



Disabled Children Matter Wales
Plant Anabl yn Cyfri Cymru



“The right information at the right time” **Reading List**

Reports

Joseph Rowntree Foundation: [User Friendly Information for Families with Disabled Children: A Guide to Good Practice](#) (2000)

This project explored the criteria by which parents judge the quality of information and their ideas of good practice in this area.

Scope: [Sharing information with disabled children in the early years: a summary of research carried out by In The Picture project in 2006.](#)

(2006)

According to this report, 68% of parents have not had access to materials that explain their child's impairment, making it impossible to communicate with the child about how they are feeling and why they feel that way.

Social Policy Research Unit: [The Information Needs Of Chronically Ill Or Physically Disabled Children And Adolescents](#) (1999)

This report looks at the information needs of chronically ill and physically disabled children and adolescents; including information relating to the condition and its management, as well as information about the impact of the condition on other aspects of the young person's life.

Social Policy Research Unit: [Care coordination and key worker services for disabled children in the UK.](#)(2004)

Reports the key findings of a survey on the situation of care coordination for disabled children in the UK. Thirty-five local authority areas (22 per cent) had a scheme in place and 50 were due to be developed. The majority had health, education and social services involved, but only eight had joint funding and only nine had permanent funding. The involvement of children and young people was not common, but parents were usually involved. Between a half and two thirds of the schemes had some form of training for key workers

Social Care Institute for Excellence: [The Road Ahead Information for young people with learning difficulties, their families and supporters at transition](#) (2004)

The Road Ahead project explores the nature of the information needed by young people with learning disabilities, their parents and supporters at transition.

Journal Articles

DAVIES, S., and HALL, D. (2005), ['Contact-a-Family': professionals and parents in partnership](#). *Archives of Disease in Childhood*, vol.90, no.10 (Oct). pp1053-1058

Considers the evidence base on the role of parent organisations in meeting the needs of parents of disabled children for information and support. Findings suggest that how and when information and support are provided will impact on how well the family adjust and cope.

GRECO, V and others (2007) [Key worker services for disabled children: the views of parents](#). *Children & Society*, vol.21, no.3 (May) pp162-174.

(Reports findings from 68 interviews with parents of disabled children who are users of seven key worker schemes in England and Wales. Findings indicate that while having a key worker did help relieve some parental anxieties, the schemes did not always work as effectively as they might. For example, some workers were not able to spend sufficient time with them as families, listening to their views and opinions about what help they required.

Mitchell, W. and Sloper, P. (2002) ['Information that informs rather than alienates families with disabled children: developing a model of good practice'](#), *Health and Social Care in the Community*, vol 10, no 2, pp 74-81.

This paper looks at how parents like to receive information and also discusses the empowering potential of user-friendly information.

PAIN, H. (1999) [Coping with a child with disabilities from the parents' perspective: the function of information](#). *Child: Care, Health and Development*, vol.25, no.4 (Jul). pp299-312.

Study explored what information parents had received, from whom and its usefulness. Personal communication was the most cited medium, while professionals, other parents and voluntary organisations were the most frequent sources. The benefits of information included emotional adjustment to the child's disability, access to services and benefits, management of the child's behaviour.

SLOPER, P., and others (2006)

[Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families?](#) *Child: Care, Health and Development*, vol.32, no.2 (Mar). pp147-158.

Research surveyed parents who were receiving a service in seven key worker schemes in England and Wales. Results indicated that key workers carrying out more aspects to the role, regular training, supervision, peer support, having a dedicated service manager and a clear job description, were associated with better outcomes for families.

This reading list was put together by the Children in Wales Policy Information Service. For further information, or if you have anything you would like to add to this list, please e-mail info@childreninwales.org.uk.