



Parents' and carers' views on how we can work together to prevent the sexual abuse of disabled children

“You fear everything that is out of your control.
Because you are their safe one”

Anita Franklin, Alex Toft, Sarah Goff

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Summary

This research was commissioned by NSPCC to better understand how to best engage with parents and carers of disabled children, including children with physical and learning disabilities, and complex communication needs, when it comes to keeping their children safe from child sexual abuse.

Research identifies that disabled children are three to four times more likely to experience abuse (Jones *et al*, 2012). Professionals, communities and parents all play important roles in keeping disabled children safe from sexual abuse. Despite the important role that parents play, there is a lack of research evidence on how parents understand and address issues around child sexual abuse, particularly preventing child sexual abuse. This study aimed to address this gap in understanding in order to provide better support for parents.

Thirty parent/carers¹ (predominantly mothers) of disabled children took part in this qualitative study, choosing to take part in either interviews or discussion groups. Their children (aged between 4 and 21 years) have a wide range of impairments, predominantly these were learning disabilities and autism (and represented the spectrum of both autism and learning disabilities). Some children had physical disabilities, learning difficulties, complex communication needs and complex health needs. The needs of the children varied from moderate to significant, and they attend both mainstream (30%) and specialist education (70%).

Insights from the interviews and discussion groups

Parents' concerns about keeping their children safe

All parents expressed concerns about keeping their disabled children safe and they all recognised the **increased vulnerabilities of their children due to their impairments making it difficult for them to recognise or respond to danger or abuse** – although it should be noted that the onus should not be placed on children to keep themselves safe.

For other parents their concerns were exacerbated because their **children needed support with personal intimate care**. Parents reported, however, that this increased vulnerability was a subject that **was often not discussed amongst parents**. One father stated that *"It is like, you don't really want to let it [the thought of abuse] enter your head really"*.

Parents raised specific concerns regarding **disabled children and their family's vulnerability to being targeted, groomed and exploited by gangs** within the area.

Across the sample there were **very few parents who stated that their child went out alone or accessed any community activities** where they were not also present. Fear of what might happen to their child meant for some parents denying their child access to freedoms. Other parents raised concerns about **potential abuse in care services** such as short breaks.

Social media was even more of a concern for most of the parents interviewed, with many not allowing their children access. They all still had concerns about what their children might access accidentally, particularly whilst at school (especially on YouTube). In one case a child had secretly created multiple Facebook accounts – 18 active ones. The young man had little comprehension of potential grooming online yet could set up the accounts with ease. This highlights the fact that **some young people have excellent technical skills but lack the social and emotional awareness to contextualise and anticipate the risks they face.**

The parents were aware that they were in some cases over-protective of their children, but they felt a responsibility to do all they could to prevent them from harm. **Many parents were aware that over-protection of their child was not an ideal or long-term strategy for keeping their children safe.** Many were concerned about their child's safety from abuse once they reached independence, or when they themselves would be no longer able to protect their child.

1 For ease of reading we refer to parents, however, this does include carers with a parental role, such as foster carers and extended family members with caring responsibilities.

Parents whose children had complex needs raised particular concerns regarding how incredibly difficult it was to teach their children about issues such as safe touch in their intimate care, puberty and changes in their bodies and about sexual abuse. Their greatest fears were that their **child would not be able to communicate if they felt unsafe**. These parents spoke about their need to know that the professionals around their children were thoroughly vetted, trained and supervised to prevent abuse. It was also highlighted as being important that these professionals were able to spot signs of abuse and changes in their child's behaviour, and be able to raise the alarm if needed. Others raised concerns that **some children relied on the same professionals to access communication such as interpreting for BSL** (British Sign Language) and thus they needed access to means of communication that did not rely on a small number of individuals.

Parental views on what support/resources would help them in keeping their children safe

The majority of discussion focused on parents expressing the challenges they face in communicating with their children about child sexual abuse, and how any support to help to facilitate this would be welcomed. Some parents were particularly concerned about their child saying or doing things which might be deemed inappropriate, such as **displaying sexual behaviours or touch in the community or at school because they had misunderstood the information they had been given, or could not comprehend social cues and social boundaries**.

Others expressed that we do not live in a culture that encourages conversations about sex and child sexual abuse and thus **it is a taboo and too sensitive a subject to discuss, especially when considering disabled children**. There was a call to normalise such discussion and bring it out into the open and for parents to be encouraged and supported to have these conversations. Some **parents were honest in expressing their own discomfort in talking about sex and potential sexual abuse**. Although there is only a small sample, fathers in the study were particularly uncomfortable with having these conversations.

Few parents had received any support to help them discuss these issues with their children, although some had tried to do their own research online.

Access to workshops (in schools, children's centres, or via parent groups) was one suggestion.

Others wanted guidance on specific issues such as parental locks on gaming consoles. **Development of a variety of resources to meet the variety of access needs of their children was seen as vital**. Many parents commented their children were visual learners and needed resources which were not abstract, whose visual content could aid learning. Others made use of social stories in other contexts, and felt that this approach might work well in terms of supporting children to understand the nuances of social context. Learning through play and toys was also mentioned for younger children or those with a developmental delay. Other parents recalled safety campaigns from their own childhood and recommended similar activities.

For some parents, they also felt that what was needed was **somewhere where they could go for advice on handling these issues**. A couple of parents, however, wanted assurances that this place would be a safe environment to ask questions and where they would not need to fear reprisals. Others felt parents should be given more knowledge of the signs of abuse and what to look out for as this was also a gap in their knowledge.

Given the spectrum of needs and abilities of the children represented within the 30 families interviewed, not surprisingly, there was a lot of discussion about how certain approaches or resources might not be accessible to individual children, and therefore **there was not a "one size fits all" solution**.

Parents wanted their children to learn how to keep safe but also stated very clearly that they also **do not want to frighten their children and were concerned about graphic images**. They felt that messages had to be clear and not complicated. What was requested was a step-by-step process focusing on concepts of private space, puberty and then increasing in complexity, where possible, concerning healthy friendships and relationships, sex and then sexual abuse but tailored to their child's age and/or developmental level.

Partnership with schools and other service providers to create more protective factors around the child

Parents highlighted **the importance of quality sex and relationship education in schools, but in their experience the quality varied**. It was not always clear to parents whether their child had received this, or whether this education had been made accessible so their child could understand it. Many parents felt it most probably focused on biology and sexual reproduction rather than understanding important areas such as consent, healthy relationships and abuse.

Some parents discussed how **when some schools taught sex and relationship education this presented a good opportunity for parents to be more involved and aware of what these lessons contained**. Some parents wanted to be able to follow up on these lessons to ensure their child understood what was being taught, or be prepared for the inevitable questions that their children would ask. The majority of parents reported that **any education and prevention work needed to be a partnership between schools, parents and other practitioners in young people's lives**.

Some parents noted **the role that school nurses or family support workers** could/should have in this area, but they had not experienced them undertaking this area of work with parents, or indeed their children.

Parents felt that **professionals, and especially teachers, need to be better informed about the signs of abuse, and should be more open to listening to the children and be able to pick up on changes in behaviour**.

In conclusion, ten actions for change were identified by the parents:

1. Improved understanding and awareness of the need for sex and relationship education for all disabled children and young people, and the need to break the taboo surrounding the sexuality and abuse of disabled people.
2. All schools should deliver accessible sex and relationship education for disabled pupils, which develops appropriately with the children's age and understanding. Access to this education should be included in children's Education, Health and Care Plans (EHCPs) and monitored as a measurable outcome.
3. Schools and multi-agencies should work in partnership with parents to ensure that disabled children receive consistent, clear, accessible information on safe touch, choice and control, puberty, sex, relationships and abuse, and knowing how to let others know when they feel unsafe.
4. All disabled children should have access to communication methods and communication tools which enable them to have a level of choice and control, and access to a number of people who understand their communication method as a safety mechanism. This should be included in all EHCPs.
5. For children's support plans, including EHCPs to be holistic and to address social and emotional needs including relationships, choices, sexuality and healthy relationships. And for disabled children to be helped to understand behavior that hurts, that they have a right to be safe and have help to learn about who and how to let know if they do not feel safe.
6. Transition planning and preparing for adulthood should include sex, relationship and safety education as it earliest stages and to be a monitored outcome.
7. The development of more accessible resources in multiple formats, which address all elements to support disabled children's safety. Resources should be developed for children, their parents and professionals.
8. Parents to have opportunities to discuss these issues and share ideas in a safe and sensitive environment via workshops or support groups.
9. Better understanding, training and a consistent, balanced approach to avoid what is deemed "inappropriate behavior" by disabled children leading to unnecessary criminalization or inappropriate investigation.
10. Improved training for professionals to spot the signs of abuse of disabled children and prioritise the prevention and protection of disabled children and their families in service settings, and within the community where they are particularly vulnerable to targeting by gangs, and all forms of criminal exploitation.

1. Introduction

This research was commissioned by NSPCC to better understand how to best engage with parents and carers of disabled children, including children with physical and learning disabilities, and complex communication needs, when it comes to keeping their children safe from child sexual abuse. Specifically, this research sought to consider their views on how to communicate with their children about child sexual abuse and deliver effective prevention activities. In this context we refer to parents, however, this does include carers with a parental role, such as foster carers and extended family members with caring responsibilities.

1.1 Link to broader NSPCC work

The NSPCC and external partners are developing place-based approaches² to prevent child sexual abuse, combining NSPCC resources and evidence with local resources and expertise to help realise a shared vision of keeping children safe.

The core principles by which the programme activities will be tested, are:

- **Co-creation** through relationships with children and families, local partners and community members,

- **Continuous learning** and use of evidence to be the best we can,
- **Strengths-based**, building from individual, community and service strengths, respecting and honoring what is good,
- **Inclusivity and accessibility** ensuring diverse representation of community members during creation, consultation and delivery,
- **In partnership**, sustaining effective partnerships at all levels,
- **Sustainability** by embedding local ownership, value and capacity.

This research linked with the place-based approach operating within an area in England. In line with the place-based approach, the research sought to develop an evidence-base which would support the partnership to build an approach to preventing child sexual abuse that works for the local area. Seeking the views of parents, building on their expertise and understanding their needs are seen as vital components of a place-based approach.

² For an explanation of NSPCC's place-based approach to the prevention of child sexual abuse see <https://www.nspcc.org.uk/globalassets/documents/about-us/nspcc-together-for-childhood-goal-1.pdf>

2. Background

Although it is difficult to establish prevalence of abuse of disabled children and young people, research identifies that this group of children are three to four times more likely to experience abuse (Jones et al, 2012). For sexual violence, estimates of prevalence are 8 to 9 per cent of all children, however, when examining the prevalence of sexual violence in children with learning disabilities specifically, the figure rises to 15 per cent (Jones et al, 2012). Disabled children are also more likely to experience the negative aspects of social media than their non-disabled peers (Miller and Brown, 2014). It is also known that the abuse and effects are more likely to go unnoticed than with non-disabled peers (Stalker and McArthur 2012, Taylor et al, 2015). The vulnerability of disabled young people continues into adulthood with, for example, disabled women and men at significantly higher risk of domestic abuse (Thiara et al, 2012).

Despite the known increased risks, there is a dearth of research specifically on the sexual abuse of this group of children. Practice can be informed by a few recent studies on disabled child abuse (for example, Taylor et al 2014, 2015; Franklin et al, 2015; Franklin and Smeaton, 2016) and on published serious case reviews (Brandon et al, 2012; Spicer, 2018). These studies highlight that risks are heightened because professionals often struggle to identify abuse of disabled children where support can be too focused on needs relating to disability and thus signs of abuse are missed. In addition, child protection can be seen to be solely the concern of social services and outside the remit of other agencies involved in a disabled child's life. Risks can be exacerbated because it can be difficult for children with communication or learning needs to express themselves, or have access to people who can understand their communication. Sometimes their attempts to express themselves can be interpreted as "challenging behaviour" or "risky behaviour" without a consideration of potential safeguarding concerns. The high levels of bullying, isolation, disempowerment and discrimination of disabled children and the significant impact on mental health and emotional wellbeing also creates vulnerability. High thresholds for support and the

invisibility of the vast majority of disabled children and young people to most services can mean that they become specifically targeted for abuse and exploitation, as they remain under the radar (Miller and Brown, 2014).

Major issues such as the isolation and disempowerment of disabled children in their daily lives, and lack of service provision, need to be addressed on a wider societal level. Specific attention also needs to be given to training multi-agency practitioners in safeguarding disabled children so that these professionals can spot the signs of abuse, whilst considering and genuinely listening to all forms of communication. Disabled children need accessible, safe ways to speak out about their concerns, but they also need professionals who will listen and create spaces where communication can be facilitated (Jones et al, 2017).

The increased risk presents particular challenges in terms of keeping this group of children safe from sexual abuse because of the need to work in individualised ways and to plan and prepare discussions to meet individual learning styles and understanding. Professionals, communities and parents all play important roles in keeping disabled children safe from sexual abuse. Despite the important role that parents play, there is a lack of research evidence on how parents understand and address issues around child sexual abuse, particularly the prevention of child sexual abuse. Little is known about what services, advice and support they access, what they feel works well, and where they feel there are gaps. Equally, attention has not been paid to understanding how parents see their role more broadly or understand the wide range of steps they may need to take to keep their children safe. Furthermore, little has been done to understand how to support them to develop healthy relationships, and how they engage with others on these issues. Parents have a role in communicating with their children about staying safe, however, it is also important that the onus is not put on children to act to stay safe. Children are not responsible for their own abuse.

The work by Briggs (2006), Hollomotz, (2011) and Franklin et al (2015) highlight that it is crucial for disabled children and young people to have personal safety skills programmes and sex and relationships information tailored to their needs. This is something disabled young people see as a need and right. Disabled young people are often not supported to understand sex and relationships as there still exists a culture that assumes that disabled people would not have, or want, sexual relationships and therefore do not need help to understand these topics. This only serves to further disempower disabled children and young people and render them more at risk.

2.1 Objectives of the study

This study aimed to address the gap in understanding identified above:

Key objectives were to develop:

- Understanding of how parents of disabled children keep their children safe from sexual abuse, including but not limited to how they have conversations with their children around this.
- Understanding of how parents of disabled children view efforts of professionals and community groups to prevent child sexual abuse.

- Understanding of what parents of disabled children feel are the most effective ways to keep their children safe from sexual abuse, and where they feel there are gaps.
- Understanding of how parents of disabled children prefer to discuss issues around child sexual abuse with other adults and professionals.
- Understanding of who parents go to for advice and support and how they would like professionals and other community groups to engage with them on preventing child sexual abuse.
- Understanding of how community leaders and professionals can better communicate about prevention of child sexual abuse, for example, through campaigns, events and through more general conversations.

2.2 Methods

Following a review of existing research, 30 parents were recruited to the study via a wide range of mainstream and specialist schools and services. The parents were given a choice as to whether they wished to take part in individual interviews or discussion groups. A full description of the methods, ethical approach and sample is included in Appendix A.

3. Findings

In order to keep the parents' views central, the findings are presented according to the issues or questions which they identified as being most important. These provide important context to their lives. In some cases, this goes beyond the identified research questions and thus in the conclusion, we will re-examine the findings in light of the overall objectives of the study and these new insights.

As noted, the literature exploring parental views on working together to prevent child sex abuse is limited and rarely presents parental voices themselves. For ease of reading we have incorporated existing evidence below alongside the views of the parents in this study.

The findings presented below are themed into:

1. Parental concerns about keeping their children safe.
2. Parental views on what support/resources would help them.
3. Parental views on how professionals should support them.

3.1 Parental concerns about keeping their children safe

All parents expressed concerns about keeping their disabled children safe and these extensive worries dominated many of the interviews and the focus of discussion within groups. Despite it being known that intra-familial abuse presents a much higher risk for disabled children, most parents did not approach this subject (possibly due to sensitivities of this subject, the group setting and/or not wishing to think this was a possibility). Most parents focused on concerns about potential abuse from strangers or outside caregivers. Further exploration of this was beyond the scope of this study.

3.1.1 Increased vulnerabilities

Ballan (2012) in an article exploring parental perspectives on communication regarding sexuality for families of children with autism spectrum disorders, found that for parents, the primary fear is that their child will be sexually abused:

Parents identified numerous reasons for their children's vulnerability to sexual abuse including an inability to judge other's negative intentions,

limited communication skills and dependence on multiple caregivers. (Ballan 2012:681)

The author noted that parents desired additional knowledge about preventing sexual abuse and found that they were keen to enhance their own skills in detecting abuse. It is clear from Ballan's research that parents viewed their children as potentially vulnerable and prone to "taking risks".

In our study, all parents interviewed were also acutely aware of the increased vulnerability of their children, often making comparisons to their non-disabled siblings or their non-disabled peers.

I think parents will always worry about their child, but when it is disability it is even more. It is amplified.

People taking advantage of them. Definitely. It is there but we don't openly talk about it. That is a worry for all of us.

The parents highlighted particular vulnerabilities in their children. These included how their child's learning disability, complex communication needs, ADHD or autism affects their ability to recognise danger or risk. In addition, many parents highlighted how their children wanted friendship, loved to interact with people and wanted to give and receive affection; yet often struggled to understand the nuances of social interaction and social boundaries, or recognise potential dangers:

The amount of children on the spectrum especially, take everything literal. I am your friend, OK. Stranger Danger type thing, it is just. I don't think they get it. What they say, they believe.

Physically, my daughter looks like a little lady but what concerns me, she is a crazy child, she is so complex, because she will go to a random person, hug you, kiss you, sit on your knee. That worries me.

She believes anything anyone tells her, if someone offered her a lift she would get in the car, if they had a dog in there, she would be straight in so she is vulnerable that way but I think because she reads loads, she speaks intellectually so people think she's quite old but she's quite young headed really. I do worry. They're not allowed to go anywhere.

The parents reported that this increased vulnerability was a subject that was often not discussed amongst parents. One father stated that *“It is like, you don’t really want to let it [the thought of abuse] enter your head really”*. This is explored further below.

For other parents their concerns were exacerbated because their children needed support with personal intimate care. This created additional vulnerabilities for their child who might have multiple carers. This also increased complexity in trying to explain to a child, and instil a sense of safe touch, personal space and privacy.

XXX has problems with his personal care so I have to, sort of, say to him, “That area is your own, however, if you need help from me, you know, it’s okay for me to wipe your bottom, or whatever.” You know, it’s a bit of a difficult one, isn’t it? Because there will be plenty of children who need that sort of help and that’s another area where they’re vulnerable as well, isn’t it? You know, with personal care.

Of particular concern to some parents was the emphasis that schools had placed on developing their children’s social and independence skills. This was of course welcomed, however, this had not been accompanied by developing their understanding of keeping safe in social and emotional situations. Understanding safety in friendships and relationships with potential partners, and understanding social and emotional cues were issues that were not widely discussed. There was a feeling that this could increase their vulnerability. Parents gave examples of how their children now had no boundaries or understanding of their social interactions and would approach strangers.

3.1.2 Vulnerability to targeting and grooming by gangs

Other parents raised specific concerns regarding disabled children’s vulnerability to being targeted, groomed and exploited by gangs within the area:

Because he is so meek and timid...too nice. And wouldn’t always understand the motives behind what the person is trying to communicate to them. You know, for instance, there is quite a gang culture in this city as well. We have got one on our estate. And they are very clever at getting the young boys...to manipulate them by being friendly, giving them stuff...

This concern is not without some foundation as research has highlighted the increased risk and specific targeting of disabled young people by gangs (Berelowitz et al, 2012; Children’s Commissioner, 2019). There was also conversation within one discussion group where parents raised concerns that vulnerable families with disabled children were being targeted and the whole family were being groomed.

3.1.3 Concerns about their child’s safety when accessing services or the community

There were very few parents who stated that their child went out alone or accessed any community activities where they were not also present. Sometimes parents were required to stay with their child at activities at the organiser’s request because they felt unable to meet the child’s needs, parents also stayed at activities out of concerns for what might happen if they were not present. Fear of what might happen to their child meant, for some parents, denying their child access to freedoms, which they described some of their peers and siblings experienced freely.

Parents whose child met the threshold to access short breaks expressed general concerns about potential abuse in such services. Parents held differing views as to whether they should use these services and manage the risk to their child. Some parents stated that they would never access short breaks, some did so with considerable reservations. Some parents suggested that it had divided their family, with one mother explaining that she went against her husband’s wishes because she thought it was vital for independence and for their family to function.

I think we are a lot more suspicious, and we scrutinise everything. You are thinking why is this person like this, why is my child behaving a certain way when they have come back from respite, what has happened. She can’t tell me, and then you start thinking and over thinking so many things, the possibility of what it could be. But you are never really going to get to the bottom of it.

For me it is respite. If she goes into respite I don’t know what is happening. You hear so many disgusting things.

Some parents had gone to great lengths to ensure that their child was safe when they had carers come into their home.

We had respite at home and we installed cameras in the house for that reason, until they went. Nothing ever happened but it was just for me for those 2 hours while they were there. My son was so young, he still wouldn't be able to explain. So I would check it every time that I would come home. Just so I knew he was safe.

3.1.4 Concerns regarding online safety

Given the vulnerabilities identified above in the “real world”, unsurprisingly the online world was even more of a concern for most of the parents. Although some parents felt that the level of their child’s impairment meant that their children would not be accessing the internet or social media.

The majority of parents stated that they neither allow their child to go online nor play online games nor access social media. Those who did monitored their use at home carefully. However, many parents had concerns about what their children might access accidentally (especially on YouTube), or the possibilities of them being groomed online.

A number of parents had experienced their child accessing what they had considered to be inappropriate material whilst at school. Parents had then faced challenging circumstances trying to explain to their child what they had seen, even though they felt they were not old enough or cognitively able to understand the material.

Parents were also acutely aware of the peer pressures that their children face to be online. Such an online presence is part of the culture of social media which is prevalent in the lives of many of their peers. Yet parents felt their children were unable to understand the online world fully.

They think this person is my friend so they will give them this information.

A small minority of the parents felt able to trust their children to know the difference between genuine friends and potential groomers online. These parents were able to have conversations about the need to know the person before allowing them to befriend you. They also trusted their child to raise any concerns with them.

I think it depends on the relationship you have with them. I have always been very careful what he goes on. And we have got a good conversation around what he is accessing, who he is adding as friends. So we have quite a good conversation around that. He is quite switched on. He will come and ask me if he is worried or concerned about something.

However, other parents shared concerns about online safety based on experiences of their children speaking with people on Facebook, which neither the parent nor their child knew. In one case a child secretly created multiple Facebook accounts – 18 active ones. The young man had little comprehension of potential grooming online yet could set up the accounts with ease. Previous work by NSPCC has highlighted the increased risks online (Miller and Brown, 2014). Some young people have excellent technical skills but lack the social and emotional awareness to contextualise and anticipate the risks they face.

3.1.5 Concerns when their child reaches independence and adulthood

The parents were aware that they were in some cases over-protective of their children, but felt a responsibility to do all they could to prevent them from harm.

I think we are all over-protective. All of us. That is the only thing you can do. What else can you physically do?

For me I just keep [name] with me, always. He comes to school and any other time really he is with me.

However, many parents were aware that over-protection of their child was not an ideal or long-term strategy for keeping their children safe. Many felt that they were postponing the inevitable time when their children would need to be independent, would want to have their own relationships and would need to learn about sexual abuse. There were some exceptions to this, with the example of one father who was determined that he would always be there to protect his child. In his opinion there was no need to educate his child about these issues:

I don't see the point if I am always there.

Most parents were keen to express that although they were concerned about their child in the present, their adulthood and future life was also never far from their minds. Some expressed that they knew their children would eventually get sexual feelings and want to seek out information and experiment. Parents felt it was therefore better to protect their child and provide them with appropriate information to support them.

Others were particularly concerned about their child's safety from abuse once they reached independence, or when they themselves would be no longer able to protect their child.

I don't think it is just at this age. They are going to be vulnerable for the rest of their life.

Especially these children. If they are always going to have a barrier, in the case of understanding. All their life they are going to be vulnerable.

One of the biggest fears that nobody probably mentions is what is going to happen when we are not here. That is...for me that is the biggest fear I have.

Although a concern for most parents, this was particularly acute for parents of children with complex needs who would require high levels of support for their whole lives.

3.1.6 Complex communication needs

Parents whose children had complex needs raised particular concerns regarding how incredibly difficult it was to teach their children about issues such as safe touch in their intimate care, puberty and changes in their bodies and about sexual abuse. Their greatest fears were that their child would not be able to communicate if they felt unsafe:

Every single one [of the children] that we have just spoken about is vulnerable. They cannot speak, they cannot tell us when things happen in general.

My issue is that she is so complex that she will never ever get to that stage. So it all depends where the child is. Her classes will never ever do subjects like that.

In addition, they expressed concerns that their child might not recognise abuse if they did experience it:

They wouldn't know that something has happened.

These parents spoke about their need to know that the professionals around their children were thoroughly vetted, trained and supervised to prevent abuse. It was also highlighted as being important that these professionals were able to spot signs of abuse and changes in their child's behaviour, and be able to raise the alarm if needed. Others raised concerns that some children relied on these same professionals to access communication such as interpreting for BSL (British Sign Language), and thus they needed access to a means of communication that did not rely on a small number of individuals. One parent explained that her son used Makaton³ to communicate, yet there were no staff in his school that could use Makaton. As a result the child had no means of communicating with anyone.

3.2 Parental views on what support/ resources would help them in keeping their children safe

Parents welcomed the opportunity to discuss support and resources that they thought would be of use, and which could enhance what they were already doing. Three areas emerged:

1. support for parents to help them to communicate with their children about these issues,
2. resources specifically for parents, and visual resources directed specifically to their children
3. partnership with schools and other service providers to create more protective factors around the child.

3.2.1 Support to help facilitate communicating with their child about sexual abuse

The parents focussed on the challenges they faced in communicating with their children and how any support to help to facilitate this would be welcomed.

It is just so hard to explain. The understanding is a massive barrier. Speech isn't a normal thing.

How do you say what is right and what isn't? That would be difficult to explain to them.

³ Makaton is a language programme using signs and symbols to help people to communicate. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order.

For some parents, this was because their children did not use speech to communicate or they had significant learning disabilities. For others, their children had a literal interpretation of information and therefore it was difficult to explain the complexities of, for example, grooming, which specifically utilises manipulation and deception. In addition, being able to transfer and apply learning to multiple situations and contexts presented another challenge. Some parents were particularly concerned about their child misunderstanding information about social cues and/or boundaries and then behaving in a manner that might be deemed as inappropriate in the community or at school (such as displaying sexual behaviours or touch). As one parent stated:

We need them to know this information, but then we don't want them to go out and do something inappropriate and get into loads of trouble for it.

A couple of parents were particularly concerned about the possibilities that this kind of incident could lead to consideration of the need for child protection enquiries if there were concerns that a child may be at risk of significant harm (under Section 47 1989 Children Act) where they would be blamed for their child's behaviour. As will be detailed below, parents called for the need in understanding their child's needs and learning style so that information could be given in accessible ways. This could be achievable through the repetition and layering of information, and the use of context so that incidences such as this could be avoided. Many parents expressed how they were starting at a basic level of a "private area", although this was not without challenges, particularly for children who relied on personal care.

For some parents whose children had less significant needs, their concerns rested on the fact that their child's body had developed faster than their cognitive development. As a result, their children needed to be supported to understand their body changes and puberty;

I think their bodies are more mature than their minds so it must be really difficult for them because they're going to be getting sexual urges and things, well just starting off to get them anyway... that's quite normal, but I don't know if they quite know how to cope with those which is why I'm glad that we are very open and they can come and ask me anything and they have asked me some corks let me tell you.

Other parents whose children possibly had a higher level of cognitive ability spoke about the importance of the relationship they had with their child and how it was important for them to be open, honest and answer any questions their children asked. They were also keen to highlight how they had to be available and ready to answer questions whenever their child was curious. This presented opportunities to discuss often difficult or embarrassing subjects. The issue for some parents was therefore the need to be ready and prepared to respond when asked. This was juxtaposed with their other children with whom they could initiate a conversation. For these parents the issue was responding well at the time the child sought the information and seeking to avoid the child becoming distracted.

For me, because he is transitioning [moving to college] and he is going to be a bit more mobile around the community and everything. He is starting to ask more questions about relationships, what a positive relationship looks like. So we are having to have conversations with him around that. But very much at his level. And I have to repeat a lot of things constantly because sometimes the concepts just don't sink in. So we have to revisit things. So he is curious and he has got lots of questions. Like you are saying, it is knowing how to handle them sometimes. I do look things up on the internet, look for ideas how to speak to him sometimes. I can see him asking questions and I can see him not quite understanding what I am trying to tell him sometimes.

In the discussions, parents raised a number of concerns about finding it difficult to talk about child sexual abuse. For some, the concern that this might happen to their child was something that they tried to avoid thinking about:

We don't openly talk about it I don't think, not me personally. It is a worry that is there, but me, because I worry about so much I don't talk about it.

I avoid talking about a lot of things because I know if I talk about things I will get upset, and cry, so we avoid it. There are times when I've talked about issues and I've been sobbing. Because I am fine getting on with it. Soon as I start talking about my children I get so emotional and upset, exactly for that reason.

Others expressed that we do not live in a culture that encourages conversations about sex and child sexual abuse. Therefore, it is a taboo and too sensitive a subject to discuss, especially when considering disabled children. There was a call to normalise such discussion and bring it out into the open and for parents to be encouraged and supported to have these conversations.

It is one of those things you don't really talk about it.

Some parents were honest in expressing their own discomfort in talking about sex and potential sexual abuse.

I don't think I feel comfortable about the sex talk.

Although there was only a small sample, fathers in the study were particularly uncomfortable with having these conversations. One felt that his wife was best placed to have conversations. As described before, another father felt it was unnecessary as he would always be there to protect his child and wanted to keep his child's innocence.

My wife would probably better word it, if she was talking to her. I would be like blah, fumbling a bit. It is one of those things, how do you approach it? What do you say? It is one of those things you don't really think about approaching. I know it needs addressing. I know they do education at school. The birds and bees and whatnot. But I am not sure they touched on that subject. It is something you don't really want to talk to your daughter about really. It is there but it is one of those things you don't really want to go over.... I know she is 16 but I see her as a lot younger....

Despite these concerns, most parents agreed that:

You can't shield them so you have to be open and honest with them because you're making them feel ashamed about their bodies and it's not going to help the situation.

Few parents had received any support to help them discuss these issues with their children, although some had tried to do their own research online.

Almost all parents welcomed the possibility of support in this area, particularly if their child's school were teaching these subjects.

No, not directly. Only stuff that I have found. I suppose from an educational angle that would be useful, if they are starting to do the conversation or approach those topics, perhaps send a parental leaflet...

Access to workshops (in schools, children's centres, or via parent groups) was one suggestion put forward by a number of parents. This would enable parents to share their concerns, learn tips on how to start to have conversations or hear about different approaches and resources to support them. It was also suggested that parents of disabled children would be good facilitators/co-facilitators to these workshops as they have personal experience and would be able to empathise with fellow parents.

I'd say other parents who've been through it because I always give anybody the time of day and say well have you tried this or what about this. Because you never know it might be the answer if it isn't you haven't lost anything.

3.3.2 Resources for parents, and resources for use with children

As detailed above, some parents indicated that they had sought advice online looking for resources to help them to communicate with their child about sexual abuse. Overall, the parents reported having little success. Others wanted guidance on specific issues such as parental locks on gaming consoles as they had been unable to find useful information.

Aside from the NSPCC PANTS⁴ materials, few parents had found any resources which they felt could support them. Some of their children had received a talk at school on the NSPCC PANTS awareness campaign which was well received by parents.

It is quite fun, it doesn't scare the "bejesus" out of him. It makes them think if they see the pants... about not touching them in that area.

The multiple NSPCC PANTS materials, which aim to help parents start vital conversations about staying safe from sexual abuse with children aged eight and under, was seen by parents as not necessarily meeting the needs of all of the children in these families. In addition, the message of PANTS is deliberately simple and specific, and is not intended to meet

4 <https://www.nspcc.org.uk/preventing-abuse/keeping-children-safe/underwear-rule/>

wider needs for greater understanding of sex and healthy relationships and of child sexual abuse. Notwithstanding the limitations of PANTS, some parents thought an online app version of PANTS would be good.

You could make a game where you get dressed and undressed and when you get to the pants it says, no they are mine.

Some parents had suggestions about what would help them, including that an accessible online game or app might meet some of the needs of their children. It was suggested that children are given scenario-based options which might help them to understand private space, and to recognise situations where they might be in danger, or need to alert someone.

You've got two things where you have like a situation, which one is right, you tick it, ding!

For other parents, having access to basic picture cards were identified as being useful. Or simply having materials available in the communication format that their child used such as PECS⁵ or Makaton, was highlighted as important. Many parents commented that their children were visual learners and needed resources which were not abstract, and whose visual content could aid learning. Others made use of social stories in other contexts, and felt that this approach might work well in terms of supporting children to understand the nuances of social context. Learning through play and toys was also mentioned for younger children or those with a developmental delay. Overall, it appeared that parents would welcome having access to a wide range of resources that could prompt conversations or understanding.

Other parents recalled safety campaigns from their own childhood and recommended similar activities:

I don't know if anyone remembers the information adverts you used to get on telly, crossing the road and Stranger Danger, we don't get half of them now. I think they were really good because I still remember, from being a kid – Charlie and the cat. They were done in such a way that I thought, I'm not going off with a stranger. It was still aimed at kids.

For some parents they also felt that what was needed was somewhere where they could go for advice on discussing these issues. A couple of parents, however, wanted assurances that this place would be a safe environment to ask questions and where they would not need to fear reprisals.

I think, if parents are concerned about sexual abuse, any type of abuse...I think parents won't go and seek support from professionals because they are terrified of safeguarding and they are terrified of children being removed. And I think that is the biggest barrier that we will always have.

Others felt parents should be given more knowledge of the signs of abuse and what to look out for as this was also a gap in their knowledge.

Given the spectrum of needs and abilities of the children represented within the 30 families interviewed, not surprisingly, there was a lot of discussion about how certain approaches or resources might not be accessible to individual children. It was clear that there was not a "one size fits all" solution.

Parents wanted their children to learn how to keep safe but also stated very clearly that they also do not want to frighten their children. They were concerned about graphic images being used in education. They felt that messages had to be clear and not complicated. Parents suggested that what was required was a step by step process focusing on concepts of private space, puberty. The process would then increase in complexity, where possible, concerning healthy friendships and relationships, sex and then sexual abuse but tailored to their child's age and/or developmental level.

I just think if you tackle it from all angles. Knowledge is power isn't it. You are putting it out there.

I would like it from all angles. I would like school to initiate and then we would carry it on at home I would even like something online, because they like to think about things so they lodge in. Just the little game thing, or the app. I'd like them to think about it.

5 PECS (Picture Exchange Communication System) allows people with little or no verbal communication to communicate using pictures. People using PECS are taught to approach another person and give them a picture of a desired item in exchange for that item. By doing so, the person is able to initiate communication.

3.3.3 Partnership with schools and other service providers to create more protective factors around the child

Parents highlighted the importance of quality sex and relationship education in schools. However, in their experience the quality of such education varied. It was not always clear to parents whether their child had received this information, or whether this education had been made accessible so their child could understand it. Many parents felt it most probably focused on biology and sexual reproduction rather than understanding important areas such as consent, healthy relationships and abuse.

I would say particularly for our kids, the social and emotional wellbeing is a far more important subject than coming away with something in maths. How to protect yourself...

Rather than forgetting because they need a lot of repeating again and again, telling them the same thing. Like with pictures, they might learn better.

One parent raised the point that in her son's school the teachers were not trained and felt out of their depth in teaching about sex and relationships. It was noted however, that they were trying to remedy this:

[Name's] school are putting into place because he is also asking his teachers a lot of questions about sex, they don't know what to do with that because a lot of their children are non-verbal so they've not really come across it so they are like oh we don't know what to do....you just need to give him some sex education, he's thirteen!

Some parents discussed how when some schools taught sex and relationship education this presented a good opportunity for parents to be more involved in and aware of what these lessons contained. Some parents wanted to be able to follow up on these lessons to ensure their child understood what was being taught, or be prepared for the inevitable questions that their children would ask. Some parents were especially concerned to raise the issue that in some cases their children could verbally repeat what they had been taught but may not understand it or be able to put what they had learnt into practice.

In terms of us having stuff, I mean like when they do sex education, you know in early years they are going to do teeth cleaning- a pamphlet will come round with a little toothbrush and prompting and things. Is there any difference? That we will be covering these bits and we have these websites that you can have a look at.

They planted the seed, he was asking questions, and that started it off. Rather than you going, right, sit down we are having this conversation. He is asking you.

The majority of parents wanted any education and prevention work to be a partnership between schools, parents and other practitioners in young people's lives. Other research has also called for such partnerships (Skarbek, 2009; Gougeon, 2009). As an example, the work of PACE (Parents Against Child Sexual Exploitation) in particular has focussed upon parents as partners in safeguarding children. Although the focus has not been upon disabled children, PACE (2016) have clearly argued that parents are crucial partners in tackling abuse. Shuker and Ackerly in a report written for PACE, focus upon the role of a Parent Liaison Officer (PLO) who offer flexible one-to-one support with parents to help develop safety plans. (2017).

Although there was mixed feeling amongst the parents about the new legal requirement for sex and relationship education, this was mainly concerned with whether the content of lessons were age and/or developmentally appropriate for their children. Conversations with parents about content and how this is being layered, and individualised to meet needs, appeared to be a useful way forward. Overall, there appeared to be consensus that parent group sessions in school settings or accessible settings might be helpful. As one parent stated, *it is a conversation.*

Even a parent group session you could do. Even when we were doing a group Makaton session, a lot of parents came in to learn, from school. They got taught it first to the teachers, then they taught us. Something on those lines, from the parents side. That is a possibility.

In one focus group, parents noted the role that school nurses or family support workers could/should have in this area. They had not however, experienced them undertaking this area of work with parents, or with their children.

Parents felt that professionals, and especially teachers, need to be better informed about the signs of abuse, should be more open to listening to the children and be able to pick up on changes in behaviour. This was linked to parents' concerns that when in education or in receipt of services, they were not there to protect their children; yet they wanted to be sure that they were safe in these environments.

The environment, where the children are going, the respite. It is mainly those people that I think you need to target and speak to and maybe address. They are the ones who are supposed to be looking after these children. They should be able to spot the signs.

People in education should be taught better. They should see the signs, a psychiatrist or psychologist come in once a year...and teach them what are the signs that a kid might be doing if they have been sexually abused.

4. Insights for practice and policy developments

Drawing on the views of the parents, albeit mainly mothers, and wider literature in the area of disabled child abuse, the following presents reflections for how practice and policy should be developed in order to better protect disabled children and young people, and support parents and others in their role as protectors and responders.

It is important to note that parents were able to very clearly articulate the concerns they have regarding keeping their children safe. Given the complexities of the issues, they found it more difficult to identify simple solutions or what might help. Helping children to make sense of how people treat each other, and to know what is abuse is a challenge. As is supporting them to understand their body as a private space over which they should have control.

Much discussion rested upon the complexities of ensuring disabled children and young people are given such information in ways that suit their learning and communication style. It was also suggested that there needs to be a focus upon providing a means to speak out or have people around them trained to spot the signs of abuse. Most of the parents recognised that their children have a right to have relationships and make choices about these vital areas of life. Alongside this they emphasised the need for their children to be helped to understand choices, safety and healthy relationships, sex and sexuality. They did, however, see it as a complex area to address. Such a viewpoint was not universal, as one father who took part in a focus group stated that he would not give his son this information as it would not be needed. This suggested that relationships would not be part of his son's life. This insight was in contrast to Ballan's study where it was noted that none of the families discussed their children in terms of '*potentially being engaged in normative social or romantic relationships and sexual behaviour*' (Ballan 2012:682).

The parents we interviewed were highly motivated in their actions to protect their children and cared very much about their child's safety and wellbeing. In addition, it is important to reiterate the need to balance the rights and needs of disabled children and young people to know about dangers, with important messaging about healthy relationships. This needs to be done without creating expectations that they are responsible for their own safety, abuse or for telling

us if they are being harmed. Research has highlighted the challenges all children face to speaking out about abuse (Cossar, 2013); disabled children and young people face additional barriers to being heard and seen (Taylor et al, 2015).

Not all parents will be as highly motivated to keep their children safe or have the abilities to undertake this role due to other demands, for example, if caring for several children and other family members. The role of professionals to prevent, identify and respond to the abuse of disabled children is critical given the increased vulnerabilities outlined above.

Similarly, in most cases there was recognition by this group of parents that in order to protect their children this meant empowering them with knowledge and information about: safe touch, indicating they felt unsafe, sex and relationships, privacy, consent and abuse. However, dominant discourses concerning disability and sexuality often deny disabled young people the right to this information, with it often being seen as something they will not require, nor want, nor be able to understand. When in many cases the issue is that it is not offered in the right form, based on the individual child's learning style, language and communication preferences, or carried out in ways that meet sensory and attention needs. In addition, disabled people are frequently infantilized, or seen as asexual. In a study by Rohleder they identified a tension between a human rights understanding of the need to provide sex education for people with learning disabilities, and one of wanting to control their sexual expression (2009).

Dominant discourses need to be challenged so that there is more awareness and understanding in the general population. Other parents may have different values and cultural contexts to this group of participants about sex and what they consider to be appropriate and safe – there may even be discord within families. This is important context as research has shown that this lack of knowledge in disabled children and young people creates and increases their vulnerability.

Many of the parents who took part in this research spoke of the battles families of disabled children face to receive support for all aspects of their child's education, health and care needs, or to access community activities for their children. They described

that this often left little time, energy or “headspace” to think beyond the immediate crisis and about some of the wider concerns or long-term needs they knew they had to address. This included topics such as reaching puberty or sex and relationships education. This is the wider context of the lives of many families of disabled children and is important to consider in the context of developing support or resources for parents and their children on this issue. Many parents in this study found it difficult to think about their own support needs in this area. They commonly defaulted to considering what their children needed, and what they could do with their children.

Parents were acutely aware of the increased risks to their child’s safety, but they often felt unsupported in knowing where or how to start communicating with their child about these issues. Some felt shame and embarrassment mainly because it still feels a taboo subject and was something that was not discussed in their own family growing up. Any support offered to parents needs to recognise and validate any feelings of embarrassment, uncertainty and shame, and indeed recognise that in some cases parents may have experienced abuse themselves, and may need support for unaddressed trauma, or may be retriggered.

It is also important to note that the parents spoke at length about the important role of schools in delivering good quality sex and relationship education. They advocated educators working with parents more closely to ensure accessible, individualised and consistent approaches. However, this does present difficulties for parents whose children are educated in schools a long distance from their homes and thus would require good regular communication. It is also important to note that many disabled children and children with special education needs are not in educational settings. Ofsted has highlighted the significant numbers of children with special educational needs out of education or being off-rolled (2018). Suggesting that these children may miss out on important sex and relationship education and not have access to pastoral support and professionals who can support them. It can also increase their vulnerability to being exploited and abused. This raises questions about the need for critically appraising reasons why this group of children are

disproportionately excluded. Furthermore, it questions whether some aspects of what is deemed “challenging behaviour” are forms of communication from children who are scared, seeking support and in some cases might be experiencing bullying, abuse or exploitation.

Parents in the study tried to protect their disabled children in multiple ways, which they felt could often compromise their freedom, and was not a strategy that would support their children as they grew into adulthood and needed independence. However, in the short-term parents felt this was justified or the only course of action available to them. This has important implications as this can create social isolation for disabled children, and creates a false sense of safety. This also indicates the vital role of support, and sex and relationships and safety education planning, for adulthood and independent living in the lives of disabled young people and must be given a high priority in transition planning. The evidence highlighted in the introduction shows that the vulnerability of disabled people does not stop after the age of 18 or 25 years which are often the current cut off points of support.

Parents in this study, in the main, wanted to be able to give their children all the information they could to make them safe. However, the task could feel overwhelming as it was felt to be such complex information with little resources and support to meet the spectrum of needs, abilities and learning styles of their children. Any resources or plans for support which are to be developed need to break down the stages, starting with simple messages such as safe and unsafe touch, giving children a voice and choice, before moving on to more complex messages for those children who will be able to understand as they grow up and develop their maturity. Parents saw protection as being reliant on good quality sex and relationship education which most thought that schools would deliver. However, there is no evidence to suggest that there is a consistent approach to this across schools. Even within this small group of parents there was inconsistency in whether this was delivered within the schools their children attended.

Changes in the law concerning the delivery of sex and relationship education may help to ensure more schools deliver this form of education. However, the quality of this and whether the lessons are made

accessible to disabled children remains questionable. One or two lessons per year will not meet the needs for some disabled children and young people who may need repeated messages, contextualised information and help to keep working through meaning.

Although not all disabled children and children with special educational needs will have an Education, Health and Care Plan (EHCPs), these could be seen as a mechanism to ensure that children receive this information and support. If this is included specifically within their plan and seen as a measurable outcome of support (RIP:STARS, 2018).

While schools will have a duty to teach sex and relationship education, the parents in this study also saw that they themselves, and other professionals supporting their child, also had responsibility for this education. They called for a partnership with education including increased dialogue so they could mirror messaging at home, and the sharing of skills and knowledge. The parents also called for the development of multiple format resources to support them in communicating with their child.

They also felt it was important for their children to have access to communication methods which grow with the child's changing needs, and can support them to indicate if they feel unsafe. And for those who are supporting their child, to understand their child's communication so that the child has safety

mechanisms around them, and people who they could indicate to that they felt unsafe.

Parents also felt that the opportunity to talk openly about these issues in a safe environment would be useful, bearing in mind the need for sensitivity and wider support mechanisms being available if required. However, it should be noted that in the main the sample were female carers, and thus the perceptions, understanding, views and needs of fathers/male caregivers should be further explored. The fathers in this study found the topic area particularly challenging.

Parents also wanted the protection of disabled children and young people to be given a higher priority. The parents wanted to feel confident that those working with and supporting their child were safe. The parents raised a number of incidences where practice had been poor. They called for better training for professionals regarding identifying the signs of abuse and improved responses. This included the need for a contextual safeguarding approach as they had particular concerns about disabled young people and their families being targeted by gangs in the area. Some parents also questioned why the police, social media companies and other agencies were not doing more to tackle the perpetrators of abuse of disabled children. They highlighted how parents can only do so much.

Similarly, the parents identified a need for improved understanding regarding what might be deemed inappropriate behaviour of their child when quite often this was part of “normal” learning and experimenting and part of their child’s need to learn and have clear messages about where and when, for example it is appropriate to touch their genitals. This frightened a number of parents who were concerned that their child, or the family would get into trouble. Thus they called for a proportionate response and thorough investigation and understanding of the context to avoid situations escalating too quickly. This again stresses the need for education and other agencies to work in partnership with families to ensure that communication and messages to children are consistent and clear to aid their understanding.

In conclusion, ten actions for change were identified by the parents:

1. Improved understanding and awareness of the need for sex and relationship education for all disabled children and young people, and the need to break the taboo surrounding the sexuality and abuse of disabled people.
2. All schools should deliver accessible sex and relationship education for disabled pupils which develops appropriately with the children’s age and understanding. Access to this education should be included in children’s Education, Health and Care Plans (EHCPs) and monitored as a measurable outcome.
3. Schools and multi-agencies should work in partnership with parents to ensure that disabled children receive consistent, clear, accessible information on safe touch, choice and control, puberty, sex, relationships and abuse, and knowing how to let others know when they feel unsafe.
4. All disabled children should have access to communication methods and communication tools which enable them to have a level of choice and control, and access to a number of people who understand their communication method as a safety mechanism. This should be included in all EHCPs.
5. For children’s support plans, including EHCPs to be holistic and to address social and emotional needs including relationships, choices, sexuality and healthy relationships. And for disabled children to be helped to understand behaviour that hurts, that they have a right to be safe and have help to learn about who and how to let know if they do not feel safe.
6. Transition planning and preparing for adulthood should include sex, relationship and safety education as it earliest stages and to be a monitored outcome.
7. The development of more accessible resources in multiple formats, which address all elements to support disabled childrens’ safety. Resources should be developed for children, their parents and professionals.
8. Parents to have opportunities to discuss these issues and share ideas in a safe and sensitive environment via workshops or support groups.
9. Better understanding, training and a consistent, balanced approach to avoid what is deemed “inappropriate behavior” by disabled children leading to unnecessary criminalization or inappropriate investigation.
10. Improved training for professionals to spot the signs of abuse of disabled children and prioritise the prevention and protection of disabled children and their families in service settings, and within the community where they are particularly vulnerable to targeting by gangs, and all forms of criminal exploitation.

Although this study has importantly filled a gap in our understanding of the views of parents of disabled children about sexual abuse, as noted above there are limitations to the sample. It is thus important to continue to seek the views of parents as they are underrepresented in research. Future studies should seek a wider understanding of the views of fathers, parents from black and minority ethnic groups and of disabled parents whom we have not been able to reach in this small-scale study. It is also important that we seek the views of disabled children and young people, as well as disabled survivors on what support they think would be helpful.

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Appendix A

Literature review

To understand any existing research in this area we conducted a rapid review of evidence across academic and grey (non-peer reviewed) literature. Professionals and academics within our network were also approached to ensure new or recently published literature was not missed. The search criteria included the following key words and all variations (e.g. for children, young people, adolescents etc. were also used): children, sex abuse, parents and prevention. To ensure we found literature that mentioned prevention, but might not be the sole focus, we also included key words such as safety, intervention and advice within searches. To supplement this initial search, and in light of the multiple research questions, we also searched for literature examining sex and relationship education for disabled children with a specific emphasis upon parental views.

The purpose of the review was not to provide a systematic review of the literature; and this would not have been possible given the divergent nature of the research questions and short timescale, but to provide a background and to demonstrate the lack of research focus in this area.

Although the research questions proposed by NSPCC were wide-ranging, the search initially focussed upon any literature pertaining to helping parents to prevent child sex abuse, specifically in terms of the views of the parents themselves. The literature exploring the key issue (Parent's/Carers views on how we can work together to prevent the sexual abuse of disabled children) is limited. Parents' views and opinions are rarely heard, and when they are it is often post-abuse or with little valid parental input. The first search resulted in the following literature which we have grouped into thematic areas for ease of reading:

- Models of prevention (without parental input)- Skarbek et al (2009)
- Models of prevention (focusing upon professionals)- Philander (2006)
- Risk factors for abuse- Murphy (2011)
- The importance of sex education, parental views- Stein et al (2018)
- The importance of sex education, professional views- Tutar Guven and Isler (2015)
- Post-abuse support- PACE (2015), Scott and McNeish (2017)

- The role of parents alongside professionals in preventing abuse- PACE (2016), Palmer and Jenkins (2014), Shuker and Ackerley (2017)
- Professional and parental experiences- YouGov (2013).

The additional search specifically exploring sex and relationship education resulted in a number of additional areas of interest that relate in part to sexual abuse, albeit through a discussion of the wider context of knowledge and understanding of sexuality and disability. The focus of this literature has predominantly been upon sexual health and prevention of STI's, illustrating a medicalisation of sexuality in disabled young people's lives

- Parental communication about sexuality- Ballan (2012)
- Sexuality of disabled persons- Brown and Pirtle (2008)
- Parental roles (mothers)- Rogers (2010)
- Sexual health- Rohleder (2009)
- Critique of sex education- (Gougeon 2009).

Rather than offering a summary of the literature here, it is more useful for this report to incorporate previous research alongside the views of the parents from the current study.

Parent/Carer Interviews:

Given the sensitive nature of the research questions, time was spent at the beginning of the research developing an ethical framework to ensure that parents were supported pre, during and post interview. This involved scoping support groups (locally and nationally), any resources (in hard copy and/or via the web) and websites which we could direct parents to should they require it. Ethical approval was sought and granted by Coventry University and NSPCC's Research Ethics Committees.

Time was spent ensuring the interview questions were accessible, the process was comfortable and that it supported parents. Advice on the research questions and approach was sought from a group of six parents recruited via a special school who volunteered to be advisors to the project.

Parents were given a choice of taking part face-to-face or via the telephone, and whether they wished to be interviewed alone, with someone else present

or in a group setting. Interviews were arranged at a time that was convenient for the parent. As a thank you for their time, parents were given a £10 gift voucher. All parents gave permission to audio record their interview/group discussion and these were fully transcribed. Data was analysed thematically.

Recruitment of parents/carers:

Recruitment of parents was undertaken via a number of avenues: special schools in the area, a parent/carer forum, short break services and via the local authority foster care and children with disability teams. Each service was asked to approach parents/carers of disabled children and children with special educational needs. An information sheet and consent form, which had been designed in partnership with the six parent advisors to the research, was circulated offering parents an opportunity to contact the researchers prior to making a decision to take part. Parents either gave permission to the service/school for the team to contact them, or contacted the team directly.

Sample of parents:

A total of 30 parent/carers took part in the study. In order to protect the identity of participants and their children, the demographics of the sample have been aggregated and are illustrated below. It should be noted that a significant number of parents were concerned about being identifiable in the report, especially given the small sample. The limited fieldwork in this area and the rare nature of the children’s impairments could potentially be used to identify parents. Therefore, there is a significant amount of missing demographic data.

This research was a qualitative study in a specified geographical area and was not designed to be representative. However, limitations of the sample should be noted. Despite attempting to recruit via a wide range of avenues, there is a lack of diversity in the sample, especially in terms of fathers/male carers views. A longer time scale would have been needed to undertake outreach work to reach fathers. The lack of engagement with fathers is possibly reflective of services predominantly working with, or being accessed by, mothers/females as the main care giver. Although reflective of the ethnicity of the area in which the research took place, the sample also does not adequately reflect the views of parents from black and minority ethnic groups, or those whose first language may not be English. In addition, there is a gap in terms of seeking the views of parents who face specific barriers to receiving support. Parents who have learning disabilities, who are Deaf or visually impaired, or who have communication needs are not well represented. Their views on the nature of the support they might need in this area would be welcome in future research.

Eight (8) parents took part in individual interviews, of which three (3) were face-to-face and five (5) were via telephone. There were no differences in the questions or format/structure of the interviews whether they were in-person or on the telephone. The remainder of the sample took part in three focus groups (6 participants, 7 participants, and 9 participants). The questions and overall schedule remained the same for the focus groups and the individual interviews.

Interviews were roughly one hour in length, and focus groups on average were 90 minutes.

Table One: Sample of Parents/Carers

Parental role	24 mothers, 3 fathers, 3 foster carers (female)
Ethnicity of parent	2 British South-Asian, 27 British White, 1 Other.
Numbers of disabled children and young people within families	Ranged from 1-4 disabled children in a family
Ages of children and young people	Range from 4 – 21 years
Gender of children	Male (66%) Female (33%)
Type of disability/special educational need of the child (as defined by the parent)	Special Education Needs, Complex Communication Needs, Autism, Learning disability, Learning Difficulties, Dyspraxia, Developmental Delay, Downs Syndrome, Physical Disabilities, Hypermobility, Cerebral Palsy.
Type of educational setting	Special (70%) Mainstream (30%)

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