



**Disabled Children Matter Wales**  
**Plant Anabl yn Cyfri Cymru**



*“The health services they need to lead an ordinary life...”*

## Reading List Disabled Children and Health Services

### Reports

AUDIT COMMISSION: [Services for disabled children: a review of services for disabled children and their families.](#) (2003)

Presents findings of a study of over 240 disabled children and young people and their siblings, parents and cares regarding their experiences as service users. Key issues addressed included play, leisure, friendships, school and education, health, housing, social services and transport. The findings were intended to provide evidence for the improvement of service planning and delivery.

Barnardo's & Whizz-Kids: [Don't push me around! Disabled children's experiences of wheelchair services in the UK](#) (2006)

This report highlights concerns about the current state of wheelchair provision for children in the UK.

Barnardo's: [Breathing Space: Community Support Of Children On Long Term Ventilation](#) (2003)

Report looking at the experiences of children who need long term ventilation – including children staying in hospital for prolonged periods because of lack of co-ordinated care in the community.

Barnardos & NCH [Are You Listening? What Disabled Children and Young People in Wales Think about the Services They Use: A Consultation to Inform the Children and Young People's National Service Framework](#) (2003)

Many disabled children and young people are anxious about attending hospital.

Children in Wales: [Shortage of Therapy Provision for Disabled Children in Wales](#)

Paper highlighting the wide variety of therapies that are available to meet the needs of disabled children and young people, and the difficulties faced in accessing them.

Contact a Family: [Wheelchair Services for Children and Young People in Wales](#) (2006)

This paper reports on the results of a survey carried out by Contact a Family in 2006 asking families about their experiences of wheelchair services. The survey highlighted a number of specific concerns for families.

Contact a Family: [The Bottom Line: What do parents want from the continence supplies service for children and young people in Wales?](#) (2007)

Highlights the problems faced by the families of children and young people who use continence supplies and to make suggestions for improving the continence service in all parts of Wales.

Contact a Family & Association for the Welfare of Children in Hospital: [Parking at Hospital Sites](#) (2004)

This paper reports on a survey carried out by Contact a Family & AWCH of parents living in Wales whose children access hospital facilities either within the principality or across the border in England.

Family Fund & Norah Fry Research Centre: [All Together Better – A guide for families of a disabled child with complex health care needs](#) (2004)

A guide for families to ensuring that at review and assessment meetings professionals consider the needs of the family as a whole, not just the medical needs of the disabled child.

SCIE: ['Necessary stuff' - The social care needs of children with complex health care needs and their families](#) (2007)

A knowledge review identifying what is known about the social care needs of children with complex health care needs and their families, and about the services designed to meet those needs.

Scope: [Fighting Hard](#) (2003)

Parents' experience of accessing communication support for their child.

Scope: [No Voice, No Choice! – Wales Briefing](#) (2007)

This research focuses on the experience of communication aids provision by people who use communication equipment.

## **Journal Articles**

DOBSON, A. (2003) [Road to good health](#). *0-19: Zero2Nineteen*, no.2. pp24-25.

Discusses the findings of two reports to the National Assembly for Wales, which highlight the need for more accessible health services for disabled and marginalised children.

Diehl, S.F., Moffitt, K.A. and Wade, S.M. (1991) ['Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings'](#), *Children's Health Care: Journal of the Association for the Care of Children's Health*, vol 20, no 3, pp 170-8.

The purpose of this paper was to identify the needs of parents of children with medically complex needs from their own perception. The most persistent need was for a general organization or framework with which the care providers could operate

MILNER, J., and others (1996) [Needs of disabled children and their families](#). *Archives of Disease in Childhood*, vol.75, no.6 (Nov). pp399-404.

In the new NHS those who provide services for disabled children need to measure and demonstrate their effectiveness, but there are no easily available outcome measures for use by child development centres and teams. The development of an alternative approach, using a series of statements of good practice, is described.

SLOPER, P., and LIGHTFOOT, J. (2003) [Involving disabled and chronically ill children and young people in health service development](#). *Child: Care, Health and Development*, vol.29, no.1 (Jan). pp15-20.

A report on a survey of health authorities that found consultation activities with chronically ill or disabled young patients are few in number, but encompass a range of ages and service settings and use a variety of methods. Young patients are rarely involved in subsequent decision-making to develop services.

TOWNSLEY, R., and ROBINSON, C. (1999) [What rights for disabled children?: home enteral tube feeding in the community](#). *Children & Society*, vol.13, no.1 (Feb) pp48-60.

Reports on the preliminary findings of a project which aims to assess the practical, social and emotional impact of home enteral tube feeding [HETF] on the lives of disabled children and their families. The evidence presented suggests that guidance and training on HETF for non-parent carers is both inadequate and inconsistent. Consequently access to education and social services may be restricted or even denied for disabled children on HETF as a direct result of their perceived need for nursing or medical care.

Watson, D., Townsley, R., Abbott, D. (2002) [Exploring Multi-Agency Working in Services to Disabled Children with Complex Healthcare Needs and their Families](#) *Journal of Clinical Nursing*, Vol 11, No 3, May 2002, pp.367-375

This paper examines the literature on barriers to disabled children and the need for multi-agency working.

This reading list was put together by the Children in Wales Policy Information Service. For further information, please e-mail [info@childreninwales.org.uk](mailto:info@childreninwales.org.uk).