

Inclusion, Social Networks and Resilience: Strategies, Practices and Outcomes for Disabled Children and their Families

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This paper explores the strategies of service providers and the benefits reported by disabled children and their parents/carers in three Children's Fund programmes in England. Based on National Evaluation of the Children's Fund research, we discuss how different understandings of 'inclusion' informed the diverse strategies and approaches service providers adopted. While disabled children and families perceived the benefits of services predominantly in terms of building individual children's resilience and social networks, the paper highlights the need for holistic approaches which have a broad view of inclusion, support children's networks and tackle disabling barriers within all the spheres of children's lives.

Introduction: disabled children, prevention and inclusion

Since the mid-1990s, there have been significant developments in policy and practice for disabled children¹ and their families. The implementation of the Disability Discrimination Act (1995) and the creation of the Disability Rights Commission in 2002 challenge services to think pro-actively about the rights of all disabled people (Russell, 2003). There is a new focus on access and inclusion of disabled children within mainstream service provision. The refocusing of children's services towards early intervention and prevention of social exclusion was given renewed momentum by the Children Act (2004), which, together with the National Service Framework, the Special Education Needs Action Programme and the introduction of direct payments, indicate positive steps towards achieving 'joined-up' services for disabled children within mainstream provision (Russell, 2003).

Despite these policy developments, research suggests that many disabled children and their families continue to experience multiple discrimination, low expectations and physical and social barriers to full participation in society (ibid; Beresford, 2002; Woolley, 2006). Parents/carers and siblings, as well as disabled children, are vulnerable to social exclusion, highlighting the need for services that support the whole family (Audit Commission, 2003). Childcare, play and leisure services open to non-disabled children often exclude disabled children (DoCMS, 2004). Parents' opportunities for respite are limited as specialist provision needs to be sought, which often means segregated services for disabled children, separating them from their peers and the wider community (JRF, 1999). However, in research with children about the services they valued, disabled children emphasised the importance of meeting friends, opportunities to gain

independence skills and being able to participate in age-appropriate community-based leisure activities (Mitchell and Sloper, 2001).

In this paper, we explore the strategies of service providers and the benefits reported by disabled children and their parents/carers in three Children's Fund programmes across England. Based on research as part of the National Evaluation of the Children's Fund, we discuss how different understandings of 'inclusion' influenced the strategies and practices adopted by providers. We explore the benefits reported by children and families and the ways that these benefits correspond with service providers' attempts to build resilience and support children's social networks. Before discussing the empirical data, however, we give an overview of two concepts that we draw on throughout this paper: resilience and social networks.

Resilience and social networks

Since the 1990s, the framework of risk, resilience and protective factors has increasingly informed the direction of preventative initiatives targeted towards children in the UK. A resilience perspective centres on understanding the protective factors that help individuals deal with adversity and emphasises the active role taken by individuals in engaging with protective factors. Research on child resilience has revealed three broad sets of protective factors: attributes of the children themselves, such as problem-solving skills, high aspirations and positive peer relationships; characteristics of their families, such as caring and supportive family relationships; and aspects of the wider social context, such as the availability of external support, positive school experiences and opportunities to engage in social life (Masten *et al.*, 1990; Newman, 2002; Schoon and Parsons, 2002).

Many researchers specifically highlight the importance of recognising children's networks as a potential source of informal support, which can help to protect children from adversity in their lives. Such networks include children's relationships with their peers, parents/carers, siblings, other family members and relationships with others in the wider community (Hill, 1989; Gilligan, 1998; Gifford-Smith and Brownell, 2003). Morris and Burford (this issue) suggest that research demonstrates the value of involving individual children's networks in the child welfare services they receive. Folgheraiter (2003) emphasises the importance of building networks around children, rather than attempting to work with an individual's problems in isolation. In addition, Gilligan (2000) suggests that relationships with extended family members or other adults, positive school experiences or leisure opportunities in the community, may represent 'havens of respite' for children experiencing adversity within the home.

Scope and methods

The Children's Fund was established in 2000 to promote multi-agency collaborative working in preventative services for children at risk of social exclusion (aged 5–13 years) across all 150 English Local Authority areas in 149 partnership arrangements (henceforth referred to as 'partnerships'). This article is based on qualitative research conducted as part of the National Evaluation of the Children's Fund (see Edwards *et al.*, 2006 for further information). It draws on case study research within three Children's Fund partnerships. Semi-structured interviews were conducted with 39 service providers from ten services and with 41 strategic stakeholders, including programme managers,

partnership board members, statutory professionals and representatives of parent/carer forums. A workshop was also carried out with eight providers in one partnership. Interviews were conducted with 48 parents/carers. Interviews, participatory activities and observations were conducted with 47 disabled children, including children with autistic spectrum disorders, learning difficulties, hearing impairments, physical impairments and complex needs. In the interests of confidentiality, the names of all participants and services have been changed.

Strategies and practices to promote the 'inclusion' of disabled children

Inclusive provision is defined by Barnardos/Children's Play Council as 'provision that is open and accessible to all, and takes positive steps in removing disabling barriers, so disabled and non-disabled children can participate' (DoCMS, 2004: 19).

Children's Fund service providers appeared to view the inclusion of disabled children in terms of one or more of the following:

- specialist services for disabled children;
- integrated services for disabled and non-disabled children;
- inclusion of the family;
- inclusion in the community.

These interpretations of inclusion differ in the extent to which children are viewed as individuals or members of social networks. Below we discuss how these different perspectives informed the different strategies and practices in providers' work with disabled children.

Specialist services for disabled children

Many service providers saw 'inclusion' in terms of enabling disabled children to have access to play and leisure provision designed specially for them. They perceived specialist provision as 'inclusive' because it provided disabled children with similar opportunities as those offered to their non-disabled siblings. This view of 'inclusion' was linked to perceptions that it was not possible to achieve complete integration of children with complex needs or multiple impairments in mainstream provision. Some service providers commented that this approach was developed partly in response to parental concerns that mainstream services were not 'geared up' to work with disabled children. In one partnership where some services were delivered by Special Schools, the development of services appeared to be underpinned from the outset by an assumption that provision for disabled children would be specialist.

Disabled children value contact with each other, which specialist provision can offer (Morris, 1998; Beresford and Sloper, 1999). Although the focus was mainly on the individual child, specialist services aimed to create safe play spaces for disabled children to meet others in similar situations and develop social networks with their peers. Through the provision of specialist Saturday and after-school clubs and holiday play-schemes, providers aimed to build children's confidence, reduce isolation and help children not to feel 'different', as well as providing respite for parents/carers.

Integrated services for disabled and non-disabled children

Some service providers interpreted 'inclusion' as providing 'integrated activities' for disabled and non-disabled children. This approach aimed to enable disabled children to build social networks with their non-disabled and disabled peers and promote their social inclusion in their locality. Some services, which began as specialist services, subsequently developed some integrated activities with non-disabled children. One service aimed to shift the practice of voluntary sector playcare providers towards more integrated activities:

We managed to get children with special needs that needed a service placed first and then we've tried to build up with more local children in that area to make it an inclusive service rather than it just be a group of children with disability.

While the service offered training to mainstream providers and playcare workers in how to support disabled children, the manager commented on the need to provide a range of services to meet all levels of need, including specialist services.

Providers commented that the creation of integrated clubs and activities did not necessarily result in disabled and non-disabled children playing together, and efforts were needed to encourage the interaction of both groups of children, so that 'inclusion' rather than 'integration' took place (Beresford, 2002). Some providers also felt that age influenced the effectiveness of 'integration'; suggesting that as children grew older and peer pressure increased, non-disabled children became less likely to engage in integrated activities.

Inclusion of the family

Several service providers saw children's family networks as a key resource in promoting inclusion. Providers aimed to improve family relationships by including disabled children's siblings, parents/carers and other family members in leisure activities and outings. They felt it was important to include siblings since they may resent the time parents devote to a disabled child. Providers also aimed to reduce siblings' sense of isolation by meeting other children with a disabled sibling, and to provide opportunities for peer support to develop among parents.

A project for deaf and hearing impaired children included siblings and parents in holiday activities and offered informal taster courses in British Sign Language for family members to enable greater communication within the family and reduce deaf children's isolation.² The service also offered specialist support and advocacy for parents/carers and involved statutory professionals in activities at the centre to improve the accessibility of mainstream services: 'so they're [parents] not intimidated or frightened about their involvement'.

Although only a minority of services worked directly with children's family networks, other specialist services offered respite for families, which providers felt helped to improve relationships and potentially prevent family crisis and breakdown. Some providers had a clear rationale for providing respite in terms of reducing the need for more intensive residential provision and crisis interventions from statutory agencies at the high end of the prevention spectrum. Such a perspective draws on the Hardiker (1999) model of prevention outlined in the Children's Fund *Guidance* to conceptualise levels of need and intensities of intervention (CYPU, 2001).

However, partnerships did not seem clear as to whether respite was within the remit of the Children's Fund and views varied between services. Tensions emerged in a workshop around the notion of 'respite' and the priority that could be given to work with families, with one provider commenting, 'We have to fight not to be seen as respite, primarily it's for the children.'

Inclusion in the wider community

Some providers saw 'inclusion' as ensuring that disabled children were 'safely integrated' into mainstream provision by supporting them to access play and leisure activities, which they would not be able to access independently. Thus, inclusion was perceived in terms of providing equal access to existing provision. This interpretation is closest to the Barnados/Children's Play Council's (DoCMS, 2004: 19) definition of inclusive provision, as taking 'positive steps in removing disabling barriers'. As one provider said: '[inclusion is] open to all, anything that a child can get involved in should be open to any child'.

Enabling schemes provided child-focused support over a period of six to 12 weeks to enable disabled children to access mainstream leisure services, with the intention that at the end of this period, the child would be able to access the service independently. The main focus was on the individual child and respite for parents/carers was seen as a 'side-effect'. Providers felt that this approach enabled children to develop confidence, social and independence skills.

While enabling schemes promoted increased access and inclusive practice within mainstream play and leisure provision, they did not actively challenge the exclusionary attitudes and practices of non-disabled people in the wider community. Indeed, only two of the services in the study focused on raising awareness of the needs of disabled children and attempted to change the practice of mainstream providers. One service supporting disabled children within mainstream provision aimed to influence the practices of play providers, while another service organised deaf awareness and British Sign Language training for mainstream services, drawing on the Disability Discrimination Act to facilitate this.

Overall, a broad range of interpretations of inclusion was evident among Children's Fund service providers, which sometimes resulted in a lack of clarity about the purposes and benefits of the strategies being adopted. Some providers called for more clarity about definitions of inclusion, and suggested that the focus should be on responding appropriately to individual children's needs.

Building disabled children's and families' resilience and social networks

Disabled children and their families reported a range of benefits and changes to their lives in the short and medium term as a result of accessing Children's Fund services. Many of these benefits helped to build resilience and social networks in the different domains of the individual child, the family and, to a lesser extent, the community.

At the level of the individual child

All services appeared to build protective factors and resilience for individual disabled children, increasing their confidence, enabling them to develop social and independence skills and social networks with their peers. Children and parents accessing a range of

services perceived the benefits predominantly in terms of building children's 'confidence' and 'self-esteem', which often had an impact on other spheres of their lives.

Many parents and staff perceived integrated and specialist services as helping to develop disabled children's social skills. Providers of a specialist Saturday club accessed mainly by children with complex needs noted gradual increases in children's willingness to engage in activities with other children, rather than playing on their own. Parents commented that attending integrated clubs where disabled children felt supported and accepted helped to re-build the confidence of children who had previous negative experiences of interacting with their peers.

Within a context in which disabled children are often discouraged from engaging in activities deemed beyond their capabilities, providers of integrated and specialist clubs felt it was important the children should have the same opportunities as non-disabled children to learn new skills. A youth club, which encouraged children to organise activities, enabled children to develop new skills and confidence in their abilities. The youth worker described the change she had seen in a girl who had a tracheotomy and who had been initially very reluctant to make phone calls due to the noise of her breathing: 'and now it doesn't faze her, she'll just get on the phone whether its bowling or cinema, she'll just get on'.

Deaf children and their parents valued the opportunity to develop their sign language skills in integrated activities with support from interpreters. A girl with a hearing impairment explained why it was important to her and her mother to learn sign language: 'We learn it just in case I do turn 100% deaf like I'll be able to know sign language.' Other skills children said they had gained from services included computer literacy, writing newsletters, football, arts and crafts. One project specifically enabled children to gain nationally accredited youth awards, which they were proud of.

Parents of many children accessing mainstream activities with support felt that children had developed important independence skills and therefore had become less reliant on support from the family. One mother commented on how her son was now able to catch the bus into town on his own to meet up with his friend, 'like other boys do his age'.

Children and parents particularly valued opportunities provided by integrated services to develop friendships and social networks with peers in their locality. Disabled children often had to travel a considerable distance from home to attend a special school or specialist unit and therefore had little opportunity to meet children living in their locality. By receiving enabling support to attend a mainstream playscheme, one girl with autism said: 'I have more friends in the local area.' Her mother thought this was particularly important, as she would attend the same secondary school as her peers in future.

Disabled children do not perceive themselves as intrinsically different to non-disabled children, but rather it is the way they are treated by other children or adults, or their experiences of a disabling physical environment that promotes a sense of difference or of being disabled (Beresford, 2002; Connors and Stalker, 2003). Parents of children attending specialist services felt that the opportunity for children to develop friendships with other disabled children helped to improve their emotional wellbeing and reduce feelings of isolation. Supportive safe environments where disabled children were not made to feel 'different' appear to help offset negative experiences of marginalisation, social isolation or discrimination, which they may experience in other areas of their life. For one girl with complex needs, who was bullied because of her impairment at the Special School she

attended and had limited opportunities to socialise at home, an integrated Saturday club provided an opportunity to develop friendships with peers in a different setting to home and school: 'I like my friends at [the Saturday club] because they are special to me, I don't feel left out like at school.' Thus community-based, rather than school-based services, may be important for some children as 'havens of respite' from adversity at school (Gilligan, 2000).

Moreover, within the context of increasing moves towards including disabled children in mainstream education, parents felt that opportunities for them to meet their disabled peers helped to promote a positive sense of identity. For example, one parent of a deaf daughter said:

there's got to be somewhere where deaf children that are in the mainstream have access to other deaf children . . . she needs to have a deaf identity as well as a hearing identity.

Many parents drew attention to the diverse, changing nature of each individual disabled child's needs. Services targeted towards disabled children may be important for children to develop a positive sense of identity during particular periods of their lives, but they may move on to more open access play and leisure opportunities over time. A parent of a boy who had a cochlear implant, said that when her son was younger, the deaf children's centre offered a space where he could meet other deaf children:

at that time he really needed the project and needed to see that he wasn't different, you know, there were other deaf children.

However, as his oral and aural skills developed, he was more able to access mainstream leisure activities with non-disabled children in the community (see also Evans *et al.*, 2006).

In addition to benefits for disabled children, parents and providers suggested that integrated activities could provide opportunities to raise non-disabled children's awareness about disabled children, helping to break down attitudinal barriers. A parent of a boy with complex needs who was supported to attend an after-school club commented on how the other children involved her son in their play: 'They actually interact very nicely with him. There are one or two that are really sweet to him and sit and play with him.'

At the level of the family

Involving family members in projects and offering respite helps to build protective factors and strengthen children's social networks within the family.

Some parents/carers reported improved relationships within the family as a result of engaging in activities together. Siblings enjoyed project activities and parents appreciated the fact that they were included. Some parents felt that siblings also gained from meeting other children with disabled siblings, as this helped to reduce their isolation and promote greater understanding about their disabled sibling. Activities, such as drama, aimed specifically towards siblings also helped some parents to understand the perspectives of their non-disabled children.

Parents, particularly single parents, valued opportunities to meet other parents whilst engaging in activities with their children, and commented on the welcoming atmosphere of family-oriented services: 'It's an outlet for the parents as well . . . it's nice to sit with parents and think oh awful week – oh I know what you mean.' Indeed, some parents appreciated the supportive environment of family-centred projects as respite from the disabling attitudes they experienced in the wider community:

Everyone accepts the children and you don't get that in the real world. You get lots of looks and you know snide little comments, but here everyone knows we're all in the same boat.'

Parents also appreciated specialist support and advice on issues affecting children with particular impairments.

Although weekend and holiday activity services did not work directly with parents/carers, they could have a 'ripple effect' on children's family relationships and networks (Gilligan, 2000). Parents whose children accessed specialist and integrated services valued the regular breaks, as this gave them more time to spend with their other children or doing other activities. One parent commented that respite relieved the pressures on families:

It's just so draining – or can be sometimes . . . parents just need that respite, even if it's once a month, just to recuperate really, just to recharge your batteries'.

Parents valued provision that was flexible and responsive to the changing needs of the family, since this meant that services could offer higher levels of support during periods of family crisis or stress.

Families' experiences suggest that respite provision can also prevent the need for more intensive residential interventions. Parents caring for two children with complex needs and a younger son commented that without the short breaks provided by an integrated Saturday club, the family would probably need to access residential care:

if it weren't for [the Saturday club] we'd be 10 foot under; I don't know what we'd do. I think it would have to be residential, just to get a break. It's not something that we would choose.

At the level of the wider community

Services which work directly with mainstream providers to raise awareness and build capacity to meet disabled children's needs challenge disabling barriers and help to develop more supportive, inclusive environments for disabled children and their families. Services that supported children's inclusion in mainstream leisure provision potentially facilitated children's engagement with other support networks, such as school- and community-based opportunities. However only two of the ten services in the study specifically attempted to raise awareness and change the practices of mainstream providers.

A service supporting disabled children within mainstream play provision suggested that they had challenged the practices of mainstream providers to develop more inclusive services: 'We've tried to develop something that is child and parent/carer-centred . . . It's

been a transition for them really, in terms of practice.’ During the course of the Children’s Fund initiative, the service was mainstreamed within Social Services, suggesting that it was in a good position to continue to influence the practice of mainstream providers. However, the manager commented on the need to challenge disabling attitudes at all levels, whether among non-disabled people, mainstream service providers or strategic stakeholders and professionals. Similarly, while parents of deaf children welcomed efforts to raise deaf awareness in the community, they recognised that bringing about attitudinal change was a slow process.

Conclusion

A broad range of strategies and practices have been adopted in Children’s Fund case study partnerships working with disabled children and families. These are linked to different interpretations of ‘inclusion’ in evidence at the operational level, ranging from notions of specialist/segregated services, integrated, family-focused, or community/service-based interventions. Few services however wholly adopted the Barnardos/Children’s Play Council definition of not only being ‘open and accessible’, but taking ‘positive steps in removing disabling barriers’. Children and families perceived the benefits of services predominantly in terms of building confidence, developing social and independence skills and increased social networks with their peers and family. Some families also perceived benefits for the family as a whole, in terms of respite for parents/carers, improving understanding of the disabled child, reducing the isolation of siblings and parents/carers, and accessing specialist family support and advocacy. However, there was much less evidence of positive outcomes in the service system or within the wider community (Barnes *et al.*, 2006).

Thus, while some services aimed to have a direct influence on several domains of a child’s life and engaged in a range of strategies, most services had a narrower focus, predominantly seeking to build the resilience of the individual child through play and leisure activities. Such strategies are largely informed by the medical model approach to disability, which locates the ‘problem’ of exclusion in the disabled child rather than considering the external factors that contribute to exclusion (Beresford, 2002). The medical model is broadly consistent with the ‘special needs’ discourse which dominates educational provision and was prevalent within Children’s Fund partnerships. We argue that services, which have a broad view of inclusion, aim to support children’s social networks and tackle disabling barriers holistically at the levels of the individual child, family, school and wider community, are likely to have a more lasting impact on promoting the social inclusion of disabled children and their families.

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Notes

1 This paper was broadly informed by the social model of disability, which points to material, social, cultural and attitudinal barriers within society as the cause of disability rather than an individual’s actual

impairment (Connors and Stalker, 2003). Hence, the term 'disabled children' is used in preference to 'children with disabilities' or 'children with special needs'. It is, however, important to note that many parents and service providers referred to 'children with special needs', reflecting the dominance of this terminology in the educational context.

2 Research with deaf young people found that most parents of deaf children (most of whom are hearing) had not learned sign language to any degree of proficiency, usually due to the advice of the medical profession who favour oral forms of communication (Skelton and Valentine, 2003). Thus, deaf children of hearing parents may be more likely to encounter medical model approaches to disability, in contrast to the experiences of children of deaf parents for whom sign language is their first language, who reject the medical model of deafness and identify with other deaf people as members of a cultural and linguistic minority community (Taylor, 1999).

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