answer to Q74.

**Consultation Question 77.**

**We provisionally propose that the law should provide that a local authority must carry out an assessment of the social care needs of a disabled child where the child is seeking to opt out of such an assessment if the child is experiencing, or is at risk of, abuse or neglect.**

Children should always be listened to and fully involved but a child should not be allowed to opt out of an assessment unless the mother/carer is in full agreement.

If a child is in “care” and they do not have the support of their mother/carer, they should have the support of an independent advocate or lawyer of their choosing so they are supported to ensure that any assessment meets their needs.

**Consultation Question 78.**

**We provisionally propose that a new legal framework for disabled children’s social care should include a right to independent advocacy for any disabled child who would otherwise have difficulty in participating in the assessment and planning process around their social care needs. This right would apply unless:**

**(1) there is already an appropriate person who can represent and support that child; or**

**(2) a child with the ability to do so (as to which, see Chapter 21) does not want an advocate to be involved.**

Children should have the right to an advocate, but they must be independent of the Council, which many are not. In our experience, advocates may be reluctant to challenge the Council (which is paying them) or express bias towards the Council’s point of view. What children say for themselves should be respected and should be fully taken into account.

**Consultation Question 79.**

**We invite consultees to provide their experiences of situations where support by an independent advocate has been provided to a disabled child being assessed under section 17 of the Children Act 1989.**When an advocate is independent of any council they have been successful in achieving good outcomes for mothers and children.

We have advocated for parents in our network who before we attended were given totally wrong information including on the law. In one case we were also left advocating for the child as well as the mother as the council advocate for the child also gave totally incorrect information. Before we attended there was parental blame, that stopped as soon as we attended and an independent body like ours was now involved.

**Consultation Question 80.**

**We invite consultees to provide us with experiences of culturally competent advocacy (both positive and negative).**

There are very few independent advocates and even fewer with different language skills. Mothers in our network, especially those outside London, have failed to secure advocacy and those that managed to get advocacy via the council found them not to represent them but rather support the views of social services against a disabled child.

With families whose English is not their first language, social workers refuse to extend time for translation despite translations taking more than half of allocated meeting time, for example. We have experience of translators who did not translate what a mother said accurately and then passed on misinformation to professionals.

**Consultation Question 81.**

**We provisionally propose that a new legal framework for disabled children's social care should provide an entitlement for parents and carers of disabled children to have advocacy support in respect of the assessment of their own needs where, without such support, they would have difficulty participating in the assessment (and where there is no appropriate person who can represent and support them).**

An advocate should be independent - See Q78 on problems with advocacy.

**Consultation Question 82.**

**We provisionally propose that disabled children should be taken out of the scope of section 17 of the Children Act 1989 and that there should be a new simplified and unified legal framework for addressing their social care needs.**

Section 17 should be amended as we have already said so it is a duty and there should be a National Standard

**Consultation Question 83.**

**We provisionally propose that any new framework should be accompanied by two sets of guidance, one for professionals applying the law, and the other for parents and carers who need to understand their rights under the law.**

Yes - there should be a separate guidance for parents written in language that is easy to understand.

**Consultation Question 84.**

**We invite consultees' views on whether any of the proposals in this consultation paper require adaptation in order to meet the needs of disabled children who are not in family-based care (for example, children in custody).**

The needs of children in foster care, residential care and/or in custody must be taken into account as their needs are even more neglected. Too often they do not receive adequate medical care or education so there should be an independent advisor monitoring that their assessments are met, especially when parents have limited or no contact.  All assessments should be made available and results published and monitored. Children are often taken into care as a way of stopping social care and EHCP support so unless this is dealt with children in care will remain unsupported.