



Do short break and respite services for families with a disabled child in England make a difference to siblings? A qualitative analysis of sibling and parent responses

Vicki Welch ^{a,*}, Chris Hatton ^a, Eric Emerson ^a, Janet Robertson ^a, Michelle Collins ^a, Susanne Langer ^{a,b}, Emma Wells ^a

^a Centre for Disability Research, Lancaster University, Lancaster, England, UK

^b Division of Clinical Psychology, University of Liverpool, Liverpool, England, UK

ARTICLE INFO

Article history:

Received 13 October 2011

Received in revised form 1 December 2011

Accepted 1 December 2011

Available online 9 December 2011

Keywords:

Sibling

Parent

Child

Short break

Respite

Disabled

ABSTRACT

Background: Previous research identifies positive and negative effects of being a sibling in a family which includes a disabled child. Short break services (also known as respite) provide families with a break from caring and offer disabled children the chance to participate in various activities. This paper investigates the effects that these short breaks have on siblings.

Methods: The research consists of a qualitative analysis of data collected as part of a survey of families using short break services. Data from 239 parent-carers (mostly biological parents) and 84 siblings are included in the analysis. Data are written responses to open questions about use of services and the effects they have.

Results: The effects of short breaks on siblings are described as being mostly positive. Short breaks have the potential to ameliorate some of the negative impacts of being a sibling in a family with a disabled child whilst also promoting the positive impacts of having a disabled brother or sister. However, some siblings also report some adverse effects of short breaks.

Conclusion: Short breaks have a significant role to play in promoting the wellbeing of siblings; however, their role currently seems to be largely unrecognised and consequently undervalued.

© 2011 Elsevier Ltd. All rights reserved.

1. Introduction

Whilst much of the literature concerning siblings who are part of families with a disabled child identifies the difficulties they face some attention has been paid to positive gains and experiences that these children may have (Williams et al., 2010). Children in families are sometimes seen as competitors for shares of finite resources, and parental time and attention; from this perspective siblings of disabled children may be faced with particular challenges as parents may need to focus a high proportion of their resources, time and energy on meeting their disabled child's needs (Abrams, 2009). However, this rivalry-based view of siblings is somewhat simplistic, since it both reduces children to passive, non-contributing consumers of family resources and ignores interactions and relationships between them (Gillies & Lucey, 2006). Several authors have responded to this critique by focussing on the connections between siblings, viewing children as active agents with the potential to contribute to the family and the welfare of brothers and sisters (Edwards, Hadfield, & Mauther, 2005; Gillies & Lucey, 2006). Siblings who are part of families with a disabled child have the potential to

contribute to their brothers' and sisters' wellbeing in many ways, just as they may receive a range of benefits from the relationship. Relationships between these siblings, as with any other siblings, are likely to contain elements of reciprocity, mutuality, negotiation and strategy (McIntosh & Punch, 2009).

1.1. Being part of a family with a disabled child

Each child is an individual who will experience and occupy a unique situation. However, research has identified a range of positive and negative effects which may impact on some siblings who are part of a family with a disabled child. For simplicity we have presented these as four spheres of impact; parental, sibling, individual and external. Whilst it is convenient to present the information in this way these spheres are not exclusive, indeed we believe they are extensively connected and overlapping. Furthermore we do not intend to imply that these impacts are 'caused' by parents, siblings, individuals and external factors, merely that since they are associated with them, they can be presented in this way (for causes we might look to the complex interplay between disability and socio-economic situation, social exclusion and other variables).

1.1.1. Parent factors

Parents of children with a wide range of disabilities have been shown to experience higher levels of stress than other parents; this in turn has been shown to have various impacts on their parenting (Beck, Daley,

* Corresponding author at: Centre for Excellence for Looked After Children in Scotland, University of Strathclyde, 76 Southbrae Drive, Glasgow, G13 1PP, Scotland, UK.

E-mail addresses: victoria.welch@strath.ac.uk, vicki.welch@btinternet.com (V. Welch).

¹ Present address: Centre for Excellence for Looked After Children in Scotland, University of Strathclyde, Glasgow, Scotland, UK.

Hastings, & Stevenson, 2004; Dyson, 2010; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008; Quintero & McIntyre, 2010). Research has observed the tendency for parents to devote less time and attention to non-disabled siblings and parents may treat non-disabled siblings differently in other ways, for example by expecting them to help care for their sibling or by having higher expectations of their behaviour (Hames & Appleton, 2009; Kresak, Gallagher, & Rhodes, 2009; Schuntermann, 2007). Siblings may perceive these differences as being unfair and may experience negative feelings such as jealousy or isolation from their parents (Williams, 1997; Williams et al., 2010). Conversely some attention has been drawn to the potential for siblings of disabled children to benefit from their parents' advanced knowledge, experience, parenting strategies and coping skills (Dyson, 2010; McConkey et al., 2008; Pakenham, Sofronoff, & Samios, 2004).

1.1.2. Sibling factors

Children may live with a disabled brother or sister who is disruptive or demanding or has violent or aggressive behaviour towards them (Fisman, Wolf, Ellison, & Freeman, 2000; Floyd, Purcell, Richardson, & Kupersmidt, 2009; Lobato, Miller, Barbour, Hall, & Pezzullo, 1991; Williams et al., 2010). Siblings may find that their activities are limited by the need for the family to cater for their disabled children such that siblings miss out on enjoyable or developmental opportunities (McHale & Gamble, 1989). Equally some may experience significant worry or concern about the wellbeing of their disabled sibling (Abrams, 2009; Gillies & Lucey, 2006; Guse & Harvey, 2010; Hames & Appleton, 2009).

Some writers have drawn particular attention to positive experiences, for example siblings can develop a positive regard for their disabled brother or sister, experience great love and closeness and have unique opportunities to be the object of their siblings' admiration and love (Floyd et al., 2009; Guse & Harvey, 2010; Kaminsky & Dewey, 2001; Williams et al., 2010). The nature of the disabled child's impairments has also been shown to be relevant to sibling experience; for example Kaminsky and Dewey (2001) found that siblings of children with Down's syndrome tend to be more nurturing and less competitive than siblings of children with autism and also that they were more likely to experience a sense of being admired by their brother or sister.

1.1.3. Individual factors

Some research has raised concerns about the negative impact of restricted childhoods through which children are forced to 'grow-up too quickly' (Abrams, 2009; Dyson, 2010; Schuntermann, 2007). Siblings may experience stress, rage, shame or guilt in respect of their disabled brother or sister or aspects of their relationship with them (Abrams, 2009; Findler & Vardi, 2009; Fisman et al., 2000; Williams et al., 2010). Some siblings have been shown to develop very high or unrealistic expectations of their own behaviour or achievements which may persist into adulthood (Abrams, 2009). A number of studies have found siblings of disabled children to be at increased risk of behavioural difficulties (Fisman et al., 2000; Verté, Roeyers, & Buysse, 2003) although other studies have not found this effect (Cuskelly & Gunn, 2006; Dyson, 1999). Explanations for behavioural difficulties draw on siblings' shared genetic, experiential and familial environments (August, Stewart, & Tsai, 1981; Rossiter & Sharpe, 2001; Yirmiya et al., 2006) or suggest that siblings learn that in order to get attention they need to have a 'problem' (Abrams, 2009; Fisman et al., 1996).

Gender has been associated with a number of differences in sibling experiences; for example Breslau (1982) noted that boy siblings were more likely to show aggressive behaviour whereas girls were more likely to experience depression and anxiety. Floyd et al. (2009) note a greater tendency for girls to provide higher levels of care and for boys to report greater levels of conflict, they suggest that this may in part be due to disparate societal expectations. Dyson (2010) found evidence of very young girls being involved in the care of

their sibling and Guse and Harvey (2010) found that females were more likely than males to express concerns for their disabled sibling's wellbeing and future.

Age and birth order have been shown to be important variables which may impact on outcomes (Breslau, 1982; Findler & Vardi, 2009; Floyd et al., 2009), for example there may be a protective effect for some older children of having experienced life before their disabled sibling was born (Breslau, 1982). It could also be that older siblings do not experience dissonance between their experience and wider expectations, for example it is not unusual to provide care for younger siblings whether or not they are disabled. In many studies the effects of age and birth order may be difficult to un-confound, together with the related parameter of timing and duration of experience. The on-going nature of family relationships means that both negative and positive impacts are cumulative and may produce greater effects over time (Quintero & McIntyre, 2010; Verté et al., 2003).

A number of researchers have noted that having a disabled sibling provides opportunities for individual growth such as the development of maturity, independence, empathy and acceptance (Findler & Vardi, 2009; Guse & Harvey, 2010; Williams et al., 2010). For example siblings may become well-informed about disability issues and may develop skills to advocate for their disabled brother or sister (Dyson, 2010; Kresak et al., 2009). In the context of intellectual disability Findler and Vardi (2009) also note opportunities for siblings to construct positive images of themselves by comparison to their disabled brother or sister, or to see themselves as being parental favourites.

It has however been pointed out that many of the negative impacts of having a disabled sibling may be experienced immediately whilst many of the positive impacts may be long-term and not fully appreciated until adulthood (Rossiter & Sharpe, 2001).

1.1.4. External factors

Research has identified factors external to the family which appear to be associated with negative impacts for siblings such as sadness and embarrassment when they are exposed to social stigma associated with their brother or sister (Guse & Harvey, 2010; Williams, 1997; Williams et al., 2010); these experiences may contribute to a child's marginalisation or sense of social isolation (Abrams, 2009; Dyson, 2010). Socioeconomic situation has been shown to be important; siblings in better economic situations having better outcomes in terms of fewer behavioural problems and greater personal growth (Findler & Vardi, 2009; Quintero & McIntyre, 2010). It has been suggested that siblings in families who are more advantaged have access to a greater range of protective resources than poorer families (Dyson, 2010; Williams et al., 2002).

Two further points in relation to socioeconomic position are important to bear in mind. Firstly there is a strong association between poverty and disability such that poverty tends to increase the risk of having a disabled child in the family and that having a disabled child in the family tends to increase the risk of poverty (Emerson, 2007, in press; Emerson & Hatton, 2010; Emerson, Shahtahmasebi, Lancaster, & Berridge, 2010). Secondly poverty itself may account for many of the variables discussed above, for example it has been shown that much of the parental stress associated with having a disabled child can be accounted for by lower socioeconomic status (Emerson, Hatton, Llewellyn, Blacker, & Graham, 2006; Emerson, McCulloch, et al., 2010).

Attention has also been drawn to positive experiences mediated through external factors; some siblings have described how being the brother or sister of a disabled child can in some circumstances give them an identity and attract positive attention or admiration from professionals, teachers or their own peer group (Guse & Harvey, 2010). Furthermore siblings may benefit from access to services, activities and opportunities that they would otherwise not experience (Kresak et al., 2009).

Download English Version:

<https://daneshyari.com/en/article/10311696>

Download Persian Version:

<https://daneshyari.com/article/10311696>

[Daneshyari.com](https://daneshyari.com)