



Improving the Life Chances of Disabled People Analytical Report

The Children's Society Submission

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1. Introduction

- 1.1** The Children's Society is pleased to be able to respond to the analytical report on Improving the Life Chances of Disabled People. As a national children's organisation The Children's Society is committed to promoting the rights and welfare of all children and young people. We believe that children and young people have a fundamental right to protection from harm and abuse and to be able to express their views, wishes and feelings freely as enshrined in the UN Convention on the Rights of the Child.
- 1.2** This response has been informed by a wide range of direct practice with children and young people including a national programme of work focussed on ensuring the rights of disabled children and young people are upheld and their voices are heard in decisions that affect them.
- 1.3** We have chosen in our response to focus on those issues that are most pertinent to children and young people. We note that the overall aim of the project relates to identifying and proposing policies that will remove barriers and improve outcomes for disabled people. We feel it would be helpful to make it explicit throughout that this includes both disabled children and adults.

2. Definition of the Problem

- 2.1** The Children's Society welcomes the focus on the understanding of terms and on the definitions of disability [pages 12 and 13]. We have recently drawn attention to the very significant difficulties for disabled children and young people caused by the lack of commonly accepted definitions across professional and agency boundaries and government departments. These are outlined in a paper that we forwarded to you earlier, for convenience this is attached again. The paper proposes an amendment to the Children Bill currently before parliament which would update the current definition of disability within section 17 of The Children Act 1989 to make it consistent with the definition of disability contained in the Disability Discrimination Act 1995. This would have the effect of ensuring consistency across legislation and would address some of the current difficulties in working together across services to ensure that disabled children's needs are met. This proposal is further reinforced by the recent decision in the Department for Education and Skills to adopt a new estimate of the number of disabled children. The new figure of 700,000, based on returns from the Family Resources Survey, more accurately reflects the size of the child population covered by the provisions of the Disability Discrimination Act .
- 2.2** We strongly support the emphasis given to the barriers faced by disabled children and young people living in institutional settings . Evidence from our practice concurs with the point made that this group have "least voice and choice" [Page 17]. The following short case

study from The Children's Society's Disability Advocacy project summaries the isolation and lack of voice and choice that this most vulnerable group of children and young people often face. It also demonstrates the crucial role that advocacy can play in ensuring that the voice of children placed in institutional settings a long way from home, is heard and taken seriously .

Case Study from The Children's Society London Disability Advocacy Project

I have been working with Jane, who is thirteen for just over a year. As with many of the young people that use our service it took a considerable amount of time to not only to get to know Jane, but to find ways to communicate with her on her level, and effectively explain what an advocate is. On this occasion it included pictures and symbols.

My job was not only to explain to Jane's residential School (where she spends 38 weeks a year) but also to her family what it is Jane may need or want. This includes attending reviews and making sure that everything is done in Jane's best interests.

After several months it became clear that her School was not attempting to teach Jane any form of effective communication, in the ignorant view that Jane was non-verbal and may not have the capacity to learn signing, and how to recognise and exchange symbols for and when she needs something. I spent many weeks convincing the School the benefits of spending time working with Jane to teach her how to recognise and share signs, which they finally agreed to include in her educational plan. Jane now recognises and uses several signs and symbols which has allowed her to communicate effectively in two-way communication with other pupils, staff and family.

2.3 We welcome the importance given in the report to the impact of negative attitudes and discrimination on the lives of disabled people [pages 20 & 21]. In The Children's Society's award winning Ask Us Cd Roms [The Children's Society,2003 & 2004] disabled children and young people speak openly about the impact of bullying and negative attitudes on their lives. Quotes include:
"It's not safe walking home, we get followed, chased and called names I think it's cos we're different"
"When I'm in college some people pick on me and swear at me and push me around"
"I got bullied quite a lot, I didn't like it, I walked out "
The impact of bullying and negative attitudes particularly on the educational attainment of disabled children and young people should not be underestimated. The Children's Society is now developing a new phase of it's successful "No Blame" anti-bullying work focussing particular attention on strategies for whole school communities to tackle the bullying of disabled children and young people.

2.4 We know that children learn about differences from an early age. For example they can see and note, often unconsciously, differences in skin colour , hair texture, physical features or size and agility [Children and Race, Milner, 1983]. Children begin to form values and responses to

these differences by observing other people's behaviour as well as through images presented to them. Children learn quickly about the way inequalities are embedded in our society and this can affect their attitude to those who are different from them. Children therefore need to be consciously presented with positive attitudes and messages about differences, in this way all children will feel equally valued. The Children's Society would like to see disability awareness become a core component of the curriculum within schools and early years settings and central to all out of school activity to help build understanding for all children and adults

- 2.5** As noted in 1 above we agree that the lack of agreement across agencies about definitions of disability continue to hinder joint planning and commissioning processes [page 25]. We believe this problem will be exacerbated as the new information sharing processes proposed in the Children Bill are implemented.
- 2.6** We particularly welcome the proposal that service providers should be held to account by disabled people and the recognition on page 194 that user involvement should not become another tick box exercise. Over the last five years The Children's Society has pioneered a wide range of participation work with disabled children and young people, demonstrating that it is possible to include children with the most profound impairments, in consultation and participation activity. The Ask Us Cd Roms are just one example of this work. Disabled children and young people speak out about their lives and their views on the services they receive. Many of the young people involved in the initiative have said they have got a lot of personal satisfaction from being involved but they also stress :
- "not enough has changed"*
"we want to see real change at a local level"
"you have listened to us, you have involved us but now it's time to change"

3. A Vision for the Future

- 3.1** The Children's Society wholeheartedly supports the three components of the proposed vision for disabled people. As indicated earlier it would be helpful to clarify that this relates to both disabled children and adults.
- 3.2** We welcome the focus on removing barriers to inclusion and the completion of the legislative programme on disability policy. We urge that significant attention is given to issues of local autonomy and compliance with national strategy. In our experience despite successive national policy initiatives, and a raft of legislation, regulation and guidance the critical issue continues to be huge gaps and considerable variation in implementation at a local level. In our view these differences cannot be explained simply on the basis of responding to local needs. There is undoubtedly a postcode lottery of service

provision for disabled children and young people.

3.3 We agree that it is critical that disabled children and young people are aware of their rights. In our experience many are not. A young man makes this point very effectively on the Ask Us Cd Rom :
“the most important right we have is to have our rights explained to us”

3.4 We are very encouraged by the set of principles outlined on page 44 and feel they are all important. From the perspective of children and young people we note the particular significance of communication aids being allocated to the child and not the establishment. We would like to see included in the principle on “voice to influence design and delivery” , specific reference being made to children, including very young children and those with communication impairments.

3.5 We feel the focus on choice in the principles as essential. Perhaps the most common theme emerging from the Ask Us Initiative was the issue of choice . Young people told us again and again:

“Ask me what I want”

“I need help to understand what the choices really mean”

“Some people take it for granted that you can’t do anything, that you can’t have a say, that you can’t decide, but really you can “

“We can do it for ourselves, we aren’t babies”

We are also pleased that the important role of peer advice and advocacy in enabling disabled children and young people to have a voice and make informed choices is recognised. We note that the results of a recent survey undertaken by The Children’s Society and CROA [Children’s Rights Officers and Advocates] indicate that disabled children have very little access to advocacy services. On average only 15% of all disabled children who are looked after accessed an advocacy service in the last twelve months and only 5% of all disabled children in need received an advocacy service in the same period.[The Children’s Society unpublished report 2004]

3.6 We would like to see the issue of safety referred to within the principles outlined on page 44. The view that disabled children are more vulnerable to abuse than other children is widely held. Both the “Working Together to Safeguard Children” Guidance [DoH, 2001] and the report “It doesn’t happen to disabled children” [NSPCC, 2003] note that disabled children are at increased risk of abuse for the following reasons:

- Have fewer outside contacts than other children.
- Receive intimate care, possibly from a number of carers, which may both increase the risk of exposure to abusive behaviour, and make it more difficult to set and maintain physical boundaries.
- Have an impaired capacity to resist or avoid abuse.

- Have communication impairments which may make it difficult to tell others what is happening.
- Be inhibited about complaining because of a fear of losing services.
- Be especially vulnerable to bullying and intimidation.

4. Early Years

4.1 This section of the report provides a very comprehensive analysis of the situation facing disabled children in their early years. There are just two points we wish to make to add to the analysis.

4.2 The Children's Society takes the view that all children and young people should be educated in a single mainstream education system which can support all children to learn, play and live together. We do not therefore agree with the perspective that "special schools are appropriate for some disabled children" [page 71 of the report]. We are clear that a range of things are needed in order to achieve the full participation of disabled children including those with sensory disabilities , in a mainstream education system . These include:

- the specialised training of teachers and other educational staff
- an accessible curriculum
- accessible teaching medium and materials
- appropriate devices such as alternative and augmentative communication means
- accessible educational establishments.

Although relatively new, there are now examples of mainstream schools which have embraced such accommodations and in which all pupils get the best of both worlds. These include adaptations for individual children in their local school and resourced mainstream provisions for groups of children within their locality. The result is of benefit to the whole community and in time will contribute to a shift in the general perception of impairment and disability within society as young people grow up together learning about one another.

4.3 We would suggest adding an additional key issue and challenge to address in the summary on page 77 of the report :

How can we ensure the voices of disabled children are heard , in the decisions which affect their lives?

We know that disabled children make an enormous commitment to communicate. In The Children's Society we feel the life chances of disabled children will be greatly enhanced when everyone around them have the skills, time and knowledge to understand them.

This issue is crucial in the early years and equally relevant to other ages ,transitions during childhood and adulthood. Listening is important for all children but particularly important for disabled children. For example disabled children:

- are subject to a much higher degree of adult intervention and their scope for making day to day choices and decisions is often severely limited
- have many things done to and for them and they are significantly more vulnerable to abuse than non disabled children [NSPCC, *“It doesn’t happen to disabled children” 2003*]
- are more likely to be subject to a number of medical interventions, treatments and assessment procedures and less likely to be involved in the process
- are more likely to be excluded from consultation process because they are so often based on written and spoken language
- are more likely to have contact with multiple carers who do not all have the skills to understand the child’s communication system
- are less likely to be able to access advocacy services

Taking disabled children and their views seriously and listening to what they have to communicate is an empowering process that can help to ensure their sense of belonging and membership of a group as well as enabling them to achieve their full potential as individuals. Disabled children through the Ask Us Initiative have emphasised that it is crucial to start making choices from an early age:

“You need to be given the chance to make choices at a young age. How can we be expected to make choices if we haven’t been given the opportunity before?”

5 From Childhood to Adulthood

5.1 This section of the report provides a very comprehensive analysis of the situation facing disabled young people facing the transition to adulthood . The points made reflect much of what we have learnt from our practice and what disabled young people have told us about the reality of their everyday lives. We would like to emphasise the importance of the following issues.

5.2 We agree that there are additional hurdles at transition faced by disabled young people living in out of county placements. There remains for some young people living away from home a confused legal status. The JRF study *“Disabled Children at Residential School” [JRF Findings, April 2000]* found that even where young people are viewed as looked after or accommodated under the Children Act 1989 it is unlikely that local authorities are fulfilling their legal responsibilities. Similarly there is evidence that health authorities are not complying with The Children Act 1989 Sections 85 & 86 requirement to notify Local Authorities of any child living in health care accommodation for three months or more [*Stalker K. Children with Complex Support Needs in Healthcare Settings for Prolonged Periods 2003*].

5.3 Morris in [*Still Missing , 1998*] suggests the most marginalised of

disabled children are those placed away from home who have complex needs and communication impairments. Morris found that many did not have access to a communication system that met their needs; did not have routine access to people who understood the ways they communicated and did not have access to independent facilitators. Advocacy practitioners within The Children's Society have noted that out of county placements are particularly isolating for young black and asian people who are often sent to rural areas with little ethnic mix and where placements may not cater for their religious and cultural needs. In our experience during the transition period many young people are in principle allocated an adult services worker who visits them as little as once a year. They are often sent to new placements with no choice and little involvement in the decision making process and parents receive only one travel allowance a year for visits.

- 5.4** For the few disabled young people who do have access to an independent advocate this service can be withdrawn when the young person turns eighteen as responsibility transfers to adult services. We agree that advocacy and involvement needs to start from a young age so that young people are used to making decisions [see 4.3 above]. The Children's Society would like to see a statutory right to advocacy in all decision making forums for both disabled children, young people and adults, jointly commissioned and with funding flexibilities during the transition to adult services. Without such support children and young people will continue to miss out on having any voice in decision making processes.
- 5.5** The Children's Society was delighted to see the extension of direct payments to 16 and 17 year olds. We recognise that there are a range of challenges in ensuring that direct payments are a real option for this age group. As well as the issues raised on page 95 and 195 of the report we would add the lack of young person friendly services available in the market place for young people to purchase and payment levels which in effect restrict what can be purchased. We agree that peer support and advocacy provision is essential to ensure disabled young people can maximise the potential opportunities that direct payments offer.