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Friendship opportunities for disabled children and young people

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1. Introduction

This briefing paper has been produced to support the *BBC Children in Need* funded *Friendships for All* project undertaken by The Children's Society. This project aimed to:

- Identify what **barriers** foster and short break carers, and service providers, face in helping disabled young people in their care to make and keep friends.
- Identify **solutions** that service providers and carers can implement to increase friendship opportunities for disabled young people.
- Identify and **create evidence based resources and a training package** to raise awareness of the issue and provide practical support to practitioners and carers.

Full details of the project and all of the resources are available to download freely from www.friendshipforall.org.uk.

Specifically, this briefing paper aims to bring together the existing research evidence available on disabled children and young people and their friendships. The evidence presented was gathered through searches of academic literature and the websites of voluntary and other agencies. It draws heavily on the previous *BBC Children in Need* funded focused literature review undertaken by University of Birmingham (2008)¹, and updates their findings. The search replicated the methodology used within the Birmingham review and utilised a number of academic search engines such as EBSCO, SCOPUS and Google Scholar. The following search terms were used:

Child*/Young pe*/adolescents/youth **and** disab*/impairment/learning difficulties/autis*/communication needs/non-verbal **and** friend*/isolation/social*/leisure/fun/play*/peers/relationships.

The following inclusion criteria were applied:

Inclusion Criteria:

- Studies published in the English language
- Studies based in the UK/and or abroad
- Studies conducted with potentially excluded groups: black and minority ethnic groups (BAME).
- Studies published from the 1st January 2007 onwards.
- Studies reporting on the experiences of social activities designed to increase fun and friendships for disabled children between the ages of 5 and 12, and for young people aged 13-18 inclusive.
- Studies reporting on any leisure-based activity for disabled children and young adults.

¹ Mason, P., Loveless, L., Lewis A., Morris, K. and Clarke, H. (2008) Opportunities for fun and friendship for disabled children and young people: A focused review of the literature. BBC Children in Need. London. <http://www.bbc.co.uk/programmes/articles/1cwPCqz3M2wdFw6NJKQkwG/fun-and-friendship>. Accessed 10.1.16.

The purpose of updating the existing literature review was to examine whether new evidence had emerged to assist in the understanding of:

- what works in building friendships and creating socialising opportunities for disabled children and young people
- what barriers do disabled children and young people face in developing and sustaining friendships.
- what gaps still exist in our research evidence base.

Overall, the searches identified a severe lack of research about disabled children's friendships or relationships with their peers and the research that does exist is more likely to have been carried out from a developmental psychological perspective rather than from a sociological/policy or childhood studies perspective. No studies were identified which examined the friendship opportunities for disabled children and young people in care (residential or foster care) or in terms of short break provision. It is also important to note that the subject of friendship emerges as part of larger studies on, for example, inclusive play, inclusion at school, in out-of-school services and in transition from children's to adult services. These studies would not have necessarily been identified in this literature review, but the inclusion of friendships in them indicates the importance of this aspect of disabled children and young people's lives.

2. Policy Context

Under the previous Labour government the social inclusion of disabled children and young people was seen as a priority with the publication of a number of policy documents and funded initiatives aimed at reducing the social exclusion of disabled children (see for example, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (DH, 2001); *Improving the Life Chances of Disabled People* (Strategy Unit, 2005) and *Aiming High for Disabled Children* (DfES, 2007).

Despite social inclusion not being given such a high prominence in current policy, the recent SEND reforms (Special Educational Needs and Disability) contained within The Children and Families Act (2014) could be a vehicle to raise inclusion and friendship higher on the agenda. In particular the emphasis on a single Education Health and Care Plan (EHCP) for disabled children with special educational needs which should involve disabled children and young people in decisions about their own care could facilitate ways of ensuring that this issue of importance to disabled children and young people is addressed. Local authorities are required to develop 'local offers', which set out what services disabled children in a particular geographical area would be entitled to and children, young people and parents must be consulted in the development of the local offer. Disabled children and young people also have the right to request a personal budget which would include elements of their education, health and social care under this new legislation. This additional degree of control for children and young people may give further opportunity to consider friendships including in the planning of services such as short breaks.

The Government also has obligations under the United Nations Convention on the Rights of the Child (UNCRC, 1989) and the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD, 2006) to ensure the inclusion of disabled children and young people within society. Specifically, Article 23 of the UNCRC refers to governments' responsibilities to "*facilitate active participation in the community*". For disabled children and young people inclusion and participation is dependent, at least in part, on their social interactions and friendships.

3. Importance of friendship

Friendships are an important part of most of our lives and the evidence indicates that having friends matters considerably to children and young people. Numerous studies have shown how children and young people identify friends as one of the most important aspects of their lives contributing to their happiness, health and well-being (e.g. Aggleton et al, 1998; Layard and Dunn, 2009; Helseth and Misvaer, 2010). Increasing evidence also illustrates that having friendships as children impacts on adult emotional and mental health (see for example, Dunn, 2004). This is no different for disabled children and young people including those children with impairments affecting social interaction such as autistic spectrum condition or communication (Bauminger and Kasari, 2000; Wickenden, 2011). Studies show that disabled children enjoy out-of-school activities and enjoy the social aspects of school as they provide opportunities for seeing friends (e.g Petrie et al, 2000; Knight et al, 2009, Beresford et al, 2010). Similarly studies examining what disabled children consider to be quality in services indicated that disabled young people highly rate services which respect their friendships and seek to protect and nurture them (Mitchell and Sloper, 2001).

Not surprisingly, disabled children and young people highlight the importance of friendships in their lives, and research provides evidence of how friendship are central to our identity, sense of belonging, understanding of relationships, enjoyment and well-being. Opportunities to make friends and manage the difficulties of friendships is part of growing up and leads to increasing independence, strengthening our abilities to negotiate, make choices and exercise control in one's own life. A consistent message from research is that creating accessible environments where children and young people can develop friendships and meet friends is a priority for disabled children and young people especially outside school (Mason et al, 2008).

4. Lack of friends and the implications for disabled children

Despite the desire for disabled children and young people to make and have friends, and experience the same social opportunities that their non-disabled peers have, research has shown that many disabled children and young people lack friends, and as a result often feel lonely and isolated (e.g.: Cavet, 1998; Murray, 2002). Although research in this area is limited and somewhat dated, it can be seen that disabled children and young people,

especially those with complex and/or communication needs tend to have a very restricted circle of friends (Smith, 2005). For example, Hirst and Baldwin (1994) found that disabled young people who participated in their study on growing up, were more likely to mix with younger children and those who were also disabled. The study also found that disabled young people wanted to see their friends more frequently, were less likely to have a close friend and found it difficult to develop and sustain more intimate, romantic relationships. A study from Greece of 154 children with mild intellectual disabilities attending special schools identified that more than half of the children reported feeling lonely and they attributed this loneliness to “interpersonal deficits”, lack of control with peers and/ or physical appearance. A fourth of them did not know why they did not have any friends. These children reported that they often withdraw from social interactions and engaged in solitary activities, although they do seek out friends and did not want to remain lonely. Some children reported that they resorted to physical or verbal aggression because they had no friends (Papoutsaki et al, 2013). Similarly, a longitudinal Norwegian study has also highlighted the difficulties children and young people with learning difficulties can face as they may find it difficult to understand the informal interaction rules and nuances that children negotiate and practice in friendships. This study identified that these challenges increased as the children got older and these children became increasingly segregated from friendship circles. The author illustrates how these children often ended up in stereotypical roles - the most withdrawn or worst behaved at school - and calls for “catalysts or translators” to help children negotiate friendships (Ytterhus, 2012). One Australian study highlighted how disabled children who were deemed disruptive in school are often physically separated from their peers by teachers with children reporting that this separation decreased their opportunities to interact with their peers and strengthen friendship opportunities (Morrison and Burgman, 2009). There are a number of Nordic studies published all of which highlight the marginalisation of disabled children and young people (See for example: Bjarnarson, 2005; Brunnberg, 2005; Soderstrom and Ytterhus, 2010 and Wasterfors, 2011). Other studies highlight how disabled children often changed schools in order to form friendship or because of negative experiences of friendship (Morrison and Burgman, 2009).

Professional Friends

Some studies have shown how many disabled young people, particularly those with high support needs are more likely to interact with adults than with their peer group and will, as a consequence, often name their carer as their friend (e.g. Morris, 1998, 2001). Many disabled children and young people have also benefitted from befriending or buddying schemes which match a young person with an adult, who often is non-disabled, to facilitate the young person’s inclusion in mainstream activities (Knight, 1998; Heslop, 2005; Knight et al, 2009). Whilst this can be very supportive, this type of service provides disabled young people with semi-professional friends and is not a genuine substitute for mutual friends and peers.

The research evidence highlights how many disabled children and young people, especially those with high support needs and/or those perceived as having learning disabilities may never be enabled to experience opportunities to engage spontaneously with their peers and develop friendships through choice – this group of children are also most likely to identify a family member as their best friend (Mason et al, 2008; Lewis et al, 2007; Murray, 2002). Murray highlights that children who use “facilitated communication” or express themselves through body/behaviour movements are unlikely to have access to communication support

outside of school and hence rely on family members to interpret for them, clearly impeding opportunities for peer-to-peer interaction and spontaneous engagement (2002).

Negative Attitudes and Bullying

Some studies have shown how some disabled young people are perceived to be “different” by their non-disabled peers, are more likely to be ostracised, to lack friends and to be bullied (Cavet, 1998; Connors and Stalker, 2000; Curtin and Clarke, 2005; Middleton, 1999, Lewis et al, 2007, Mason et al, 2008). Many of the children and young people who participated in a study carried out for the Disability Rights Commission reported that they had experienced negative attitudes and bullying towards them from other children at school (Lewis et al, 2007).

Another form of negative attitudes that some disabled children and young people have experienced, and that impacts on their opportunities to form and sustain real friendships, is that they may be viewed as objects of pity and/or charity. Woolley’s examination of the inclusion of disabled children in mainstream primary school playgrounds found examples of disabled children being “smothered” by their non-disabled peers (2006). A finding echoed by a study undertaken by Knight and Petrie (2008) which focused on the school experiences of children with spinal cord injury. Some of the young people in this study also found that their friends were very cautious and wary of them when they returned to school following their injury. The research points to the quality of friendships made in school being dependent on the ethos of the school regarding disability and inclusion. Mulderji highlighted the strategies used by disabled children when dealing with negativity which included sarcasm, humour, compensation, initiating, acceptance and creativity (1996). Others highlight how some disabled children become adept at minimising impairment in order to maintain friendships (Barnes et al, 2000; Woolley et al, 2006).

Social isolation and links to safeguarding disabled children and young people

Recent research which has examined safeguarding of D/deaf and disabled children and the sexual exploitation of young people with learning disabilities highlighted the link between social isolation and increased risk of abuse. Two recently published studies, both of which sought the views of disabled children and young people, provide illustration of how adult perpetrators of abuse used the child’s isolation to groom them - offering them friendship and companionship – and how in some instances these “relationships/friendships” were not questioned because the child had an impairment (Taylor et al, 2015; Franklin et al, 2015).

5. Barriers to creating friendships

Disabled children and young people face a range of barriers to accessing and developing friendships. These barriers can be at a societal, attitudinal or physical level. Mason et al summarise the barriers as:

- A reliance on school and a lack of out of school opportunities,
- A reliance on structured and targeted activity and a lack of provision for spontaneous fun with friends,
- Adult assumptions structuring activity without the involvement of children and young people,
- A reliance on family members for support coupled with a lack of family-focused provision to build upon the positive features of these relationships,
- A focus on short-term provision often segregated provision rather than mainstream inclusion (2008).

Practical Barriers to Friendship

Disabled children and young people face a number of practical barriers to making and maintaining friendships, mostly notably because of a lack of access to mainstream provision and the way in which they can often be isolated from the community. Lack of access to suitable transport is consistently identified as a barrier to inclusion and creating difficulties when trying to meet friends (Lewis et al, 2007; Mason et al, 2008). Studies indicate that a majority of disabled young people are unable to access appropriate transport independently which means a reliance on parents/carers for transport or remaining at home (Barnes et al, 2000). In addition, a lack of appropriate toilets and changing facilities, lack of availability of specialist equipment and provision of parking spaces, ramps and doors that are accessible for disabled children create barriers to inclusion. A lack of accessible information is also consistently identified as an inhibitor, especially information about accessible events, activities and facilities (Mason et al, 2008).

Although physical barriers and accessibility issues are identified more frequently in the evidence, research also indicates that inclusion is less about the physical and more about wider societal attitudes. There are rare examples of services addressing exclusionary attitudes and practices in local communities, despite legislation that is meant to prohibit discrimination (Mason et al, 2008).

Friendships at School

School plays a central role in all children's lives and provides most children with the opportunities to establish and maintain friendships and build friendship networks. However, for disabled children who may travel some distance from their home or community to school, seeing friends and sustaining friendships can be difficult without transport and resources (Barnes et al, 2006; Lewis et al, 2007; Sloper et al, 2007). Research from the US which explored friendships amongst a group of 16- 17 year olds with "developmental disabilities" illustrated that friendships that were dependent on school were less intimate, stable, of a lower reported quality and were less mature than the friendships of non-disabled young people who maintain and develop friendships outside school (Matheson et al, 2007).

Research with disabled young people shows that seeing friends during out-of-school periods, particularly during the school holidays, is often difficult as a result of the distance and the reliance on parents for transport (Cuckle and Wilson, 2002; Curtin and Clarke, 2005;

Mason et al, 2008; Knight et al, 2009). Petrie et al illustrate how disabled children's reported enjoyment of school holidays depended on whether they were able to see friends (2007).

Consequently, many disabled young people in these situations experience high levels of social isolation and social exclusion, and there is some evidence to suggest that this has detrimental effects on their social skills which can affect their friendships when back in school (Lewis et al, 2007). Access to summer play schemes or other holiday activities can be significant for disabled children but there is patchy provision and increasingly a lack of accessible provision (Mason et al, 2008).

In addition, there can be limited opportunities and barriers to making and keeping friends **within** school when disabled children spend a lot of time with adults. This can often mean little time for age appropriate interaction and behaviour or spontaneity and autonomy (Barnes et al, 2000; Wolley et al, 2006). These authors argue that the support systems put in place to support inclusion can often have the opposite effect and unintended consequences of isolating and separating disabled children from their peers. These studies illustrate how disabled children and young people can often be "thrown together" at break times or on school transport on the basis that they have, or share, an impairment rather than on the basis that they have common interests or are friends.

Disabled children's lack of choice and control

Choice and control for disabled children and their families is often restricted. Leisure opportunities can be reliant on a limited range of targeted and structured activities with little opportunity to engage in mainstream leisure provision or community activities (Mason et al, 2008). Lewis et al identify the dependency of some disabled children and young people with complex and/or high support needs on adult support and on leisure time spent in more structured environments, thus limiting opportunities for independent and spontaneous interaction with friends.. Barriers, such as lack of accessible transport, faced by disabled children to accessing community based informal activities were identified as restricting opportunities for disabled children to interact with their peers (2007).

Barnes et al highlighted some of the detrimental effects of specialist provision for disabled children in comparison to mainstream inclusive provision. This study found a lack of long term and sustained outcomes for disabled children using these services, partly because provision did not support disabled children to develop networks outside of school sites and/or in the community. In addition, because the impact on the children could only be seen when they were accessing the service (and many services only had short-term funding) there was a lack of sustained long-term change for disabled children. These authors identified that disabled children highly rated provision which enabled them to access mainstream provision and concluded that this approach would be more likely to achieve a sense of inclusion (2006). Similarly, Murray argued that choices limited to segregated provision can mean that disabled children have limited opportunities to engage, and develop friendships, with their non-disabled peers and conversely, non-disabled children have little opportunity to develop friendships with their disabled peers (2002).

Disabled young adults

The evidence suggests that there is particularly a lack of provision for older/ teenage disabled young people, especially mainstream activities and everyday opportunities to meet up with friends in the same way as non-disabled young people do (Mason et al, 2008). Disabled young people's wishes for autonomous experiences may conflict with their support needs, and their parents/carers desire to keep them safe and protected. Identified solutions which can overcome some of these barriers include improved and accessible transport, money, personal assistance, communication support and support to help facilitate friendships and relationships (Murray, 2002; Buttimer and Tierney, 2005).

Transition to adulthood

Research has highlighted how disabled young people's transition to adulthood can be a time of vulnerability to isolation (Clarke et al, 2011; Sloper et al, 2010). Morris argued that it is still the case that many disabled young people have little or no experience of an independent social life and thus have few opportunities to make friends (2002). For many disabled young people their time is spent with a paid adult carer or family member and they have little opportunity to access independent travel. Leaving school or moving from one residential setting to another can often mean loss of friendships and disabled young people with high levels of support may be moved into residential care where they have little or no contact with people of their own age (Morris, 2002; Mason et al, 2008).

6. Supporting access to friendship opportunities

There is very little evidence that addresses how access to friendships might be supported, or evaluation of provision to identify good practice. Research highlights how children with communication needs, high support needs and/or learning disabilities might require support to access their friends or take part in leisure activities suggesting that the type, level and nature of support needs to be flexible and responsive and may vary from facilitating communication to accompanying a child to an activity session until they have the confidence to access this independently. The evidence also suggests that there needs to be a range of provision and shift to make mainstream activities inclusive. However, this gap in evidence and lack of research focus on this area needs addressing.

7. Reflections on the evidence

The paucity of research on an area which disabled children and young people define as of great importance is disappointing. There are evidence gaps in understanding what works and which models of practice can provide opportunities for friendship, meet children's individual needs and overcome the barriers. Significantly, there is a dearth of research on

friendships for young disabled people in care who often face multiple moves and changes in their care settings which can be assumed to have detrimental effects on their abilities to make and keep friends. The research also appears to treat disabled children as a homogenous group with little reflection on issues of diversity such as disabled children from Black, Asian and Minority Ethnic groups, young disabled people who are LGBT (Lesbian, gay, bisexual or transgender) or indeed to examine gender issues. Diversity appears to only have been examined from the viewpoint of impairment with studies choosing to focus on specific impairment groups such as those with a learning or physical disability. There is also a lack of evidence on the role of social media and whether this can act as a facilitator or barrier to disabled children's friendships.

What the evidence does show is that to enhance the opportunities for disabled children and young people to develop and nurture friendships we need to address the social, physical and attitudinal barriers disabled children face and examine practice through a "lens of friendships". Some barriers such as physical access or improved transport requires whole scale change, however, some of the barriers appear to be that people have not thought of the importance of friendships before for this group. The new SEND legislation gives impetus to *THINK FRIENDSHIPS* and include this dimension in a child's EHC plan and reviewing process especially at times of transition. The design and commissioning of services should also now include an opportunity to *THINK FRIENDSHIPS*. Evidence emerging from the Friendship for All project indicates that some local authorities (e.g. Solihull and York) have taken this on board successfully and have included friendships as a requirement in the procurement of their short break services or have a strong emphasis on friendship throughout their EHC plans. These appear to be resulting in good outcomes for the young people (see www.friendshipforall.org.uk)

The evidence suggests that what disabled children and young people really want is for services and support to consider how to encourage, empower and enhance their opportunities to develop and maintain meaningful peer connections, have choices and opportunities to make and maintain friends on their own terms.

As far back as 2001, Morris commented that there is currently no policy initiative that views friendships as a dimension of social inclusion. This gap in research evidence, policy and practice relating to the friendship opportunities needs to be addressed.

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