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Living Away From Home: The Long Term Substitute Care of Disabled Children

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Abstract

The Centre for Child Care Research at Queen's University Belfast has been involved in a three and a half year, three part study reviewing how the services provided to meet the needs of these children and young people with disabilities have been affected by the implementation of the Children (Northern Ireland) Order 1995.

This article reviews the research literature pertaining to long-term substitute care for children with disabilities in the UK and, with regard to the Children (NI) Order Legislation, will present some results from a survey about such services provided by the 11 Northern Ireland Health and Social Services Trusts undertaken by the Centre for Child Care Research (Monteith & Cousins, 1999). Particular attention is given to adoption and fostering, residential homes, residential schools, hospital placements and disabled children's own experiences of using, and leaving, long-term care.

Key Words: Children; Disability; Long-term Care; Children Order; Northern Ireland.

Introduction

The long-term placement of disabled children in substitute care encompasses the use of foster care, adoption, residential or hospital settings. Hall (1996) argues that in a small number of cases, long-term care is the most appropriate solution to a child's needs although Beresford et al (1996) refute this by stating that considerable concern exists

about the numbers of children in long-term care, their experiences and vulnerability to abuse (Utting 1991; Marchant and Page 1993). Russell (1996) observed that long-term care was used in desperation by parents and with considerable guilt

A prevalence study published in 1992 by the Northern Ireland Department of Finance and Personnel's Policy Planning and Research Unit (PPRU) identified 14,600 children under the age of 16 in Northern Ireland as having some level of disability. The rate of disability was 35 per thousand of the population under the age of 16 compared to a slightly lower rate of 32 per thousand in Great Britain (Bone and Meltzer, 1989)

The Children Order Guidance and Regulations

The Children (NI) Order came into force on 4 November 1996 and was widely welcomed for its apparent coherence and emphasis on developing services that support and enable families. This piece of legislation was the most significant change in UK child care legislation in almost 30 years. It holds out to disabled children the promise of new safeguards and fuller social integration. Children with disabilities are to be recognised as children first, with the right to have their particular needs met by the provision of services.

Kelly and Coulter (1997) note that the Children (NI) Order is, in all its main provisions, a re-enactment of the English and Welsh Children Act 1989 and represents a return to the principle of 'parity' between Northern Ireland legislation and that in England and Wales with the main differences between the Order and the Act relating to Northern Ireland's very different structures for delivering social services. Since 1972 four unified Health and Social Services Boards have been responsible for the social services (including child care services) in Northern Ireland. The responsibility for delivering the Children (NI) Order reforms falls to 11 independent Health and Social Services Trusts, which are the "providers" in a "purchaser/provider" relationship with these Health and Social Services Boards. The whole structure is overseen by Department of Health, Social Services and Public Safety (formerly known as the Department of Health and Social Services or DHSS)

The Children (NI) Order states children are best looked after within the family however it also makes provision for other accommodation to be provided as a service to children in need and their families.

Article 21 of the Order requires that every authority shall provide accommodation for any child in need, within its area who appears to the authority to require accommodation. Article 27 goes on to state that an authority shall provide accommodation and maintenance for any child, whom it is looking after, by placing him with a family, a relative of his or any suitable person, maintaining him in a

home, a voluntary home, a registered children's home, maintaining him in a home or institution provided by a government department or a prescribed public body, or making such other arrangements as seem appropriate to the authority and comply with any regulations made by the department.

In Volume 5 of the Department of Health and Social Service's Children Order Guidance and Regulation publications, which relates to children with disabilities, particular attention is given to the need for Health and Social Services Trusts to ensure that accommodation meets the needs of disabled children. It is noted that it is against government policy that children with a learning disability or with serious health problems should be placed for long-term residential care in a hospital setting. New notification duties are also recommended to ensure that children are not 'forgotten' and that Trusts assess the quality of child-care offered.

The Guidance and Regulations also deals with the placement of disabled children with foster parents and pays particular attention to the recruitment of these foster parents and the training and support provided to them. To ensure successful placement of children with disabilities, the need for H&SS Trusts to ensure stability of foster homes is stressed. H&SS Trusts are urged to make every effort to ensure that accommodation for children with a disability is suitable for their needs. The guidance advises that recruitment campaigns may be targeted at particular groups in the community, especially where the Trust has a need for foster families from a particular racial, cultural or religious group and with practical experience of disability.

The Children (NI) Order also requires Trusts, voluntary organisations and privately run children's homes to establish procedures for considering representations and complaints about children's services. It also recommends that every effort should be made to work with local disability groups to ensure that the procedures are accessible, usable and effective when dealing with issues relating to disability. Support and advice should be offered in cases where disability may impede communication.

Service Provision

The Centre for Child Care Research at Queen's University, Belfast asked the 11 Northern Ireland Health and Social Services Trusts to provide details of the number of children with disabilities who were referred, assessed, or provided with a social care service during the year ending 31 March 1998. Table 1 lists the number of children with disabilities in receipt of various kinds of long-term care in Northern Ireland.

From this it can be seen that a significant majority (57.5%) of the 87 children with disabilities in long-term residential care were cared for in foster homes. This is a very similar figure to the 60.5% of the total 'Looked-After Child' population in foster care according to the Social Services Inspectorate (1998) report on Fostering

in Northern Ireland. A minority of children accessed other forms of care, including care in residential homes and hospital care. It should be noted that 6 out of 7 children in residential care were in generalist children's homes rather than facilities especially for children with disabilities and 2 of the 6 children in hospital were being cared for long-term on adult wards. It is also worth commenting that a total of 24 children and young people were listed as receiving 'other' kinds of long-term care away from home, where the Trusts did not specify the particular nature of this care on the questionnaire.

Table 1: Long Term Residential Care for Children with a Disability (for the year ending 31 March 1998)

TYPE OF CARE	NO. OF CHILDREN IN RECEIPT OF LONG-TERM CARE
Residential Care	7
Foster Care	50
Hospital Care	6
Other	24
Total	87

(From Monteith and Cousins, 1999)

Adoption and Fostering

There has been an increase in the number of disabled children adopted and fostered in recent years, however, a number of obstacles still exist when finding permanent placements. Very little research has been conducted on adoption and permanent foster care services for disabled children and there is a particular dearth of knowledge of the experiences and views of disabled children and their families and existing information appears to be obtained from secondary sources (Baldwin and Carlisle, 1994, Blacher 1994 Morris 1998).

A number of studies have demonstrated that disabilities can significantly influence the child's care experience. Mc Murty and Lie (1992) found older children and those with disabilities were slower to return home or be adopted. Pinderhughes (1998) examined the pre-placement life histories and short term outcomes of 53 children adopted over the age of five, found that children who were disabled, spent longer periods in the foster care system and often displayed greater problems adjusting to their new situations.

Schmidt-Tieszen and Mc Donald (1998) examined 147 case records in order to identify child characteristics that distinguished those children from whom, the social

services long-term goal was adoption as opposed to long term foster care. They identified factors as being influential: age, race, developmental disabilities, genetic or family history which increases the child's risk of requiring medical intervention. They found that children who were most likely to be placed in long term fostering placements included older children, and children with developmental disabilities. They argue that such findings reflect the difficulty in moving children with particular characteristics through the foster care system.

Berridge (1996) emphasised that there remains a significant shortage of foster carers and these conclusions are supported by a Social Services Inspectorate report (1996) for Great Britain which argued that one consequence of this problem is that the majority of children are not given a choice about their foster placements. The difficulty of finding carers for children with disabilities was compounded by the fact that the amount foster care provision was simply insufficient. Sixty nine percent of local authorities questioned in one survey carried out by the Association of Directors of Social Services (1997) acknowledged that they had an inadequate number of carers needed to meet existing demands for foster care while an additional 11 percent conceded that finding carers for children with special needs was problematic.

In Northern Ireland, similar issues exist and to help deal with the shortage of foster families the Northern Ireland Foster Care Association, in conjunction with a number of health and social services trusts across the region, organised National Foster Care Week in order to raise awareness of the fostering issue. (British Broadcasting Corporation, 2000)

Residential Homes

Monteith and Cousins (1999) found that only 7 out of 87 children in long term substitute care in Northern Ireland were living in residential homes. This conforms with UK government policy and previous literature which has shown that there has been a marked decrease in the use of residential care throughout the UK over the last twenty years (Kahan 1994). Only for hospital care and residential special schools is this decline proportional to demographic change. Of the six attributes that Moss (1975) identified as determining placement in residential care, at least four of these (gender, age, health and behaviour) remain significant predictors in the 1990's. The most significant change to have occurred since Moss's (1975) survey is the virtual elimination of long-stay residential hospital care for learning difficulties and/or physical difficulties. Although the number of hospital beds for children had remained constant in proportion to the relevant population, patient turnover has increased considerably (Audit Commission 1994).

The policy shift away from institutionalised care has resulted from a widespread and explicit desire to reduce the number of children in institutions and may be attributed

to a combination of ethical, financial, or efficacious reasons. The commitment to such an ideology is most visible in the public sector, where emphasis on the importance of the natural family and the reciprocal benefits of parenting had been particularly noticeable.

However, historically a number of opposing views have been expressed by members of social work, health and education professions regarding the benefits and downfalls of residential care for both children with disabilities and those without. Middleton (1992) reports that social workers have stressed the importance of family life for children and argue that substitute parental care is preferable to residential care if the child is unable to remain at home. Educationalists see group living as beneficial and reject the argument that emotional and psychological may be endangered based on a lack of supporting evidence. They emphasise that risks such as physical and sexual abuse exists within foster homes as well residential care. The belief that residential care is second best can result in instability and uncertainty amongst the children and young people (Berridge 1985) and an over-emphasis on foster placements by social services can result in succession of breakdowns. Kahan (1994) in a evaluation of residential care found that it can provide a stable environment, within which young people the opportunity to develop their full potential and it was preferred by some young people to foster care.

Children Living In Residential Schools

The shift from institutionalised care to foster care has resulted in the closing of many residential units. One result of this shift in policy appears to be an increase in the use of residential schools to provide care for disabled children.

As Table 2 shows, a proportion of children with disabilities in Northern Ireland also spend significant amounts of time in such schools. Of the total number of children with disabilities living away from home in Northern Ireland 41.6% of these are boarders in special schools. While the child's education is important, there have been some concerns raised regarding the quality of care received by children who spend much of their life in residential schools.

Morris (1995) found that many residential schools are now offering 52 week placements and discovered that many placements were requested because 'the school term structure was not appropriate for the child because parents could not cope for the whole school holidays'. She argues that based on such evidence, two conclusions may be drawn, firstly, residential schools are open longer than normal schools. Secondly, it confirms that many children are placed in residential schools in response to social as opposed to educational factors. For example, as a response to family circumstances or the parents' inability to care for their child full time.

Yet many parents of disabled children send their children to boarding school because they feel their child will benefit from the experience although others may feel they have no choice but to send their child away due to the failure of the local schools to accommodate their child's needs.

However Morris (1998) argues that children living in such establishments are less likely to benefit from the protection afforded to them by the Children Act (or Order) legislation. She found that some disabled children are seemingly invisible to the child care system, attending residential schools during term time and respite care or short term placements during holidays, with some spending considerable periods of time in hospital settings. These children may have very little opportunity to experience family life and, as they are not viewed as being separated by their family, may have their needs overlooked by social services.

Table 2: Boarders in Special Schools in Northern Ireland at 9th October 1999

EDUCATION AND LIBRARY BOARD	NUMBER OF BOARDERS
Belfast	10
Western	No special schools with Boarding Departments
North Eastern	11
South Eastern	16
Southern	25
Total	62

(Figures provided by the Department of Education for Northern Ireland 2000)

Children Living in Hospitals

Although the Children Order Guidance and Regulations note that it is against UK government policy that children with a learning disability or with serious health problems to be placed for long-term residential care in hospital, 6 children in Northern Ireland were living away from home during the year ending 31 March 1998 under this type of care and 2 of these children were being cared for in adult hospital wards.

Morris (1995) however commented that, perhaps surprisingly, some parents seem to prefer care provided in a hospital or educational setting for their child as they may view social services provision as stigmatised and final. She conducted research with

adults who had lived away from their families for 'large parts of their childhood' and found that as disabled children they had spent much of their childhood in residential care which was made up of various combinations involving the use of children's homes, respite care, boarding schools, and hospitals.

Parental Views of Long-Term Care

As Morris has noted, parental attitudes have influenced the usage of hospital or residential settings for placements of their disabled children, with parents sometimes opposed to attempts by social services to move children from long term placements in such settings. Lyon (1990) found that the likelihood of children in residential settings being placed with foster parents depended on their legal status. Of 33 children formally 'in care' 28 of them were on foster placements at the end of the research compared to 4 of the 28 children in the study who were not formally 'in care'. Lyon felt that disabled children living away from home but not formally in care were not offered a family placement partly due to their parents' attitudes and feelings, and partly due to how social services dealt with these children. Lyon felt the child's right to experiencing a normal family life was not given enough consideration. Mountney (1991) highlighted the need for specialist expertise in Social Services Departments to provide support for foster families of disabled children and promote placements in families.

Day (1997) conducted an exploratory qualitative study of staff and thirty parents views of a respite care service provided in a residential care home for children with disabilities. Parents perceived a number of social and emotional benefits for their children including gaining independence from their family and meeting new friends. One parent observed that their son was 'able to cope with his emotions better by being with other children with disabilities'. The main benefits were the ability to attend to other children or being able to spend time together as a couple as well as relaxing. On the other hand, a number of parents reported communication problems with the residential centre, ranging from lack of information about their child's stay to a lack of control over their child's visit, which proved inconvenient for them.

Children's Experiences of Using Long-Term Care

The Children (NI) Order requirements on representations and complaints can be seen as providing new channels whereby children can express their own interests. Yet despite this, it is likely that due to their age or a disability many children in long-term substitute care will not be able to directly participate in the proceedings which concern them and thus will be denied the chance of having their voices heard.

Monteith and Sneddon (1999) in a study of 76 young disabled people in Northern Ireland making the transition to adulthood found that half of the young people

interviewed remarked that social workers listened more to parents and carers than they did to the young person themselves. Several young people had concerns about getting their point across clearly and lacked confidence in their ability to speak to the social worker.

Morris (1997, 1998) argues that there is a particular need for more research into the lives and experiences of children who live away from home, particularly regarding the use of residential schools and hospital settings primarily for care. Not enough is known about these children and their experiences, including whether they are offered family placements and how their right to experiencing a normal family life is given consideration.

Leaving Long-Term Care

Adolescents with disabilities who successfully made the transition to adulthood report that their own childhood experiences can have a significant influence upon their ability to adapt to changes that adulthood entails. Morris (1995) in her study entitled "Gone Missing?" examined the impact of growing up in an residential establishment on ten adults. All ten individuals reported experiencing a great deal of emotional distress such as depression, anger, feelings of abandonment, with three required in-patient psychiatric treatments. Morris (1997) notes that one of the greatest failures of the system is that it not only fails to recognise the emotional, physical and sexual that many children experienced in such establishments but in addition leads many adults with disabilities to feel they have been forsaken the system on account of its inability to provide the support they need to confront and deal with their past.

Monteith and Sneddon (1999) also noted the importance of adequate social work resources being targeted at this key stage and commented that service provision to young people and their families in Northern Ireland often falls across a range of professional groups with no-one having a lead responsibility for monitoring and co-ordinating integrated transition plans.

In Conclusion

In considering why children with disabilities are still living long-term in out of home settings it is important to consider the alternatives. Glendinning (1992) found that the amount of help provided for parents and their disabled child was 'far less' than was needed. This was confirmed by a study carried out by the Office of Population Census and Surveys (OPCS) which found only 12 percent of families caring for their disabled child had a regular social worker, 4 percent had used short term respite care, and 9 percent had received a holiday for their child in the last 12 months.

A study by the National Children's Home (1991) found unequal access to services and that higher income families and non-manual classes were more likely to receive respite care. Robinson and Stalker (1993) similarly found those from ethnic minority communities and those in lower socio-economic groups had less choice in the provision of respite care. Lack of support and difficulty accessing services may in turn lead to increased use of residential establishments including schools.

Further research is needed to investigate the extent to which families in Northern Ireland receive the types of help and support, which enables children with disabilities to stay at home and experience a normal family life rather than receiving some kind of long-term out of home care provision. For those children who do spend long periods of time in out of home care further consideration should be given to their experiences and opinions of it and the difficulties they may face on leaving.

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