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Chapter 11

Children with disabilities: international perspectives for developing practice

Monica Dowling

I thought this chapter was enlightening, identifying the knowledge, skills, core values and ethics that are required to support practice with children with disabilities and their families. It also identifies the importance of research and how informative this can be to one's own practice.

Introduction

Children with disabilities and their families constantly experience barriers to the enjoyment of their basic human rights and to their inclusion in society. Their abilities are overlooked, their capacities are underestimated and their needs are given low priority. Yet, the barriers they face are often as a result of the environment in which they live rather than a result of their impairment.

(UNICEF 2007: iv).

This chapter poses the question - how can social workers and other professionals help children with disabilities and their families overcome barriers and support their inclusion in activities and opportunities that other families take for granted?

The principle themes which will be discussed in relation to this question are: working with parents and children with disabilities to discover and define disability; working with parents and children with disabilities when a child needs to be protected from harm or abuse and working with parents and children to build community based services.

Research examples quoted here are from an Open University and UNICEF sponsored qualitative study of 140 parents, disabled children and providers in Bulgaria and Bosnia and Herzegovina. While they relate to a particular set of circumstances, the professional practices illustrated here offer insights which can be applied to the context of other disabled children's lives and family situations. This research also demonstrates that community based services which are led by families, children and young people can be developed by countries with different levels of service provision.

Discovering and Defining Disability

Because of the stigma associated with disability in some countries and cultures, families may be reluctant to report that their child has a disability. In countries where diagnosis is more advanced and the likelihood of survival is greater or where state benefits are available to support the child, there is a greater incentive to register a child's disability, thus contributing to a higher recorded prevalence of disability. Disabilities are also not always discovered in very young children and some children acquire impairments through accidents or illness.

How a disability is discovered and defined will vary from time to time and place to place – however there are complex issues surrounding discovery and definition that need to be examined. For a practitioner to have a good knowledge about different types of disability is important in parents' eyes, but so is understanding the child's disability from the parent and child's perspective. Bailey et al. (2006) have a 'top down' approach to practitioners sharing information about a child's disability. In an evaluation of US programmes working with families of young children with disabilities, they suggest that successful family outcomes are measured by how well the parents understand the information provided by the professional and share it with others, advocate for services and respond effectively to the child's needs. However, such an approach does not allow for an interactive dynamic between parent and professional and it can be argued that a more child focused approach is also needed.

Such an approach is suggested by Howe* (2006) who notes the importance of sensitive interactive communication with families and cites the example of communicating with a blind child - where parents will need to learn to develop their sense of touch, sound and movement rather than be rewarded by visual facial communication through smiles and facial gestures:

Parents need to be helped to get inside their child, to think about how she experiences the world and the sense she is likely to make of this.

(Lewis 2003: 306).

An understanding of families' social context and the impact of practitioner intervention is also relevant. For example, from Canada, Goddard et al. (2000) suggest that professionals need to be aware of the invasiveness of intended help and the lack of appreciation of the parents' personal context:

Once you have a child with a disability, it's almost like it's not your child, it belongs to the system...I already had a child and nobody came into my life. I had this child and within 3 months I had probably visits from 4 different professions – the health unit, child development centres, infant development on and on...I never had so many people in my life and you felt like this child did not belong to you.

(Goddard et al. 2000: 282)

What also appears important in relation to overcoming barriers for parents in discovering and defining disability is peer group support (UNICEF 2005, Dowling 2006). Mahoney and Wiggers (2007) suggest social workers can be instrumental in supporting and developing such groups and in involving parents in early intervention, 'One of the major barriers is that the majority of professionals in this field do not come from a theoretical and experiential background that emphasizes the role of parents in child development services' (2007: 14).

Therefore, training in parent and child focused communication for health care professionals, social workers and civil servants is needed, which would include: more accessible information provided by children, parents and professionals within government and within voluntary projects; dissemination of information through health and social work centres and children and parents' organizations.

Protecting a Child with Disabilities from Harm

Most social workers would support the social model of disability and are aware of the existence of barriers, inequalities and unequal opportunities for children with disabilities and their families. They would view this model equally as important as the medical model of disability which seeks to define, quantify and objectively test and then improve and sometimes cure different impairments. Dowling and Dolan* (2001) proposed that social organization disables, not just the family

member with impairment, but the whole family unit. They argue that by applying the social model to the family unit rather than just to the individual child, new ways for creating policies and practices can be developed for children with disabilities. This perspective fits well with the previous discussion concerning the involvement of families in the planning and implementation of early intervention initiatives. However if domestic violence and/or abuse of the child with disabilities is occurring within the family it is more difficult to apply such a model. Parents of other children with disabilities can encourage and support the individual family to seek help (Dowling 2006) but the complexity of the situation is that on the one hand the difficulties the family as a unit is facing need to be addressed while on the other hand the child with disabilities has a right to be protected from harm.

Baldry et al.* (2006) suggest that internationally, the occurrence of domestic and other forms of violence in families affecting children with disabilities is poorly understood. Studies suggest that the rates of abuse for children with disabilities are much higher than for children without disabilities but importantly available international studies do not distinguish between abuse in residential settings by carers and others unknown to the child or young person and abuse within the family (Sullivan and Knutson 2000).

The costs of looking after a child with disabilities: giving up work to look after the child, the costs of travel to appointments, treatment, special food and medical

equipment and medication, have meant hardship for many families. If families are also experiencing domestic violence, this may increase their sense of social exclusion at being 'different' and non-offending members of the family may be prevented from going out. These combined effects are likely to result in the non-offending carer of the child with disabilities being unable to leave. If the child has complex needs, it may be impossible to provide adequate care outside the family home. It has further been suggested that child protection and safeguarding teams do not have the knowledge of disabilities that is needed to complement their interventions (Morris 1999, Aarons and Powell 2003).

The combination of disability and child protection issues makes for a vulnerable population of children and creates dilemmas for professionals working with families with a child with a disability. A number of recommendations are suggested here to aid professionals where there is suspected violence and/or abuse to the child.

- It is important not to make assumptions about the level of impairment that the child is supposed to have. Many children in situations of domestic violence will be aware of threatened and actual violence in the home.
- Practice is enhanced when professionals work together with, and alongside, families to construct solutions which families can own and live with.

- Understanding the many different methods of communicating with children with disabilities is essential to give children the opportunity to create some control over their situation.
- For many children with disabilities relating to a stranger can be stressful and exacerbate difficult behaviours – it is important to seek advice on how to interact or talk to a child.
- Knowledge about local services – for example, short term respite care, intensive family support, or accessible women’s refuges - can be essential when determining a child’s safeguarding needs.
- Co-ordinated cross agency arrangements are invaluable and can determine for example the legal position regarding the non offending carer and child’s rights to stay in already modified accommodation.

Lundeby and Tøssebro (2007) point out that in Norway the family structure in raising a child with a disability is similar to other families. Whether this is a positive finding for parents’ relationships, or whether having a child with a disability may produce a stronger feeling of obligation to stay together, is not known. They also point out that the Norwegian welfare state system allows both

parents to work, while caring for their child with a disability, which can help maintain positive relationships within couples.

Supporting families and building community based services

Changing an institutional system to a community-based system is not a task that social workers can deal with alone, but when policies support that approach they can intervene to implement community based support systems. Additionally, their contribution in ensuring that parents and children have been consulted and have been heard can be of fundamental importance in changing policy and practice. For example it is important that parents and children are involved in defining criteria both in the development of community based projects and the evaluation of the outputs and impact of projects and interventions. However, even when providers create what they see as a positive transition from institutional care, it does not necessarily lead to a better quality of life for the young person or child with disabilities.

For example, in Bulgaria social workers' focussed intervention and development work with residents could have helped transform one Bulgarian institution (example 1) into a centre that offered day care, foster care, respite care, leisure and educational opportunities for disabled children and young people and group support for parents and providers (UNICEF 2005):

Example 1: Changes to institutional care – Bulgaria

The staff in the residential institution demonstrated an eagerness to modify their work towards community style living. They are building smaller houses in the nearby village with the idea that this form of accommodation is more suited to the needs of their residents. However the children and young people living in them hardly have any contact with the village residents and they still have their classes, meals and attend events in the main buildings of the institution. This well intentioned change is producing institutionalization in the community. Disabled children are still denied a voice and choice of where they live. Even though the new houses are well equipped, living in a remote village with elderly locals and heavy supervision from institutional staff has not brought mainstream socialization, inclusive education or employment

(Bećirević, M., Dowling, M., Seden, J. and Buchanan, I. 2010).

Example 2 shows another community based approach that *has* involved social workers in multi disciplinary work with NGOs and health professionals and defectologists (medical professionals in Eastern Europe who are qualified in disability practices):

Example 2 Good practice – day centre – Bosnia and Herzegovina

The day centre for children with multiple disabilities 'Koraci Nade' (Steps of Hope) is recognized for its ways of working. It was opened in 1994 with support from Oxfam and it has developed into an important community resource for children and parents. For several years the centre was financed by various international organizations and NGOs and now half of the financing comes from the Ministry for Social Policy and the rest from various fundraising activities. This centre emphasizes inclusion, with activities aimed at the promotion of children's rights, rehabilitation and socialization, and the encouragement of disabled children into mainstream schools. It also provides education for parents in order to equip them for their role. The centre works closely with the Faculty of Defectology in Tuzla which organizes some of the practical teaching and provides student volunteers for the centre employment

(Bećirević, M., Dowling, M., Seden, J. and Buchanan, I. 2010).

Developing community-based services, which are led by families and young people with disabilities, is a policy that can be applied to a variety of countries with different levels of service provision. The following further two examples develop this theme.

A group of parents with children with disabilities in Newham London were elected to the local council and began the process of radically changing mainstream schools so that all children, whatever their needs, could learn

together. They changed the percentage of children assessed as having special educational needs and attending mainstream schools from 7 per cent in 1986 to 79 per cent in 2001. An independent report noted that having to make better provision for all pupils had resulted in a marked improvement in school examination results throughout the Borough (UNICEF 2007).

In Mexico PROJIMO (Programme of Rehabilitation Organized by Disabled Youth of Western Mexico) has promoted many community based health and rehabilitation initiatives including the Children's Wheelchair project which produces over one hundred low cost customized wheelchairs a year from the Sierra Madre mountains (UNICEF 2007).

Foster care, independent living, personal assistance, respite care and outreach services can be developed and organized by local NGOs in cooperation with social workers. Successful local grassroots initiatives with parents and NGOs need to be identified and supported by social workers, national governments and international donors (Holland 2008).

Conclusion

This discussion of the role of professionals in delivering services for children with disabilities in different parts of the world shows the criticality of the three principle themes in relation to working with parents and children outlined in the

introduction. While services in some countries are embryonic, there is no room for complacency in the so-called developed world. Many of the issues raised remain unresolved for families in the UK and elsewhere. For the newly qualified practitioner, consultations with children with disabilities and their parents on what services they need and how these services could be achieved is essential. As well as close liaison with the family after the child's diagnosis, professionals' time is also well utilized by developing and supporting peer groups in the community that could help and advise children and young people and their parents.

There are some clear messages from the research included here. Parents and children in the community are still far from adequately supported and served. At the same time in many countries institutionalization is still the only option for disabled children. Improving community services and de-institutionalization are dependent on recommendations for action in a number of key policy areas (UNICEF 2005, 2007). Further research on domestic violence and child abuse in relation to children with disabilities is essential.

Best practice is associated with rights and the recognition that children and parents can be supported to exercise choice and control over services (United Nations 1989, 2006). The important message to take away from this chapter is that good working partnerships with parents, young people and children with disabilities are fundamental, accompanied by an active approach to skills development and building capacity in communities.

Questions for reflection

In what ways do I and my employing agency ensure that children with disabilities are heard and protected?

How can I use research findings to support and develop my work with children with disabilities and their families?