

“Parents views of services for early years children with disabilities”

Bernice Bird, Sam Carson & Rita Lewis

Structured interviews were carried out with a sample of parents [16] who had children with severe or profound disabilities. When parents were approached for this research, they were invariably cooperative and keen to have their views heard. When asked about the services and supports that they had received, they readily praised those aspects that they found valuable; and were modest in their criticisms. For many parents, there were things that could have been done differently that would likely have had significant benefits for them and their children. Both service systems and communities will learn from listening to the views of parents.

Considerable research suggests that families cope better when they have strong support from their own families, friends and communities. These are their contextual resilience, which help to reduce the likelihood of mental health problems, parental conflict, etc. Conversely, families do not cope well when they do not have good natural supports. They are seen to have significant risk factors.

“We must delight in each other; make others’ conditions our own; rejoice together; mourn together; labor and suffer together; always having before our eyes our community as members of the same body.”
Winthrop (1965)

Families cope better when they receive appropriate services. Likewise, families do not cope as well when they do not receive appropriate services; or if they receive inappropriate services.

“Professionals now have the responsibility to collaborate with families in ways that empower families; rather than assuming an expert-novice relationship.” Klein & Gilkerson (2000)

Planning and provision for the complexities of different childhoods and family lives are essential but make unique demands on even well established services. Children with apparently similar presenting difficulties will be quite different to each other and will be growing up in very different family situations.

There were three inter-related but distinctive areas for which parents wanted help :

Specific programmes for the child:

Early, evidence-based and specialist interventions are effective for establishing and extending early skills. e.g. Portage interventions; speech & language programmes; Early Bird parent training, etc.

Social inclusion opportunities for the child:

Traditionally, disabled children have often had their social lives postponed in favour of focusing on remediation of their disabilities. i.e. their disability was seen as the most important thing about them and was treated as priority. By putting the child first, the challenge of successful inclusion in mainstream settings and activities has only begun to be faced.

Support for the parent(s):

The wellbeing of the child is intimately entwined with the wellbeing of their parents. If it all becomes too much for the parent and the family, in spite of their best efforts, then the child suffers. Parents also have needs. With the right support, they can provide the optimum family life for their children and themselves.

BME parents referred to the 'double disadvantage' of children with a disability who are also black or from an ethnic minority. Consequently this can increase the likelihood of them being social excluded. Practitioners working with these children need to understand the child's and their family's cultural context, to ensure that services and support are appropriate, accessible and acceptable.