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Service provision of the differently abled children through social inclusion

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Abstract

Social inclusion is an important goal for people with intellectual and developmental disabilities, families, service providers, and policymakers; however, the concept of social inclusion remains unclear, largely due to multiple and conflicting definitions in research and policy. Social inclusion is a right as well as a goal of community-based services and supports. This paper identified Preventing Social Exclusion through different service Provision of Differently Abled Children and their Families. A narrative approach to synthesize the findings. Current directions in service development and delivery are importantly being shaped by the implementation of existing disability discrimination legislation, and with reference to children's rights.

Keywords: service, social, inclusion, exclusion

Introduction

In introducing this review, it was highlighted that human rights and disability rights approaches provide a key context within which to consider service delivery to disabled children and their families. Together they provide a useful framework from which to consider recent legislation and associated developments in the provision of services. For example, the Disability Discrimination Act 1995 highlights the importance of access to services, both 'mainstream' and specialist. The reiterates that the Disability Discrimination Act 1995 (and the subsequent Special Educational Needs and Disability Act 2001) has been an important driver in the improvement of services for challenged children and their families. The Council for Disabled Children (1999) have, however, reported in their review of local authority responses to Quality Protects that significant work was required to ensure that the intended impact of the Disability Discrimination Act 1995 occurs. For example, strategic planners were found to have little awareness of the implications of the Disability Discrimination Act 1995 for delivery of services, with a further lack of local data on population needs impeding a strong response to the requirements of the Act. The creation of the Disability Rights Commission in 2002 has increased the strength of the challenge to services to respond proactively to the rights and needs of both disabled children and adults.

Current Directions: Developing Integrated Services

Ensuring coordination between agencies, and developing multi-agency approaches, is a significant challenge. For example, some difficulties were identified in an SSI inspection programme of services to disabled children and their families conducted in 1997. This focused on eight Social Services Departments, and in each case explored inter-agency approaches with the voluntary sector, health and education. Two resulting reports (Removing Barriers for Disabled Children and Disabled Children: Directions for their Future Care) presented the evidence from the inspections and the outcomes of parallel initiatives and research. In bringing these reports to the attention of Directors of Social Services, the Chief Social Services Inspector raised a number of concerns about the ways in which services were offered to children and their families (Social Services Inspectorate, 1998). These included:

- A range of barriers to (and a limited range of) services.
- The rarity of needs-led assessment in Social Services Departments.
- A lack of staff training and a lack of staff groups with appropriate skills and knowledge.
- A lack of transparency to services users in terms of the roles and responsibilities of the different professionals who were working with them.
- Limited progress in joint planning and joint commissioning.

The move towards family support is important to stress within this review, given the acknowledgement that childhood disability can have implications for the whole family and family experiences can impact on individual children's opportunities and development. Walker (2002a) has identified that family support has received significantly less focus than immediate statutory protection concerns in British policy despite both being core within the Children Act 1989. In addition, family support was the underpinning within the 1989 UN Convention on the Rights of the Child. More holistic responses require greater cross-agency cooperation and multi-agency approaches. Families themselves have often had to take on the role of 'co-ordinators' of services for their children, which can be a source of stress for parents. This is perhaps particularly the case when parents take on this role but feel that their particular expertise and knowledge is not appreciated and taken on board by professionals.

The National Service Framework

The National Service Framework (NSF) for Children. has been set up as a ten year programme which aims to develop services that are child and family-led rather than organisationally driven. It is valuable to flag up the NSF Disabled Children's Standard (Standard 8), which is the central principle around which local service standards that are specific to disabled children. The main intended outcomes of this standard are presented as including improving health care and social care interventions, including diagnosis, assessment and access to services; and developing better early intervention and multi-agency responses, including the use of key workers and direct payments.

Every Child Matters Every Child Matters is a central element of the Government's strategy to tackle social exclusion among families with children (see ODPM, 2004a). This Green Paper for England was built both on concerns about past child protection failings, and an aim of integrating child protection and specialist services for children in need within the context of universal services. A common assessment framework has been identified as central to the implementation of Every Child Matters, to ensure that assessments build on previously collected information, reducing the possibility that parents and children would need to 'tell their stories' again and again. Also key is supporting parents and carers through both universal services and targeted specialist services. Integrated services and information availability are themes throughout, with the development of key worker provision an important method identified here.

Coordinating service delivery

It is clear from families' experiences that fragmented services can be disruptive to children and parents, and reduce the overall family time available for leisure and rest. For example, Heaton, Sloper, Roberts and Have highlighted from their research with families with technology dependent children, that hospital appointments could be better coordinated with school timetables and parents' own schedules to minimise disruption overall to families. Service coordination continues to be prioritised within Labour Government policy for social care, health, education and welfare services.

Education and Social Inclusion

Education provision, and non-educational (including multi-agency) services within educational settings, is increasingly recognised as central to the support and development that is required in ensuring social inclusion. Within this review, it is important to highlight the contribution of education to work with disabled children, both in terms of the delivery of teaching and learning, and in terms of the overall contribution to child, family and community well-being that the school can contribute towards. It is also important to acknowledge here that the childhood disability literature is not synonymous with work exploring 'special educational needs', and to be aware of the conceptual differences. Whilst it is not possible to provide an in depth review of the (broader) special educational needs literature, key concepts involved in policy debate and implications of school based practice for the social inclusion of disabled children are of value within this review. Inclusion itself as a concept has had specific meaning in relation to education and the support of children with special educational needs, and special needs, and it is important to consider the different use of language which exists in education-focused debate.

Special Educational Needs and disability

Since the introduction of education 'for all' in the late 19th century, children's needs have been characterised and categorised with reference to ability and disability, with corresponding consequences for the structural organisation of education and the delivery of teaching . This development of categorisation within the educational arena is relevant to the development of new understandings of impairment or disability, particularly those which are identified as having a cognitive or behavioural basis. This 'psychologization' of children and their development, explored by, presents as a largely clinical or medical model approach to understanding disability which is an important context to some of the 'special' education literature.

Education, disability and inclusion

The outcome of the Warnock Report was an understanding that the delivery of services to children with SEN could be placed on a continuum, rather than having a fixed approach to delivery as either 'mainstream' or 'special'. Provision for disabled children and children with SEN was developed whereby resources and services to support children with individual learning needs could be provided within mainstream schools: thus integration (where children considered to have SEN enter unchanged mainstream schools), and then inclusion (whereby schools respond to the diversity of the needs within the community served), became particular responses that sought to develop more diversity within schools and less segregation. Some writers have argued the resulting organisation of education could be understood to be 'systemic dualism', whereby both inclusive education and special education co-exist. 'Special' educational delivery to disabled children remains a high profile issue, for example as developed within recent policy debates during the 2005 general election.

The extended school and inclusion

Whilst the provision of both inclusive and 'special' education are relevant to understanding of social inclusion for disabled children, so too are the general developments being enacted in school-based services as a whole. Extended schools (e.g. see DfES, 2002b) are one potential way of ensuring that non-stigmatising services are offered to disabled children and other non-disabled children and families who require support or advice. The availability of services within school environments may also improve accessibility as well as professional knowledge and understanding concerning the range of provisions available. As Axford and Little (2004) note, children and families with social needs first of all turn to the services they currently engage with.

Leisure Services and Social Inclusion

We have previously seen that a significant concern amongst disabled parents and their families in relation to housing is the lack of space within the home for their children to engage in play, and that this should be considered an important part of any assessment of housing need. For services providing leisure and play opportunities to children, the particular problems posed by home environments for day-to-day leisure and play might be an important context to understand children's (including disabled children's siblings') support needs.

identifies the positive potential impacts of leisure as important in:

- Increasing self-esteem, confidence and psychological well-being.
- Enhancing physical health and fitness.
- Reducing the risk of illness.
- Contributing towards positive social interaction and relationships.

Family Support and Social Inclusion

The whole family is vulnerable to social exclusion. Parents may experience employment problems because of caring responsibilities. They have little time to themselves, and often miss out on holidays or even free evenings. Siblings sometimes feel restricted in taking part in everyday activities by the needs of their disabled siblings or by public attitudes towards them. In discussing the impact of disability on the disabled child and their family, the Audit Commission highlight the ways in which the whole range of service areas are important in preventing the social exclusion of all family members. Our earlier discussion of the impact of low family resources and restricted living spaces clearly has implications for all family members (e.g. as considered by. In addition, different individuals may have different needs – and even different interpretations of needs – which make whole family support a less than straightforward issue. The delivery of specific services to disabled children without addressing other individuals' needs may marginalise some family members (Beresford, Sloper, Baldwin and Newman, 1996) and perhaps especially fathers, as supporting parenting has often been equated with supporting mothering. For example, found that fathers of disabled children (who had arthritis) were in particular need of more support and information. also identified within her small-scale qualitative study that fathers of disabled children felt a particular need for more information and for someone (i.e. a particular worker with knowledge and understanding) to talk too.

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Parental reports suggest that in some families the service could be involved in looking after nondisabled siblings alongside the disabled child (enabling parents to recharge batteries, have space, and pursue another activity and so on). Other families were told that it was not possible for Outreach service staff to look after healthy or non-disabled siblings, and this meant that some families had not used the service as a result. Whilst there was no space within this review to include more clinically orientated research, it is important to note that there is evidence from clinical and psychological research that would support the importance of a whole family approach, that could acknowledge the import of the family as a system which can support young people's resilience when faced with difficult situations.

Conclusion

The development of services for disabled children has been contextualised in relation to the family home and resources, and many of the material and structural barriers faced by families are identified within the research literature. Current directions in service development and delivery are importantly being shaped by the implementation of existing disability discrimination legislation, and with reference to children's rights. The full breadth of policy as regards services for children (including educational policy and child care policy) is of direct relevance to the experiences of families of disabled children, and the abilities of services to develop and provide joined up services. Some of the research suggests that there are training needs and resource needs to support service development, for example in increasing the amount of inclusive and accessible leisure services for children. The research also suggests that the specific needs of families which include more than one disabled family member should be considered within the development of services. The complexity of family life, and the ways in which a fragmented organisation of services can exacerbate stresses within the family, are increasingly recognised within policy. Currently strong moves towards multi-agency working are being developed, although there are barriers faced within this process. Some of these barriers are specific to disability, and this includes issues concerning definition and discourse in the understanding of disability and need.

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