

Antaki, C. (2002). Shaping clients' answers: Departures from neutrality in care-staff interviews with people with a learning disability. *Disability & Society*, 17(4), 435-455.

What can happen when care staff interview clients with a learning disability? We examine tape-recordings of five questionnaire-based interviews designed to yield information on the clients' perceptions of the quality of the service provided to them. Of interest was the way in which the care staff, who were not formally trained in interview skills, delivered the 42-item questionnaire that formed the basis for the interview. It was discovered that interviewers replicated a number of non-neutral practices previously identified in a set of similar interviews administered by formally-trained professionals. They also introduced further deviations from neutral interviewing. The effect of these practices on the information recorded as the respondents' answers is discussed. We note that any interviewer is faced with a dilemma of choosing between literal (but potentially robotic and insensitive) and tailored (but potentially unstandardised and invalid) administration of a questionnaire. We argue that the deviations we see here show the interviewers falling on the side of 'liberal' administration. The net effect was arguably to prompt 'better' answers. When what is being recorded is an 'audit' of services provided to respondents, there is a real-life danger that their perceptions are being improved by what is ostensibly a neutral interview.

Association for Self-Advocacy, Croatia, Association for Promoting Inclusion, Croatia, & Inclusion Europe (2007). *Human rights of persons with intellectual disability. Country report Republic of Croatia*. Retrieved 30th November 2009 from <http://www.inclusion-europe.org/main.php?Lang=EN&level=1&s=83&mode=nav2&n1=164&n2=151>

The core of the project was the publication of a National report based on a social political and economic analysis of the country situation in regards to the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the newly adopted UN Convention on the Rights of Persons with Disabilities. The organization Lebenshilfe Bochum <http://www.lebenshilfe-bochum.de/> lead this project in collaboration with Inclusion Europe, and the Croatian Association for Self- Advocacy (ASA) (<http://www.samozastupanje.hr/> and the Croatian Association for Promoting Inclusion <http://www.inkluzija.hr/Index.htm> (API). A new idea came out with this project: the national report has been totally in the hands of self-advocates, people with intellectual disabilities who are speaking for themselves. Inclusion Europe has developed an ETR questionnaire; which structure follows the different thematic areas and aspects of the UN Standards Rules and of the UN Convention. The questionnaire contains more than 50 questions covering all aspects of life. 10 self-advocates have interviewed more than 80 persons in five different places in Croatia. With the findings and results of the questionnaire, a national report has been written both in English and in Croatian. Half of the people who have been interviewed have lived in large

residential institutions and reported about negative attitudes as well as bad treatment. A large number of people frequented special schools and have experienced discriminatory attitudes and comments. Very few of them have a job currently. This is the most important aspects for self-advocates nowadays. Although they are living independently in their own apartments or at their parents, they feel excluded and frustrated because they cannot get a job position. This is clearly linked to the vocational training opportunities; which are often not adapted to the labour market needs and does not respect the training choices of self-advocates.

Barr, O., McConkey, R., & McConaghie, J. (2003). Views of people with learning difficulties about current and future accommodation: The use of focus groups to promote discussion. *Disability & Society*, 18(5), 577-597.

There is growing emphasis on inclusion as a central philosophy in services for people with learning difficulties in the UK, Europe and the USA. Coupled with this is recognition of the need to actively involve people with learning difficulties in the research process through the use of more inclusive approaches. This paper reports the use of focus groups as a strategy for data collection from people with learning difficulties in a project that sought to review existing accommodation and support. A number of important key themes emerged relating to the importance of social networks, inclusion, reciprocal relationships, privacy and security. The implications arising from these findings for the provision of accommodation and support are considered. Furthermore, it was concluded that focus groups are potentially a valuable approach in research that seeks to actively involve people with learning difficulties.

Bjornsdottir, K., & Svendsdottir, A. S. (2008). Gambling for capital: learning disability, inclusive research and collaborative life histories. *British Journal of Learning Disabilities*, 36(4), 263-270.

This paper is about a partnership between a self-advocate with learning disabilities and a university student. • We think it is important for people with learning disabilities to be involved in research as partners with university researchers. • We think it is important for people with learning disabilities to have the opportunity to tell their story. We believe it can help others; both people with learning disabilities, carers and researchers. • We think that people with learning disabilities are not taken seriously as researchers by university researchers. The aim of this paper is to reflect on research collaboration between a research participant with learning disability and a nondisabled doctoral student. In the paper we explore the inclusiveness of our research partnership and how collaborative life histories can be empowering both for participants and researchers. We suggest that it is possible to make any kind of research inclusive, although doctoral projects can perhaps not be fully inclusive because of academic requirements. We argue that people with learning disabilities should have the

opportunity to be involved in research and that collaborative writing between nondisabled researchers and people with learning disabilities is no less valuable than other disability research and should be taken seriously by policy makers and academia. A second aim of the paper is to reflect on our position, as a nondisabled researcher and a researcher with learning disabilities, in the field of disability studies. We state that as researchers we have little power in the field of disability studies because researchers with learning disabilities are not taken seriously and nondisabled researchers tend to be met with scepticism.

Bonham, V. L., Basehart, S., & Boswell Marchand, C. (2003). *Ask me! FY 2003. The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA Funded Supports*. Annapolis, MD: The Arc of Maryland. Prepared for the Maryland Developmental Disabilities Administration.

The Ask Me! Survey collects information directly from the people supported in the community through funding from the Maryland Developmental Disabilities Administration. People report a high quality of life in the domains of physical well-being and emotional well-being, a quality that has increased over the past three years. They report lower quality of life in the domains of self-determination and rights. Rights has not changed at all over the past three years. Providers can make a difference in people's quality of life if they set goals of self-determination and rights. A provider is not constrained by the types of supports it offers in promoting self-determination and rights, nor is a provider constrained by the characteristics of the people it supports. Services that are most likely to enhance quality of life are those that support people to respond for themselves, to see transportation as available, and to move toward employment.

Booth, T., & Booth, W. (1996). *Sounds of silence: Narrative research with inarticulate subjects*. *Disability and Society*, 11(1), 55-69.

This article addresses the challenge of using narrative methods with people who have learning difficulties. Such informants present four particular interview problems: inarticulateness; unresponsiveness; a concrete frame of reference; and difficulties with the concept of time. The authors focus on the first two of these problems and argue that neither of them constitutes an insuperable barrier to people telling their story. Drawing on detailed interview material from an informant with learning difficulties, the authors set out to show in practical terms how these problems might be tackled, emphasising in particular the importance of being attentive to what goes unsaid. They conclude that researchers should put more emphasis on overcoming the barriers that impede the involvement of inarticulate subjects in narrative research instead of dwelling on their limitations as informants.

Booth, T., & Booth, W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society*, 18(4), 431-442.

This paper presents the results of a photovoice project involving mothers with learning difficulties. Photovoice is a technique that challenges the established politics of representation by putting people in charge of how they document their own lives. The authors describe how the project was carried out and the problems they encountered. Analysis of the content of the mothers' photo albums in the context of their own personal stories throws light on both their individual lives and their collective experience. The results challenge discriminatory views of the women as different mums.

Chapman, R., & McNulty, N. (2004). Building bridges? The role of research support in self-advocacy. *British Journal of Learning Disabilities*, 32(2), 77-85.

Carlisle Research Co-op is a group of eight people who aim to do person-led research in a way that changes ideas and makes life better for people labeled as having learning difficulties. The group includes four men and four women. Six members of the group are labelled as having a learning difficulty. The other two people act in a role of involved support. This article features an attempt by the two members of the group who have support roles to explain what they do, and to look at the changes that have taken place within this group. Support is a role that bridges the gap between what people want to be doing, and what they are rejected from doing by the way things are.

Dearden-Phillips, C., & Fountain, R. (2005). Real power? An examination of the involvement of people with learning difficulties in strategic service development in Cambridgeshire. *British Journal of Learning Disabilities*, 33(4), 200-204.

Securing meaningful involvement in service development and provision can be seen as a particular challenge for people with learning difficulties. The National Health Service & Community Care Act [(1990) HMSO, ISBN 0105419907] and more recently Valuing People [Department of Health (2001) Valuing people: a new strategy for learning disability for the 21st century, Cm5086] have stressed the importance of statutory providers working in partnership with people with learning difficulties, without giving any clear guidance on how to achieve this. This paper is written from the perspective of Speaking Up – a voluntary organisation that has developed the 'Parliament' model to give people with learning difficulties a strong collective voice. Through self-advocacy taking the leading role in shaping the way people with learning difficulties and statutory providers communicate, it is argued that the Parliament model enables people with learning difficulties to genuinely influence services. After considering the link between self-advocacy and user-involvement, this paper describes the Parliament as it has developed in Cambridgeshire and discusses whether what has

been achieved represents a real increase in power for people with learning difficulties. It concludes with a short assessment of the potential for replicability of the Parliament as a model for other areas of the UK. Craig Dearden-Phillips is Chief Executive of Speaking Up and Rob Fountain a Project Leader with the organisation.

Emerson, E., Malam, S., Davies, I., & Spencer, K. (2004). *Adults with Learning Difficulties in England 2003/4: Full report*. Retrieved November 30th 2009, from http://www.lancs.ac.uk/staff/emersone/FASSWeb/Emerson_05_ALDE_Main.pdf.

In 2001 the Government published a White Paper called *Valuing People*.¹ In it the Government said that it would help people with learning disabilities 'to live full and independent lives as part of their local communities'. In 2005 the Government published a paper called *Improving the Life Chances of Disabled People*.² In it the Government said that 'By 2025, disabled people in Britain will be respected and included as equal members of society.' The Government also said in *Valuing People* that they would carry out a survey 'about the lives of people with learning disabilities and their families'. It could be the first time a national survey of adults with learning disabilities in England had been done. This is the report of that survey. It tells us how much more needs to be done if people with Learning Difficulties are to be more included and have a better life. Emerson, Malam, Davies, and Spencer reported that people with learning difficulties are often socially excluded; people who are socially excluded are also likely to have bad things happen in their lives; people with learning difficulties often have little control over their lives; people with learning difficulties have few opportunities to be independent; some people with learning difficulties are more likely than others to have bad things happening in their lives.

Freire, P. (1970). *Pedagogy of the oppressed* (30th ed.). New York: Continuum.

In this landmark account, first published over twenty years ago, Paulo Freire argues that the ignorance and lethargy of the poor are the direct result of the whole situation of economic, social, and political domination. By being kept in a situation in which it is practically impossible to achieve a critical awareness and response the disadvantaged are kept "submerged". In some countries the oppressors use the system of education to maintain this "culture of silence", while in others the advance of technology has condemned many people, particularly the less well off, to a rigid conformity. Through the right kind of education, avoiding authoritarian teacher-pupils models and based on the actual experiences of students and on continual shared investigation, every human being, no matter how impoverished or illiterate, can develop a new awareness of self which will free them to be more than passive objects responding to uncontrollable change. As Freire presents it, each individual wins back the right to say his or her own word, to name the word.

Garcia-Iriarte, E., Kramer, J. C., Kramer, J. M., & Hammel, J. (2009). "Who Did What?": A participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 10-22.

Background: This participatory action research (PAR) project involved a collaboration with a self-advocacy group of people with intellectual disabilities that sought to build group capacity for advocacy. Materials and Methods: This study used a focus group, sustained participatory engagement and a reflexive process to gather qualitative and quantitative data over 15 months. All methods were adapted to ensure accessibility and to support active participation. Results: The collaboration generated action products, including tools to support advocacy and an accessible action and reflection process. Research findings suggest that active participation is essential for group control, but alone does not automatically lead to control. The manner in which supports are provided, including member supports, advisor supports, strategy supports and systems supports, influences the extent to which members have a sense of control over decision making and participation and thus, improved capacity for advocacy. Conclusions: A PAR approach can be used to increase a group's capacity for advocacy and meaningfully involve self-advocacy groups in participatory research that leads to change.

Heller, T., Pederson, E., & Miller, A. (1996). Guidelines from the consumer: Improving consumer involvement in research and training for persons with mental retardation. *Journal of Mental Retardation*, 34(3), 141-148.

Assesses consumer involvement of individuals with *mental retardation* in research and training. Barriers to meaningful participation; Guidelines for fostering meaningful consumer involvement.

Johnson, K. (2009). No longer researching about us without us: A researcher's reflection on rights and inclusive research in Ireland. *British Journal of Learning Disabilities*, 37 (4), p250-256.

There is now a statement from the United Nations that sets out rights for disabled people. One of their rights is to participate in their communities. • One way of participating is when people with intellectual disabilities do research on issues that are of concern to them. This is called inclusive research. • No Longer Researching About Us Without Us was a national project to support people with intellectual disabilities and support workers to do inclusive research. It went on for 18 months. • This paper tells about two of the projects that were done by getting people in some services together to talk about what they wanted to do. One of the projects was about a coffee shop and its place in a small town. The second was about how to stop bullying. • We found that doing the projects led some people with intellectual disabilities to become stronger self advocates. We

also found that the projects raised important issues about their lives that other people had not thought of and that people began to work together in groups to do their own research and to make change happen. No Longer Researching About Us Without Us was an innovative national project which aimed to develop inclusive research with people with intellectual disabilities in the Republic of Ireland. This paper is my personal reflection as co-ordinator of this project on work undertaken by and with people with intellectual disabilities during its 18-month life. Using examples from the project, this paper explores links between the inclusive research aspect of project and the rights of people with intellectual disabilities to participate in their communities. As a result of the project we found that people with intellectual disabilities began to initiate and take action on some issues that were important to them and that this resulted in the development of longer term changes in their role within one service in Ireland.

Mactavish, J., Mahon, M., & Lutfiyya, Z. (2000). "I can speak for myself": Involving individuals with intellectual disabilities as research participants. *Journal of Mental Retardation*, 38(3), 216-227.

Examines involvement of individuals with intellectual disabilities in a qualitative study entitled 'The Lifespan and Disability Project' in Western Canada. Views of individuals regarding social integration; Use of interviews and focus groups in collecting data; Effects of the factors cited by the individuals on the promotion of social integration.

McClimens, A. (2008). This is my truth, tell me yours: Exploring the internal tensions within collaborative learning disability research. *British Journal of Learning Disabilities*, 36(4), 271-276.

Collaboration within the research and publishing process provides opportunities for shared learning and increased knowledge production and dissemination. It can also provide opportunities for conflict if the contributors are divided over issues of authority and authorship. While this situation can be managed, the potential for misunderstanding to arise is heightened when the combination of academics/ professionals and individuals labelled with learning disability work together. The scenario described here outlines some of the difficulties that can threaten successful collaboration. Possible remedies are suggested.

National Health Committee, New Zealand (2003). *To Have an "Ordinary" Life- Kia Whai Oranga "Noa" report*. Retrieved November 30th 2009 from [http://www.moh.govt.nz/moh.nsf/pagescm/681/\\$File/NHCOrdinaryReport.pdf](http://www.moh.govt.nz/moh.nsf/pagescm/681/$File/NHCOrdinaryReport.pdf).

Over the past two and a half years, the National Advisory Committee on Health and Disability has been collecting information to build a detailed picture of the lives of adults with an intellectual disability who are supported by government-

funded services in New Zealand. What has been unique in this project is that the NHC has collected much of this information through direct dialogue with the people themselves, giving a comprehensive insight into the lives of adults with an intellectual disability in New Zealand. The project sought to gather information across all areas of a person's life to enable the committee to fully understand the impact of services in general, not just of health-funded services. Adults with an intellectual disability are a diverse group, with a wide range of skills and abilities. The common features of people with an intellectual disability are intellectual impairment and impaired social functioning from birth or early childhood. People with an intellectual disability have 'ordinary' goals and aspirations. In order to achieve these they need support to minimise the barriers created by their impairment. One way in which this is done is through family, whānau, friends and service providers acting as 'social interpreters'. This important role – making sense of the cognitively complex world we live in – is often unrecognised. The NHC's findings indicate that although services in New Zealand have, with good intent, sought to move away from institutional-based services, much of this has focused on removing bricks and mortar rather than on ensuring support is provided in a way that is not institutional. Service purchase and provision have failed to keep up with international best practice. The nature of the support provided at present tends to be custodial and constrictive, focusing on keeping things the same, rather than actively moving towards community membership of people with an intellectual disability. This is to a large extent a result of the limited range of services that are contracted, the disability support workforce being undervalued, lack of understanding and knowledge about the potential of adults with an intellectual disability, and the narrow focus of assessment and planning processes.

Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, 31(2), 181-190.

The concept of quality of life (QOL) is increasingly being used in the field of intellectual disabilities as a conceptual and measurement framework for program planning and evaluation. This article describes the development of a QOL conceptual and measurement framework, and summarizes how this framework is currently being used both nationally and internationally to assess and report personal QOL-related outcomes, to guide quality improvement strategies, and to evaluate the effectiveness of those strategies. Implications of such use are discussed, including those related to understanding mental models, developing internal data systems, supporting organization change, and building on current public policies. The article concludes with reference to the evolving nature of the QOL concept and the impact of this on model development and transdisciplinary research.

Schoeters, L., Schelfhout, P., Roets, G., Van Hove, G., Townson, L., Chapman, R., et al. (2005). Partnership working between university researchers and self-advocacy organizations: 'A way forward for inclusion?' in England and 'Fine feathers make a fine bird' in Flanders. *Journal of Intellectual Disabilities*, 9(4), 345-357.

This article gives accounts of differing experiences of self-advocate partnerships in research with universities in England and Flanders. In England the partnership grew up within a local People First group built upon a personal working relationship with one support person. It is focused almost exclusively on empirical research and, because it is aimed at influencing policy and practice, questions of funding and control are to the fore. In Flanders the partnership is closely linked with the development of a national movement of self-advocates in which the university was a close ally. Research is important in both contexts but in Flanders the university is more dearly identified with the wider movement. Partnerships have their ups and downs but in both countries researchers with the label 'learning difficulties' wish to set their own agendas and place great importance on trust in their work with their support worker (England) or ally (Flanders).

Townson, L., Macauley, S., Harkness, E., Chapman, R., Docherty, A., Dias, J., et al. (2004). We are all in the same boat: Doing 'people-led research'. *British Journal of Learning Disabilities*, 32, 72-76.

This article shows why people with learning difficulties need to do research about learning difficulties. The authors' research group has been running for about 4 years. It has eight members. About 6 years ago the Adult Training Centre in Carlisle, England started closing down. The authors went in to ask people with learning difficulties what they thought and felt about it. The first People First group came about in October 1984 after some people went to a conference on self-advocacy in the U.S. It was called People First of London and Thames. Since then it is thought there are about 1200 self-advocacy type groups in Great Britain for people with learning difficulties.

Ward, L., & Townsley, R. (2005). 'It's about a dialogue...'. *British Journal of Learning Disabilities*, 33(2), 59-64.

It is very important that people with learning difficulties help make easy information. • People with learning difficulties should be involved in all the different parts of making easy information. • Involving people with learning difficulties costs money but it is very important. A key element of producing easy information is working together with the target audience. This should mean that the information produced is easier for them to understand and more likely to make a difference to their lives. If possible it is good to work together with both 'expert' or experienced information users and those who are new to the area. Partnership working needs to happen throughout every stage of information production: at the

outset; testing rough drafts; involving people in information production and testing the final draft before it goes public. Evaluating the information after it is produced is also important. Working in partnership has costs and benefits: the article concludes with a review of these.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16(2), 187-205.

In this article I set out to trace the influence of two major sets of ideas: normalisation/srv, and the social model of disability on inclusive research in learning disability. The argument is that normalisation set the agenda for learning disability research for two or more decades. Inclusive researchers continue to apply normalisation thinking to work with people with learning difficulties, particularly in assuming the role of advocate - offering people the opportunity to take on valued social roles and assuming responsibility for promoting positive images. Latterly, a number of researchers have tried to rise to the challenges posed by emancipatory research, particularly in attempting to find ways to put people with learning difficulties in control. This illustrates the influence of thinking emanating from disability studies. However, the paper shows that whilst some ideas from emancipatory research have been applied in learning disability, there are debates in the disability literature that have not been addressed in learning disability research to date. The result is that inclusive research in learning disability is in danger of being marginalised, both in the context of disability studies and in the context of the broad sweep of learning disability research.

Walmsley, J. (2004). Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 32, 65-71.

In this paper, the role of the nondisabled researcher who supports inclusive research in learning disability is explored. The author argues for more transparency about the role in order to highlight the challenges of working inclusively on research projects, the real contribution of people with learning difficulties to research, and the training/support implications of working inclusively.

Walmsey, J. & Johnson, K. (2003). *Inclusive research with people with learning disabilities: past, present and futures*. London & New York: Jessica Kingsley Publishers.

In this thought-provoking book, Jan Walmsley and Kelley Johnson discuss the participative approaches to research and provide an up-to-date account of inclusive practice with individuals with learning disabilities. Drawing on evidence from two major studies, they explain how lessons learned from inclusive research in the learning disability field are applicable to others working with marginalized groups. The authors examine the origins and the process of inclusive research,

describing: how and why it takes place, who carries it out, who funds it, how is it designed, how it relates to policy and practice. They look at the challenges inherent in this work, such as balancing the voice of the researcher with that of disabled participants and clarifying roles within research projects, and explore how it can become more inclusive and empowering. Providing valuable information and advice to researchers, policy makers and students as well as other health and social care professionals, this book presents a comprehensive examination of participative research in social care.

Walmsley, J. & Mannan, H. (2009). Parents as co-researchers: a participatory action research initiative involving parents of people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, 37(4), 271-276.

Most adults with intellectual disabilities in Ireland live with their parents. • In this research some parents worked with us as researchers. We called them co-researchers. • They talked with groups of other parents about what life is like for them and how well services support them. • The co-researchers learnt new skills, and have started to talk with service providers about how they can support families better. This paper evaluates a participatory action research (PAR) approach to conducting family research in Ireland. Drawing on PAR methodology it describes how parents of people with intellectual disabilities were recruited and trained to facilitate focus groups of parents in Ireland, in order to create an evidence base to support improved dialogue between parents and service providers. Its findings are that a PAR approach has considerable potential to contribute to improved understanding of the realities of family life with an adult with intellectual disabilities, particularly if plans to create a dialogue with service providers and to build sustainable networks of parents are included in the project.

Wyre Forest Self-Advocacy & Tarleton, B. (2005). Writing it ourselves. *British Journal of Learning Disabilities*, 33(2), 65-69.

People with learning disabilities have lots to say. They know how to say things to people with learning disabilities. • People with learning disabilities can get many skills by making easy information. The paper describes how a group of self advocates wrote a book. It discusses each of the stages of writing and developing the book. It says why they wanted to write a book, what they thought about making information easier and how they chose the right words and pictures. It shows that people with learning disabilities can make easy information for other people with learning disabilities. It also shows how making the information helped the self advocates develop lots of skills and how proud it made them feel. The self advocates knew how important it was for people with learning disabilities to be involved in making 'easy information'. They said they knew how it felt to be in their situation.