



The following information resources have been selected by the National Health Library and Knowledge Service Evidence Virtual Team in response to your question. The resources are listed in our estimated order of relevance to practicing healthcare professionals confronted with this scenario in an Irish context. In respect of the evolving global situation and rapidly changing evidence base, it is advised to use hyperlinked sources in this document to ensure that the information you are disseminating to the public or applying in clinical practice is the most current, valid and accurate. For further information on the methodology used in the compilation of this document—including a complete list of sources consulted—please see our [National Health Library and Knowledge Service Summary of Evidence Protocol](#).

YOUR QUESTION

Methodologies or protocols for, or experiences in, recruiting persons with disabilities onto national committees or working groups or consultative committees or policy development groups for effective co-design in disability services.

IN A NUTSHELL

There is general consensus that those who are effected most by decision making relating to disability services and policies should participate in the decision making process where possible [6, 17, 18, 20, 21](#). In 2016, the National Disability Authority¹ published a report which aimed to identify and examine models of engagement and participation of people with disabilities in developing services. The report points out that the engagement and participation of people with disabilities in developing services can be complex and requires careful consideration of the following factors including the development of user-led organisations; underpinning user involvement in policy and practice with a statement of principles that has strong political support; assurance or formal and systematic evaluations of participatory mechanisms which involve people with disabilities; adequate funding; and achieving participation among users in rural or more remote areas.

Ottmann and Laragy⁷ outline the 10 lessons learned from the development of a consumer-directed care programme in Australia including early participant involvement; open, inclusive communication; ongoing commitment and support from management and key stakeholders; effective knowledge transfer and cultural change; capacity building; mediation of power differentials; community building; and participant re-engagement.



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GUIDANCE AND GREY LITERATURE (ADULT)

[National Disability Authority \(2016\) Research on engagement and participation of people with disabilities in developing services \(policy and practice\)¹](#)

The NDA, as the statutory independent advisory body on matters concerning disability, commissioned research to inform the Transforming Lives working group in their process to develop systems and structures to promote effective participation. The purpose of this study was to identify and examine models of engagement and participation of people with disabilities in developing services in at least 4 jurisdictions.

Table 1 on page 9 sets out categories of user participation:

System Level	Individual Level
Forum; council; partnership board; expert reference groups; user representation on government; advisory and provider committees; planning boards; involvement in commissioning services.	User-led organisations and networks, advocacy groups and individually oriented activities
System Level Activities	Individual Level Activities
Evaluation: eg citizen's jury; staff appraisal; staff recruitment; auditing services. Involvement in the design and delivery of education and training programmes. Users employed to represent and advocate for others.	Person-centred planning. Control of own care including the use of personal budgets: eg direct payments/personal assistance. Participation in surveys; interviews; focus groups; consultations.

See also Section 1.6: Key Learning for Ireland

One of the key findings is that there is no one method or model of participation which is recommended over another. Participation and engagement mean different things to different individuals. Individual countries use different approaches and methods of engagement based on their social, cultural and institutional histories and they have adopted a variety of approaches in different policy areas: eg in relation to mental health

or intellectual disability. The countries considered in this research have all increased the level of user involvement in disability services in recent years. Key points for Ireland to consider include:

1. User-led organisations have a role to play in developing and supporting effective engagement and participation.
2. It is important to underpin user involvement in policy and practice with a statement of principles that has strong political support.
3. A whole systems approach to service user participation is recommended which incorporates culture, structure, practice and review.
4. People with disabilities should be supported to participate at multiple levels in society, from the micro or individual to the macro council/board and ministerial level.
5. Online services should be used to promote user engagement.
6. Different models of involvement are appropriate for different people.
7. The provision of personalised budgets can play a significant role in empowering and engaging people with disabilities in the development of services and supports.
8. Initiatives for user involvement, engagement and participation should be regularly evaluated and reviewed.
9. People who are involved with services should always be given feedback on the outcome of their involvement.
10. Countries should adopt a long-term perspective to user engagement and participation.
11. User engagement and participation should be adequately resourced.
12. The objectives of any engagement or participation should be clear and realistic.

See also Section 1.7 Key Issues for Consideration

The engagement and participation of people with disabilities in developing services can be complex and requires careful consideration of the following factors:

1. Successful engagement and participation of people with disabilities demands a culture shift within services whereby the service user is viewed as a partner in developing services.
2. User participation initiatives require continual awareness of the context of power relations. Exclusionary structures, institutional

- practices and professional attitudes can affect the extent to which service users can influence change.
3. Formal and systematic evaluations of participatory mechanisms are needed which involve people with disabilities. The implementation of national engagement and participation policies has to be monitored. As noted in a number of studies, there have been limited formal and systematic evaluations of participatory mechanisms and practices by service providers. There has also been limited inclusion of people with disabilities in evaluations. This highlights the need to: carefully build in a plan to evaluate any mechanism which may be adopted to encourage participation; and take steps to include people with disabilities in ongoing service evaluations.
 4. Funding, resource and payment requirements need to be addressed. It is vital to give sufficient attention to the funding and resource requirements for user involvement when policies and programmes are being developed and implemented. The need to reimburse costs incurred by those using services who participate in particular kinds of initiatives is generally accepted.
 5. The engagement and participation of people who live in remote areas needs to be facilitated. Whilst the scale of the physical distances involved are greater in many of the countries considered here than in Ireland, there is evidence that achieving user involvement in rural and more remote areas is more problematic. Services operating in such areas may need more resources to successfully secure user participation. A possible learning point is that the resources allocated to rural services may need to be reviewed and monitored if opportunities for user participation are to be the same across the country as a whole.

Implementing engagement and participation policies involves education, training and resources, alongside effective leadership and political will in order that policy is translated into action.



[HSE \(2018\) Effective Participation in Decision-Making for People with Disabilities and Families Planning for Ordinary Lives in Ordinary Places A Step by Step Guide to Implementation for HSE Managers and Social Care Staff²](#)

This guide offers a route-map to the effective participation of people with disabilities in making decisions about the design and delivery of the supports needed to live fully inclusive lives as valued members of the community.

[Inclusion Ireland \(2017\) Making Equality and Rights Real: A toolkit for setting up Equality and Rights Committees in Disability Services Toolkit³](#)

In 2017, Inclusion Ireland completed a year-long project to develop a toolkit for setting up equality and rights committees in disability services.

[Centers for Disease Control and Prevention \(2020\) Disability and Health Resources for Facilitating Inclusion and Overcoming Barriers⁴](#)

The CDC provide a document from the ADA on their website: [Accessible Information Exchange: Meeting on a Level Playing Field](#). It provides guidelines and strategies to help organizations make their meetings accessible and welcoming to people with disabilities.

INTERNATIONAL LITERATURE (ADULT)

What does the international literature say?

[Lakhani et al \(2018\) Perspectives of self-direction: a systematic review of key areas contributing to service users' engagement and choice- making in self- directed disability services and supports⁵](#)

Self-directed disability support policies aim to encourage greater choice and control for service users in terms of the health and social care they receive. The proliferation of self-directed disability support policies throughout the developed world has resulted in a growing amount of research exploring the outcomes for service users, and their families and carers. Our understanding of the issues faced by people with disabilities, particularly how they make health and social care decisions and the key areas that determine their engagement with service providers within a self-directed environment is limited. A synthesis of research is timely and can provide knowledge for service users and health and social care support providers to ensure their

successful participation. A systematic review guided by the PRISMA approach explored: 1. the key areas determining service users' engagement with self-directed disability services and supports; and 2. how service users make informed decisions about providers. In October 2014 and April 2016, three databases — MEDLINE, CINAHL and Web of Science — were searched for research and review articles. 18 sources met the search criteria. Findings were mapped into either: key areas determining service user engagement, or service users' informed decision-making. Findings concerning key areas determining engagement fell into three themes: personal responsibility for budgeting, personalised approaches, and a cultural shift in practice and delivery among service providers. Findings about decision-making yielded two themes: supporting informed decision-making and inhibiting informed decision-making. Literature suggests that self-directed models of care may provide service users with increased control over the services that they receive. Increased control for some service users and their families requires independent external decision-making support, particularly around the domains of budgeting, planning and hiring. Future research must continue to investigate the perspectives of service users pertaining to their engagement, as their participation is central to the effectiveness of the approach.

[Goodrich et al \(2017\) \[Conference Abstract\] ISQUA17-1743 People with learning disabilities as equal partners in service improvement⁶](#)

Introduction: A national UK charity which campaigns alongside thousands of people with a learning disability and their friends and families for the changes they want to see in society states that “learning disability has been invisible for too long. It's time to see people with a learning disability for all they are and all they can be.” A series of public inquiries has highlighted poor care in health and social care services for people with learning disabilities. Experience based co-design (EBCD) is a participatory action research method which has also been used increasingly as a quality improvement approach to improve the experience of service users. The majority of projects in England have been in acute hospitals. However, it has been successfully adapted for learning disability services and has enabled service users and their carers to make their experiences heard and to work as equal partners in making improvements. Objectives: 1. to improve the experience of care for people with learning disabilities using the EBCD approach; 2. to demonstrate that the EBCD method can be adapted successfully in learning disability services. Methods: EBCD is a method with two phases: the discovery phase; and the design phase. The discovery phase involves collecting information about the



experience of both service users and staff through interviews which are filmed, observation and emotional mapping. Events are held separately with staff and service users to identify priorities for improvement. The co-design phase involves staff and patients meeting together to discuss priorities, review the films and choose three or four areas to re-design. Working groups are formed and over the next few months, staff and service users together create ideas, prototype and test and implement improvements. There is now a good body of evidence to show that positive outcomes are achieved in terms of service improvements and impact on participants. Results: Better communication with service users was made an absolute priority, and both projects resulted in introducing innovations: communication passports for service users; staff contact cards; the use of a social media platform to communicate. Other changes include new training for health care staff in communication, patients on interview panels and a new community network for family carers. In both projects the method was successfully adapted and service users and their family carers felt that they had expressed their views, but also suggested and helped to bring about change. Conclusions: EBCD can be used successfully to ensure the voices of service users with learning disabilities are heard and to enable them to improve their own services as equal partners with healthcare staff.

[Ottmann and Laragy \(2010\) Developing consumer-directed care for people with a disability: 10 lessons for user participation in health and community care policy and program development⁷](#)

The authors outline 10 lessons derived from the development of a consumer-directed care program for families with disabled children in Melbourne, Australia. The following program elements proved to be of importance over the course of the development process: 1. research participants should be involved as early as possible; 2. an open, inclusive communication style in conjunction with a good understanding of potential concerns and a careful framing of the policy issue is required to build trust and allow meaningful collaboration; 3. various strands of evidence have to be woven together; 4. ongoing commitment and support from management and key stakeholders; 5. effective knowledge transfer and cultural change processes; 6. capacity building; 7. mediation of power differentials; 8. community building; 9. participant re-engagement strategies; and 10. solid project management skills.

[Cardoso da Silva and Correa \(2019\) Disabled persons on the way to participatory democracy⁸](#)

The authors discuss the social participation of disabled persons and the exercise of social control; and build a relationship between understanding about disability, the issue of representativeness and the role of this segment in the struggle for rights and in the social control of public policies.

[Sherlaw and Hudebine \(2015\) The United Nations Convention on the Rights of Persons with Disabilities: Opportunities and tensions within the social inclusion and participation of persons with disabilities⁹](#)

The United Nations Convention on the Rights of Persons with Disabilities opens up opportunities to drive forward inclusive policy for people with disability. It may serve as a benchmark for the evaluation of policy aimed at improving the lives of people with disabilities. In order for this to occur, it is vital to fix priorities for evaluation using participatory research methods that place disabled people and especially those who are hard to reach at the heart of the participatory process. Within this process, it will be vital to stress the commonality of disability since the goals of different organizations representing disabled people may be in tension. It is also crucial when evaluating policy to be clear of definitions and aims. There are also fundamental tensions within the concept of social inclusion. In particular, it is vital to take into account the potential tension between a social justice agenda founded on redistribution or recognition. This may be particularly well illustrated through the case of cochlear implants and infantile screening for deafness. Nevertheless, it is also equally crucial to preserve a space for both dimensions within the policy agenda. This may partly be achieved through participatory parity where all participants within the deliberative process have the possibility of equal status and voice. Ultimately, both tensions associated with the participatory process and the principles underlying inclusion will be resolved through making choices that are necessary for action. It is preferable such choices are made by disabled people themselves. Such choices may be informed through participatory action research in which disabled people are involved.

[Andersen \(2015\) User councils for disabled people in Norway: from reactive to proactive?¹⁰](#)

User councils act as advisory bodies for the agencies with which they are associated. This article is based on interviews with user participants and agency representatives from a sample of user councils in Norway. In general,

the findings show that among user councils there are active discussions and that most of the user informants feel that they are respected as equal partners and are taken seriously. However, the work is characterized by representatives from the agencies taking the initiative to raise issues and the user representatives responding to these initiatives, and in that way the user participants function reactively. Most of the informants from the agencies want the user representatives to be more active and critical. This raises concerns about how user participants can be more proactive. Finally, some prerequisites for improving the functioning of user councils are discussed.

[Kim and Ross \(2008\) Developing service user involvement in the South Korean disability services: lessons from the experience of community care policy and practice in UK¹¹](#)

The authors consider the scope for the integration of service user involvement within services for people with disabilities in South Korea at a time of rapid development in social policy and practice. Using the UK experience of introducing community care and a mixed economy of service provision over the last 14 years, this study considers the barriers to service user involvement inherent in the South Korean context and concludes that in a society where there is a shortage of services and a provider-orientated delivery system where most services are delivered by voluntary organisations, more public services are needed and a democratic rather than a consumerist approach to user involvement is required. Some elements of the UK system could inform the development of a systematic approach to user involvement in South Korea, notably the right to assessment within a care management structure, the setting of quality care standards and inspection processes and a complaints procedure.

[Derrett et al \(2019\) Health systems and genuine engagement: experiences and outcomes of a New Zealand Community Health Council¹²](#)

New Zealand's health system is largely government-funded (80%) and low cost (9%GDP). The population of 4.7 million has services planned, purchased and provided via 20 District Health Boards. Hospital services are usually accessed via general practitioner practices. Organisationally, general practices are supported by 33 not-for-profit Primary Health Organisations. In 2016, the Southern District Health Board, covering 320,000 people, and WellSouth Primary Health Organisation began establishing a health council to provide lay advice, guidance and support to improve the Southern health system. In February 2017, the Community Health Council held its first

monthly meeting with an appointed chair, a Southern DHB facilitator and community members representing a range of geographical areas and health interests.

INTERNATIONAL LITERATURE RELATING TO INTELLECTUAL DISABILITY

[Dew et al \(2018\) Current representation of people with intellectual disability in Australian mental health policy: The need for inclusive policy development¹³](#)

People with intellectual disability in Australia experience poor mental health, are underrepresented in mental health policy, and encounter major barriers in accessing mental health services and treatments. This study interrogated the current representation of people with intellectual disability and recommended strategies to enhance the inclusion of intellectual disability in mental health policy. A policy analysis framework was developed that included context, stakeholders, process and content. Nine pieces of Australian mental health legislation and 37 mental health policy documents were analyzed using the framework. Fifteen of the 37 documents included mention of intellectual disability with limited attention to the specific mental health needs of people with intellectual disability and mental illness. Only two documents identified specific strategies or measurable actions and targets to improve the access of people with intellectual disability and mental illness to mental health services. The documents' strengths that may be applied to develop inclusive intellectual disability mental health policy included being values-based, recognizing diversity, taking a life-course approach, focusing on workforce development, and ensuring checks and balances. An inclusive approach to the development and implementation of intellectual disability mental health policy will best meet the mental health needs of individuals with intellectual disability. An inclusive policy approach will be based on a sound evidence base and include a comprehensive understanding of the context in which the policy is developed; consultation with key stakeholders including people with intellectual disability and mental illness, their family and carers, and those who work with them; cross-sector collaboration and workforce training. An inclusive approach to the development and implementation of intellectual disability mental health policy using an integrated knowledge translation approach will address the

current lack of attention to the important area of how to best meet the mental health needs of individuals with intellectual disability.

[Chenoweth and Clements \(2011\) Participation opportunities for adults with intellectual disabilities provided by disability services in one Australian state¹⁴](#)

The participation of service users in the planning and delivery of disability services is an unequivocal ideal in many countries. However, making the shift from espoused ideals of participation to effective, credible involvement of people with disability and families in agency planning and delivery is often challenging and not fully realized. The authors undertook a study to discern the nature and extent of service user participation opportunities within a range of organizations that provide disability services in one Australian state. A snapshot of how services are involving service users and their families, carers and advocates in all aspects of their service, including service planning, development and delivery, was obtained via a mailed survey instrument. Some 200 agencies or services receiving funding from the state government participated in the survey. Findings reveal that service providers overall are providing a broad range of opportunities and activities for service user participation in the service, but their effectiveness is variable across different organizations and subject to differing conditions. The authors concluded that characteristics of the service, the community and the service users and their families, carers and advocates, all influence the dynamic environment for participation.

[Reppermund et al \(2018\) Representation of people with intellectual disability in Australian mental health policy¹⁵](#)

The current approaches to policy development lack coherence and detail in describing how the support needs of people with intellectual disability and mental ill health can be met. Of major concern is the impact that unaddressed mental health problems have on people with intellectual disability, their families and support persons. Every State or Territory has an obligation to address this issue; doing so will ensure that the human rights of one of the most vulnerable and marginalized groups in our community are upheld. The strong link between physical and mental health for people with an intellectual disability highlights the importance of policy and legislation which clearly addresses the complex issues for this population and facilitates implementation via a joint framework cross-agency service provision. The latter is urgent given the implementation of the National



Disability Insurance Scheme, and the need for cohesive supports across both health and disability sectors.

[Berlin et al \(2019\) Service managers' experiences of how the participation of people with intellectual disabilities can be promoted in Swedish group homes¹⁶](#)

Background: People with intellectual disabilities in staffed group homes often need lifelong support and dependency on others. Thereby, special demands are placed on staff and service managers to ensure opportunities for participation in everyday life. This study aims to explore how service managers promote participation in Swedish group homes for adults with intellectual disabilities. Method: A qualitative research design involving individual interviews with 14 service managers was used to gain an understanding of how the participation of adults with intellectual disabilities can be promoted in Swedish group homes. Results: The results comprise two main themes: creating preconditions for participation; and barriers for promotion of participation. Conclusions: It was the experience of service managers that promoting service user participation in group homes was an important part of their responsibility. The findings indicate that structural strategies such as coaching, supervision and reflection are important and should be further developed.

[Doody et al \(2019\) The experiences of adults with intellectual disability in the involvement of nursing care planning in health services \[Irish paper\]¹⁷](#)

Background: Adults with intellectual disability should be involved in decision-making about their care. However, little is known regarding their experience of engaging in care planning within health services. In a rapidly changing healthcare environment, the relevance and necessity of demonstrating care delivered and care outcomes is essential for all professionals and this review highlights the need for intellectual/learning disability nurses to prioritise disseminating this evidence beyond the practice environment.

Materials and Methods: Integrative literature review. CINAHL, Scopus, Web of Science, PsyArticles, PsycInfo, MEDLINE, Cochrane Library, Embase and Academic Search Complete were searched for papers published between 01 January 2005 and 01 June 2017.

Results: No study met the inclusion criteria for nursing care planning. However, through examining the literature that made it to the full-text

review stage, two recurring themes were identified: exploring the relevance and categorization of plans; and disseminating evidence.

Conclusion: This integrative review provides evidence that the experiences of adults with intellectual disability involvement in care planning within health services are absent within the literature. While guidance exists regarding involving adults with intellectual disability in planning their care, there is confusion, ambiguity and an interchangeable use of terms that makes it difficult to distinguish between nursing care plans, person-centred plans, individual programme plans, individualised support plans, health action plans, personalised support plans and personalised plans.

[Hoole and Morgan \(2011\) “It’s only right that we get involved”: service-user perspectives on involvement in learning disability services¹⁸](#)

Promotion of service- user and carer involvement is part of the mainstream policy agenda in health and social care. Much effort has been invested into involving people with learning disabilities in decisions regarding aspects of their lives through advocacy projects and the utilisation of person- centred planning approaches. However, people with learning disabilities continue to be a group of people who are the most excluded, least independent and most likely to lack control in everyday life. This article describes a focus group that was conducted to explore the lived experiences of people with learning disabilities as users of services. Thematic analysis revealed three key themes: feelings of unfairness and inequality; experiences of inclusion and power; and future visions. Implications for practice are discussed.

[Mooney et al \(2019\) Getting Involved in the Community--What Stops Us? Findings from an Inclusive Research Project¹⁹](#)

Background: Social isolation is an issue that affects many people and especially people with a learning disability. There is an association between social exclusion and feeling lonely, an issue currently highlighted as a growing concern which needs to be addressed both in the media and by the government.

Methods: The Building Bridges Research Group do inclusive research projects about the issues that are important to them. Over the summer of 2018, the research group undertook an inclusive research project to identify some of the specific barriers that prevent community inclusion and the opportunity to develop friends. The people involved mainly lived independently and did not use learning disability services, with the exception of evening clubs, so needed to use universal services.

Results: Pictorial cards were used to organise the data into themes. These included transport, fear and anxiety, limits on choice and control, risks and personal safety.

Conclusion: The inclusive research design enabled people with a learning disability to contribute to all stages of the research project, from identifying the issue, gathering data, analysis and writing up. They also made suggestions of ways to increase social networks, friendships and well-being and so decrease loneliness. These include more access to easy read information, more support and advocacy and measures to address community safety including a wider roll-out of the Safe Places scheme. There also needs to be further research undertaken with other people with a learning disability in different areas to widen the understanding of the impact of these barriers on people's lives.

[Fyson et al \(2014\) Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning²⁰](#)

Social inclusion is a key principle that underpins the provision of services for people with learning disabilities in England. Learning Disability Partnership Boards, which are responsible for local strategic planning of learning disability services, hold a particular role in promoting inclusion since they are required both to operate inclusively and to achieve inclusive outcomes. This study sought to explore the extent to which these ambitions for inclusion were being achieved. It consisted of three phases: a scoping exercise to elicit the views of key stakeholders; a postal survey of Partnership Boards (response rate 51%); and semi-structured interviews with Partnership Boards members in six local authorities. Findings suggest that Partnership Boards are struggling to fulfil their dual role, with tensions emerging between the desire to operate in fully inclusive ways and the ability to affect strategic change within local services.

[Roy et al \(2019\) Working with Deafblind people to develop a good practice approach²¹](#)

Summary: There is growing recognition of the importance in social research and social policy development of engaging with people with lived experience and using intervention approaches characterised by co-design and co-production. However, the inclusion of some minority groups such as those who are Deafblind has proven challenging. Working from the perspective of Appreciative Inquiry, a qualitative research methodology called the World Café was used to generate patterns of insight and collective discoveries

from Deafblind participants. Data from the Deafblind World Café were analysed using inductive thematic analysis.

Findings: Four themes were produced that could inform the development of a good practice model for engaging with people who are deafblind: 1. being deafblind ³/₄ it's who we are, not what we are; 2. we welcome co-production with outsiders who are prepared to make the effort to become insiders; 3. being culturally inclusive is about both what you say and what you do; and 4. listen to our story [and] don't try to count it.

Applications: Group-based and interactive approaches, such as World Café, though challenging, can be successfully adapted for those who are deafblind. How this might be up-scaled is yet to be explored.

INTERNATIONAL LITERATURE (CHILDREN)

[Council for disabled children \(UK\) \(2020\) Participation Resources²²](#)

This webpage features policy, practice and resources, including a [literature review on the participation of disabled children and young people in decision making](#).

[Ingólfssdóttir et al \(2018\) Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland²³](#)

Despite the avowed aims of the Icelandic legislation to provide family-centred and inclusive services, families raising disabled children commonly express their experiences of fragmented services provided more on the terms of the service providers than the users. This article is based on data derived from an ongoing qualitative multi case-research in three municipalities in Iceland. The aim of the paper is: 1. to identify the main contradictions that explain tensions and dilemmas within the service system as experienced by the parents; and 2. to suggest potential solutions for improving practices in accordance to family-centred inclusive policy and enhanced user-participation. The cultural-historical activity theory was applied as an analytical framework. Three activities central to the wellbeing of the children and their families were identified as the unit of analysis and contradictions within the activities were located and classified by following the expansive learning theory. Based on our findings we propose Edwards's three "gardening tools" of relational practices as innovative and appropriate



tools for the necessary changes needed. By utilising these tools, the disabled children and their families are brought to the forefront and the professionals enhance their expertise in partnership with all stakeholders.

[McAnuff et al \(2017\) Improving participation outcomes and interventions in neurodisability: co-designing future research²⁴](#)

There is an urgent, agreed need to improve participation outcomes and interventions for children and young people with neurodisability. We worked together with service users and providers to design research into participation outcomes and interventions in neurodisability. We built on existing evidence about participation outcomes and interventions and the WHO International Classification of Functioning, Disability and Health. We: 1. specified seven participation outcome categories for measurement; 2. prioritized these for improvement: self-care, friends and social, and physical activity ranked the highest; 3. identified 11 potential intervention categories for targeting the top priority, self-care, through eight hypothesized change mechanisms and agreed for the interventions to be delivered as a menu of interventions for personalized self-care support; and 4. designed a before-and-after mixed methods feasibility study to evaluate the Menu with children and young people (0-12 years) and their parents and therapists.

[Sloper and Lightfoot \(2003\) Involving disabled and chronically ill children and young people in health service development²⁵](#)

Aim: To investigate the extent and nature of involvement of physically disabled or chronically ill children and young people in local health service development.

Methods: A postal survey of all health authorities (n=99) and NHS Trusts (n=410) in England.

Results: 76% of health authorities and 59% of Trusts responded. 29 initiatives involving chronically ill or disabled children and young people in consultation regarding service development were identified. Over half of these were carried out in partnership between health services and other agencies, usually local authorities and/or voluntary organizations. A variety of methods was used for consultation, including child-friendly methods such as drawing, drama and making a video. 17 initiatives reported that children's involvement had resulted in service changes, but only 11 went beyond consultation to involve children and young people in decision making about service development. Only a third of the organizations had someone with designated responsibility for children's involvement.

Discussion: The involvement of this group of children and young people in service development in the NHS is at an early stage. The failure of policy documents on user involvement to identify children and young people as a group for whom methods of consultation need to be developed, and the lack of people with designated responsibility for developing children's involvement may be a reason for slow progress in this area. The initiatives identified show that such involvement is possible and can have a positive impact on services.

[O'Reilly \(2007\) Involving service users in defining and evaluating the service quality of a disability service²⁶](#)

Purpose: This study proposes to examine how a particular service quality model, the PCP attributes model, can be used to develop a measurement tool for a disability organisation, which involves service users in defining and determining service quality.

Design/Methodology/Approach: The evaluation focused on a physical disability service within the voluntary sector in Ireland. To identify the service quality dimensions, which were important, a series of focus groups were completed with service personnel and service users. A questionnaire was then developed from the information identified relating to a number of service quality dimensions.

Findings: The results illustrated an overall high level of satisfaction with the service. There were a number of service dimensions identified in each of the attribute groupings, which could be improved. Respondents also made a number of recommendations for improvement.

Research Limitations/Implications: The study identified limitations to the model relating to whether the actual experiences of service users are captured.

Originality/Value: This paper outlines from a consumer perspective the service attributes that provide satisfaction with service delivery but also highlighted areas where improvement was necessary and that the PCP model is a suitable framework for use.



BOOK CHAPTERS

[Goodman et al \(2009\) Occupational therapy for people with learning disabilities: a practical guide²⁷](#)





Chapter 13 of this book is entitled: "More Than Having a Say: User Participation in Learning Disability Services." More details are available [here](#). This book is available from the library at University Hospital Limerick and they can supply a copy of this chapter as required.

[Kemshall and Littlechild \(2000\) User involvement and participation in social care: research informing practice²⁸](#)

This text explores strategies for effectively involving users in the planning, delivery and evaluation of services. It discusses how the key concepts of empowerment, participation and user involvement in areas such as mental health are applied. It features a chapter on "Participation and Involvement in Social Care: An Overview." This book is available for loan from the library at Mayo University Hospital.

Produced by the members of the National Health Library and Knowledge Service Evidence Team[†]. Current as at [17 August 2020]. This evidence summary collates the best available evidence at the time of writing and **does not replace clinical judgement or guidance**. Emerging literature or subsequent developments in respect of COVID-19 may require amendment to the information or sources listed in the document. Although all reasonable care has been taken in the compilation of content, the National Health Library and Knowledge Service Evidence Team makes no representations or warranties expressed or implied as to the accuracy or suitability of the information or sources listed in the document. This evidence summary is the property of the National Health Library and Knowledge Service and subsequent re-use or distribution in whole or in part should include acknowledgement of the service.

The following PICO(T) was used as a basis for the evidence summary:

	PERSONS WITH DISABILITIES
	COMMITTEE REPRESENTATION
	
	EFFECTIVE CO-DESIGN OF DISABILITY SERVICES

The following search strategy was used:

disabilit* OR disabled OR blind* OR deaf* OR impairment* OR impaired
 AND
 representation OR inclusion OR participation OR empowerment OR co-design OR codesign OR mainstreaming OR "user participation" OR involvement
 AND
 committee OR working group OR consultat* OR policy OR "disability service**"

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- ¹ National Disability Authority (2016) Research on engagement and participation of people with disabilities in developing services (policy and practice) <http://nda.ie/Publications/Disability-Supports/Disability-Services/Research-on-engagement-and-participation-of-people-with-disabilities-in-developing-services-policy-and-practice.html> Accessed 14th August 2020.
- ² HSE (2018) Effective Participation in Decision-Making for People with Disabilities and Families Planning for Ordinary Lives in Ordinary Places A Step by Step Guide to Implementation for HSE Managers and Social Care Staff <https://www.lenus.ie/bitstream/handle/10147/623812/effective-participation-in-decision-making-final.pdf?sequence=1&isAllowed=y> Accessed 14th August 2020.
- ³ Inclusion Ireland (2017) Making Equality & Rights Real: A toolkit for setting up Equality & Rights Committees in Disability Services Toolkit <http://www.inclusionireland.ie/making-equality-rights-real> Accessed 14th August 2020.
- ⁴ CDC (2020) Disability & Health Resources for Facilitating Inclusion and Overcoming Barriers <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-resources.html> Accessed 14th August 2020.
- ⁵ Lakhani, A., McDonald, D. and Zeeman, H. (2018) 'Perspectives of self- direction: a systematic review of key areas contributing to service users' engagement and choice- making in self- directed disability services and supports', *Health & Social Care in the Community*, 26(3), pp. 295–313. <https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12386> Accessed 14th August 2020.
- ⁶ Goodrich, J., Edwards, S., Munks, S. & Parr J. (2017), ISQUA17-1743 People with learning disabilities as equal partners in service improvement *International Journal for Quality in Health Care*, Volume 29, Issue suppl_1, p 9, <https://doi.org/10.1093/intqhc/mzx125.9> Accessed 14th August 2020.
- ⁷ Ottmann, G. F. and Laragy, C. (2010) 'Developing consumer-directed care for people with a disability: 10 lessons for user participation in health and community care policy and program development', *Australian health review : a publication of the Australian Hospital Association*, 34(4), pp. 390–394. <https://www.publish.csiro.au/AH/AH09759> Accessed 14th August 2020.
- ⁸ Cardoso da Silva, A. C. and Correa Oliver, F. (2019) 'Disabled persons on the way to participatory democracy', *Brazilian Journal of Occupational Therapy / Cadernos Brasileiros de Terapia Ocupacional*, 27(2), pp. 279–292. https://www.scielo.br/pdf/cadbto/v27n2/en_2526-8910-cadbto-2526-8910ctoA01604.pdf Accessed 14th August 2020.
- ⁹ Sherlaw, W. and Hudebine, H. (2015) 'The United Nations Convention on the rights of persons with disabilities: Opportunities and tensions within the social inclusion and participation of persons with disabilities', *ALTER: European Journal of Disability Research, Journal Europeen de Erche sur le Handicap*, 9(1), pp. 9–21. <https://www.sciencedirect.com/science/article/pii/S1875067214000649> Accessed 14th August 2020.
- ¹⁰ Jan Andersen (2015) 'User councils for disabled people in Norway – from reactive to proactive?', *Scandinavian Journal of Disability Research*, 18(4), pp. 284–294. <https://www.sjdr.se/articles/10.1080/15017419.2015.1064028/> Accessed 14th August 2020.
- ¹¹ Kim YD and Ross L (2008) 'Developing service user involvement in the South Korean disability services: lessons from the experience of community care policy and practice in UK', *Health & Social Care in the Community*, 16(2), pp. 188–196. <https://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=105770916&site=eds-live> Accessed 14th August 2020.
- ¹² Derrett, S et al 2019 Health systems and genuine engagement: experiences and outcomes of a New Zealand Community Health Council. *International Journal of Integrated Care*, 19(S1): A477, pp. 1–8, DOI: [dx.doi.org/10.5334/ijic.s3477](https://doi.org/10.5334/ijic.s3477)
- ¹³ Dew, A. et al(2018) 'Current representation of people with intellectual disability in Australian mental health policy: The need for inclusive policy development', *Journal of Policy and Practice in Intellectual Disabilities*, 15(2), pp. 136–144. <https://onlinelibrary.wiley.com/doi/10.1111/jppi.12239> Accessed 14th August 2020.
- ¹⁴ Chenoweth, L. and Clements, N. (2011) 'Participation opportunities for adults with intellectual disabilities provided by disability services in one Australian state', *Journal of Policy and Practice in Intellectual Disabilities*, 8(3), pp. 172–182. <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1741-1130.2011.00307.x> Accessed 14th August 2020.
- ¹⁵ Reppermund, S. et al(2018) 'Representation of people with intellectual disability in Australian mental health policy', *Australian and New Zealand Journal of Psychiatry*, 52(7), pp. 618–619. <https://journals.sagepub.com/doi/10.1177/0004867418773882> Accessed 14th August 2020.
- ¹⁶ Berlin Hallrup, L., Kumlien, C. and Carlson, E. (2019) 'Service managers' experiences of how the participation of people with intellectual disabilities can be promoted in Swedish group homes', *Journal of Applied Research in Intellectual Disabilities*, 32(2), pp. 427–434. <https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12540> Accessed 14th August 2020.
- ¹⁷ Doody, O., Lyons, R. and Ryan, R. (2019) 'The Experiences of Adults with Intellectual Disability in the Involvement of Nursing Care Planning in Health Services', *British Journal of Learning Disabilities*, 47(4), pp. 233–240. <https://onlinelibrary.wiley.com/doi/10.1111/bld.12281> Accessed 14th August 2020.
- ¹⁸ Hoole, L. and Morgan, S. (2011) "'It's only right that we get involved": service-user perspectives on involvement in learning disability services', *British Journal of Learning Disabilities*, 39(1), pp. 5–10. <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1468-3156.2009.00563.x> Accessed 14th August 2020.



- ¹⁹ Mooney, F., Rafique, N. and Tilly, L. (2019) 'Getting Involved in the Community--What Stops Us? Findings from an Inclusive Research Project', *British Journal of Learning Disabilities*, 47(4), pp. 241–246. <https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12283> Accessed 14th August 2020.
- ²⁰ Fyson, R. and Fox, L. (2014) 'Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning', *Disability & Society*, 29(2), pp. 239–254. <https://core.ac.uk/download/pdf/33576216.pdf> Accessed 14th August 2020.
- ²¹ Roy, McVilly & Crisp (2019) 'Working with Deafblind people to develop a good practice approach'. *Journal of Social Work*. <https://doi.org/10.1177/1468017319860216> Accessed 14th August 2020.
- ²² Council for disabled children (UK) (2020) Participation <https://councilfordisabledchildren.org.uk/our-work/participation> Accessed 14th August 2020.
- ²³ Jóna G Ingólfssdóttir, Thurídur Jóhannsdóttir and Rannveig Traustadóttir (2018) 'Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland', *Nordisk Vælfærdarsökun*, 3, pp. 33–46. <https://opinvisindi.is/handle/20.500.11815/1820> Accessed 14th August 2020.
- ²⁴ McAnuff, J. *et al* (2017) 'Improving participation outcomes and interventions in neurodisability: co-designing future research', *Child: Care, Health & Development*, 43(2), pp. 298–306. https://eprint.ncl.ac.uk/pub_details2.aspx?pub_id=229123 Accessed 14th August 2020.
- ²⁵ Sloper & Lightfoot (2003) 'Involving disabled and chronically ill children and young people in health service development', *Child: Care, Health and Development*, 29(1), pp. 15–20. <https://onlinelibrary.wiley.com/doi/full/10.1046/j.1365-2214.2003.00315.x> Accessed 14th August 2020.
- ²⁶ O'Reilly, P. (2007) 'Involving service users in defining and evaluating the service quality of a disability service', *International journal of health care quality assurance*, 20(2–3), pp. 116–129. <https://www.emerald.com/insight/content/doi/10.1108/09526860710731816/full/html> Accessed 14th August 2020.
- ²⁷ Goodman, J., Hurst, J., & Locke, C., (2009) Occupational therapy for people with learning disabilities: a practical guide. Edinburgh: Churchill Livingstone. <https://books.hslibrary.ie/cgi-bin/koha/opac-detail.pl?biblionumber=1845> Accessed 14th August 2020.
- ²⁸ Kemshall & Littlechild (2000) User involvement and participation in social care: research informing practice. London: Jessica Kingsley. <https://books.hslibrary.ie/cgi-bin/koha/opac-detail.pl?biblionumber=79071> Accessed 14th August 2020.