

Minority ethnic families with disabled children

A review of the literature

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The project ethnicity and disability

- There is limited knowledge about minority ethnic families with disabled children
- Systematic literature review
- Researchers in the disability field have been "colour blind"
- The field of immigration seems to have overlooked the fact of disability among the minority ethnic population

The studies presented

- From USA – Mexican and Puerto Rican families
- From UK – people from South Asian countries
- Denmark – minority ethnic families with children with rare disabilities
- Norway – families from Pakistan and from minority ethnic communities
- Most studies – qualitative interviews

Social deprivation, inequalities and discrimination

- Families with disabled children in USA and UK face relative deprivation
- Minority ethnic families in general experience being disadvantaged
- The combination of being minority ethnic and have a child with a disability means magnifying the disadvantage

Prevalence

- Emerson et al. (1997) have found higher prevalence of persons with intellectual disabilities in South Asian families in UK
- A well established link between poverty and higher rates of intellectual disabilities

Lack of information

- About the disability of the children
- About the service system
- Due to structural discrimination: information given in majority language, infrequent use of interpreters

The importance of the disclosure process

- Influence on how parents accept their child and how they cope with everyday stress (Hatton et al. 2003)
- Problems of meaning and acceptance
- Practical every day adaption to the disability of the child
- For South Asian parents: the disclosure process had a huge effect on their understanding of the condition of their child
- Informing their social network
- Facing the practical challenges
- Accessing the service system

Family attitudes towards disability

- Families primarily accept Western medical explanations and treatment
- Many families find consolation in their religion
- Little evidence that families seek alternative treatment instead of medical treatment
- Some seek alternative treatment in addition to medical ones
- A complex relationship between religion and medical treatment
- Families risk meeting negative attitudes and different explanations in their extended families and social networks
- May lead to isolation or fear of bringing their children to family, religious or social events

Living with a disability when one is a member of a minority ethnic family

- Strong an positive sense about their ethnic identities
- Bullied because of disability, discriminated against because of ethnicity: double discrimination
- Religion a key factor in shaping identity
- Ambivalence because of lack of religious socialising
- Ambivalence about ethnicity, more positive attitudes towards disability in the British society
- Not one identity as disabled, regarded oneself as normal
- Identity formation a dynamic process and always negotiated in context

Meeting the service system

- Met with stereotypes about how they react to having a disabled child
- Stereotypes of the extended family
- Language and communication are the biggest barriers to the access and uptake of services
- Limited use of interpreters
- Lack of knowledge about the service system, especially the more specialised services
- As in other families: lack of co-ordination of services, lack of availability, quality and timeliness
- Need of a key worker
- Parents want information in relevant languages and services that are culturally sensitive