



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



## ***“A real say in planning the services they receive”***

### **Reading List**

## **Participation and Consultation with Disabled Children**

### **Books and Reports**

Barnardos & NCH: [Are you listening? What disabled children and young people think about the services they use](#) (2003)

This consultation was carried out with disabled children and young people to inform the development of the Children and Young People National Service Framework. It asked for their views on the services they use and recommendations for health, education, social care and leisure services across Wales.

Children in Scotland: [Onwards and upwards: involving disabled children and young people in decision making.](#) (1999)

A training manual for professionals Based on research and consultation with young disabled adults and practitioners. Manual includes discussion activities with sections on communication and advocacy; why children should be involved; what 'involvement' is; ways in which children may be involved.

Joseph Rowntree Foundation: [Consulting with disabled children and young people](#) (2001)

Report giving an overview of two projects that supported disabled children and young people to have their say in policy, and through producing a training video for practitioners on communication.

Joseph Rowntree Foundation: [Don't leave us out: Involving disabled children and young people with communication impairments](#) (1998)

Don't leave us out explains how Jenny Morris and her co-researchers set about obtaining the views and experiences of 30 young disabled people, many of whom were described as having severe communication and/or cognitive impairments, regarding the plans and provisions made for them by local authorities and others.

Mencap: [Listen Up](#) (2004)

Listen up is a toolkit of multimedia resources to help children and young

people with a learning disability complain about the services they use. The pack contains materials for children / young people / parents and professionals. It is free and can be ordered from Mencap.

NCB: [Listening to young disabled children](#) (2004)

This is part of a series about “listening as a way of life”. Available to order from NCB.

Save the Children: [Learning to listen: consulting children and young people with disabilities](#) (2001)

This report is based on a consultation with disabled children carried out by Save the Children in Hammersmith and Fulham.

Scope: [A Lot to Say!](#) (2002)

A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments.

The Children’s Society: [“Ask us 2”](#) (2003)

A CD – ROM presenting key messages from disabled children and young people using images, words and music produced by them. Important issues addressed include children's rights, safety and security, social inclusion, independence, choice, and participation in decision-making.

The Children’s Society: [How to Ask Us](#) (2005)

This addressed how The Children’s Society involved disabled children and young people and what was learnt from the experience. The pack includes: a CD Rom illustrating the many methods that were used to involve disabled children and young people, a briefing paper summarising the learning from the “Ask Us” initiative including messages from young people and staff about consultation and a report on the impact of Ask Us.

Triangle: [Getting it right: involving disabled children in assessment, planning and review processes.](#) (2003)

A practice guide for involving disabled children in assessment, planning and review processes. Written with help from disabled young people, it is full of practical ideas for making initial contact with children, working directly with children, observing children respectfully and representing children's views.

## Journal Articles

Badham (2004) '[Participation – for a change: disabled young people lead the way](#)' *Children and Society* 18 (3): pp 143-54.

This paper proposes a framework for social inclusion that is influenced by children and young people and not reliant on changing fashions in Government.

Carnaby, S., Lewis, P., Martin, D., Naylor, J., and Stewart, D. (2003) '[Participation in transition review meetings: a case study of young people with learning disabilities leaving a special school](#)', *British Journal of Special Education*, 30 (4), pp.187-193

Report of a two-phase study in a special school which looked at the extent to which young people with learning disabilities are involved in the transition process.

Cavet, J. and Sloper, P. (2004) '[The participation of disabled children in individual decisions about their lives and in public decisions about service development](#)', *Children and Society* 18 (4): pp 278-90.

Reports on a literature review looking at existing evidence relating to disabled children's participation in decision-making. The evidence suggests that disabled children hold and can express their views, given the right environment. However, participation of disabled children needs further development.

DAVIS, J.M. (2007) '[Analysing participation and social exclusion with children and young people: lessons from practice](#)'. *International Journal of Children's Rights*, vol.15, no.1. pp121-146.

Critically reflects on a variety of definitions of social exclusion, including the idea that for children social exclusion can be overcome by their involvement in participatory projects. Compares these with the views of disabled children and young people themselves on participation and exclusion who were involved in two projects carried out in Liverpool.

HOLME, N., and HANMORE, R. (2001). '[Consulting with disabled children and young persons: a methodological framework](#)'. *Research Policy and Planning*, vol.19, no.1. pp25-33.

Describes a consultation exercise undertaken with disabled children who were attending at least one local authority, health or voluntary service in Blackpool. The methodology used, its evaluation and the main findings are discussed.

JONES, H. (1999) [The right to be seen and heard: bringing disabled children into focus.](#) *Childright*, no.161 (Nov). pp8-10.

Describes a project initiated by the International Save the Children Alliance which is documenting examples of violations of rights and good practice in relation to disabled children and the UN Convention on the Rights of the Child. An emerging issue is the invisibility of such children.

MILLER, A. (2003) [The ask force.](#) *Community Care*, no.1458 (6 Feb) pp34-35.

Reports on a project run by the Children's Society that aims to give disabled children an opportunity to tell the government and professionals what they want and need, and how important it is for them to be involved in planning services.

PRIESTLEY, M. (1998) [Listening to disabled children.](#) *British Journal of Social Work*, vol.28, no.6 (Dec). pp969-973.

Emphasises the need for researchers to engage directly with children and take seriously their interpretations of the world. Uses three examples to illustrate some recent attempts to listen to the experiences of disabled children.

RUSSELL, P. (2003) ['Access and achievement or social exclusion?'](#) *Children & Society*, vol.17, no.3 (Jun). pp215-225.

This paper argues that services for disabled children are characterised by innovative and effective models for parent and child participation in decision-making. Concludes that wide regional variations and issues of resources and staffing remain a challenge if disabled children are to remain central to policy and are to benefit from the range of services they require.

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.

FRANKLIN, A., and SLOPER, P. (2006) [Participation of disabled children and young people in decision making within social services departments: a survey of current and recent activities in England.](#) *British Journal of Social Work*, vol.36, no.5 (Jul). pp723-742..

Franklin and Sloper surveyed all social services departments in England in order to identify and investigate current work concerning the participation of disabled children in

decisions regarding not only their own care but also service development. The results show that disabled children are being involved in a range of decision-making areas; however, participation is not yet embedded or sustained across all social services departments, and the involvement of disabled children at a higher strategic level is still rare.

TISDALL, E.K.M., and DAVIS, J. (2004) [Making a difference? Bringing children's and young people's views into policy-making.](#) *Children & Society*, vol.18, no.2 (Apr). pp131-142.

*Drawing on the literature on policy networks, charts how adults, children and young people involved in a consultation project undertaken by Children in Scotland were able to increase the resources of the participating groups so they did have influence. The project involved consulting disabled children and young people on the Scottish Executive's policy review on special educational needs.*

WATSON, D., ABBOTT, D., and TOWNSLEY, R. (2007) [Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services.](#) *Child: Care, Health and Development*, vol.33, no.1 (Jan). pp90-95.

Children with complex healthcare needs are often excluded from direct consultation in services. During a 3-year research study into multi-agency services for children with complex healthcare needs, the authors involved children in a number of innovative ways.

WILSON, L.M. (2004) [Towards equality: the voices of young disabled people in Disability Rights Commission research.](#) *Support for Learning*, vol.19, no.4 (Nov). pp162-168.

Considers Disability Rights Commission research findings in relation to the need for the voices of young disabled people to be heard in research, policy and planning. A key finding was that young disabled people want to be regarded and treated as equal to their peers, with the same rights of access and educational opportunity.

## **Parent Participation**

Children in Scotland: [Dad's the word.](#) *Children in Scotland Magazine*, (May). pp14-15. (2005)

Reports on a pioneering support group in Scotland that aims to give fathers a voice in matters that affect the care of their disabled child

Contact a Family: [Participation and parents of disabled children in Wales Survey](#) (2006)

Contact a Family set out to find out how far parents of disabled children in

Wales are involved in the planning and delivery of the services which most affect them and their children.

Contact a Family: [Parents' Voice Project Reports on Parent Participation work: Isle of Anglesey County Council & Special Families Forward Group in Swansea](#)

Two reports on work by the Development Officer for the Parents' Voice Project which provided opportunities for parents to comment on and influence policy at national and local level.

Contact a Family & Council for Disabled Children: [Parent participation: improving services for disabled children: Parent's Guide](#). (2004)

Guide intended for parents offering examples and suggestions to help professionals and parents become effective participants in the planning, development and delivery of services for disabled children..

Contact a Family & Council for Disabled Children (2004)

[Parent participation: improving services for disabled children: professionals' guide](#). (2004)

Guide intended for professionals covering key principles involved in successful participation. Offers practical examples detailing methods and good practice on consulting with parents to improve services for disabled children. Includes a section on monitoring and evaluation.

DICKINS, M. [Forging an alliance](#). *Coordinate*, issue 67. pp4. (1998)

The Government has put great emphasis on the importance of partnership with parents of disabled children in their early years, and on the value of early diagnosis of special needs. The author explores the emotional and political context of partnership with families.

Parents for Inclusion: [All our children belong: exploring the experiences of black and minority ethnic parents of disabled children](#). (2004)

Report on the result of a three-year pilot project which examined the experiences of black and minority ethnic families seeking inclusion for their disabled children. It outlines how families described being subject to discrimination and negative stereotyping when trying to access services, information or support.

RUSSELL, F. (2004) [Partnership with parents of disabled children in research?](#) *Journal of Research in Special Educational Needs*, vol.4, no.2. pp74-81. (1997)

This article sets out the rationale for parent's partnership in educational research and proposes a parents' participatory research approach.

RUSSELL, P: [Working in partnership with parents of children with](#)

**disabilities. Children UK**, no.12 (Spring). pp14. (1997)

What does partnership with parents really mean for professionals working with the families of children with disabilities? Russell, Director of the Council for Disabled Children, explains.

WELLARD, S. [It's the taking part](#). *Community Care*, no.1589 (8 Sep) pp44. (2005)

Short article on involving parents of disabled children in service developments

West, S. (2000) [Just a Shadow? A Review of Support for the Fathers of Children with Disabilities](#), Birmingham: Handsel Trust.

This book reports the findings of interviews with four fathers of children with disabilities.

## Policy Context

### [United Nations Convention on the Rights of the Child](#)

Article 12: “*States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.*”

## Wales

Children and Young People's Participation Consortium and the Participation Unit: [National Standards for Children and Young People's Participation for Wales](#)

Children and young people are all different but you **all** have the same right to have a say about the things that matter to you. We want everyone to feel welcome and be able to get involved if they want to be.

Welsh Assembly Government: [Children and Young People: A Framework for Partnership](#) (2000)

Proposes a way in which all of the local partners who provide services for children and young people can work together in an integrated framework, designed to meet the needs of children rather than those of service providers

Welsh Assembly Government: [Children and Young People: Rights to Action](#) (2004)

The document gives details of the progress that has been made by the Assembly in relation to children and its commitments for the future.

Welsh Assembly Government: [Extending Entitlement](#)

Extending Entitlement is the Welsh Assembly Government's flagship policy for youth support services in Wales. It includes all services, support and opportunities for young people between 11 and 25, wherever they happen, whoever is delivering them and wherever the funding originates.

Welsh Assembly Government: [The National Service Framework for Children, Young People and Maternity Services \(2005\)](#)

A 10 year strategy which sets national standards to improve the quality and reduce variation in service delivery for children and young people across health, social care and other local services. Sets out that children, young people should participate as partners in planning and evaluation of the services that affect them.

Welsh Assembly Government: [Special Educational Needs Code of Practice for Wales \(2002\)](#)

- "Partnership with parents plays a key role in promoting a culture of cooperation between parents, schools, LEAs and others. This is important in enabling children and young people with SEN to achieve their potential." (Section 2.1)
- "Children and young people with special educational needs have a unique knowledge of their own needs and circumstances and their own views about what sort of help they would like to help them make the most of their education. They should, where possible, participate in all the decision-making processes that occur in education including the setting of learning targets and contributing to IEPs, discussions about choice of schools, contributing to the assessment of their needs and to the annual review and transition processes." (Section 3.2)

## UK

[Health and Social Care Act 2001\(England and Wales\)](#)

The Health and Social Care Act 2001 places a duty on health authorities, primary care trusts and NHS trusts to involve and consult 'persons to whom those services are being or may be provided' on 'the planning of the provision of those services, the development and consideration of proposals for changes in the way those services are provided, and decisions to be made by that body affecting the operation of those services.' (Section 11)

[The Children Act 1989](#)

The Act emphasises the importance of the role of parents in their children's lives, and a key theme is that of partnership with parents.

[Disability Discrimination Act 2005](#)

Disability Discrimination Act 1995 amended by the Disability Discrimination Act 2005 introduced a new Disability Equality Duty on all public authorities. The duty ensures that any public body should promote equality of opportunity

between disabled persons and other persons and encourage participation by disabled persons in public life. It also requires the public body to issue a Disability Equality Scheme and state how disabled people have developed the scheme.

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](mailto:info@childreninwales.org.uk).