INCLUSIVE RESEARCH READING LIST - November 2010.

Abell, S., Ashmore, J., Beart, S., Brownley, P., Butcher, A., Clarke, Z., et al. (2007). Including everyone in research: The Burton Street Research Group. *British Journal of Learning Disabilities*, *35*(2), 121-124.

•We are people with and without learning disabilities doing research together.
•In this paper we talk about the good bits and the bad bits of doing research together. In our paper we talk about what it is like to be a group of people with and without learning disabilities researching together. We describe the process of starting and maintaining the research group and reflect on the obstacles that we have come across, and the rewards such research has brought us. Lastly we put forward some ideas about the role of professionals in such a group that we hope people might find useful. [ABSTRACT FROM AUTHOR]

Atkinson, D. (2005). Research as social work: Participatory research in learning disability. *British Journal of Social Work*, *35*(4), 425-434.

The social-work literature has already made links between social work and research, and has argued in favour of practitioner-research. This paper turns the argument around and looks at how research can come to look and feel like social work. This happens particularly, but not exclusively, in participatory research in the learning-disability field, especially in auto/biographical or life-story research, where long-term research relationships are more in evidence. Drawing on the participatory research methodology literature, and her own oral and life-history research, the author explores the areas in which research comes to emulate social-work practice. There are, of course, practical and ethical issues to be addressed and, as the author concludes, safeguards are needed to clarify roles and foster openness in research relationships. [ABSTRACT FROM AUTHOR]

Biewer, G., Fasching, H., & Koenig, O. (2009). Participation of Persons with Intellectual Disabilities in Education, Working Life and Research. *Sws-Rundschau, 49*(3), 391-403.

A research project at the Department of Education and Human Development at the University of Vienna, financed by the Austrian Science Fund (FWF), tries to assess participation experience of persons with intellectual disabilities who are either at the interface of school and occupation or who are already integrated into the labour market. Besides a first nationwide collection of structural quantitative data concerning the transition phase of school to working life and of the labour market opportunities for persons with intellectual disabilities, the investigation focuses on reconstructing possible perspectives. A qualitative longitudinal study with two groups, of youths and young adults in the transition phase and of occupationally integrated persons, analyses the particular participation experiences, based on a grounded theory approach. By including persons with intellectual disabilities into processes of interpretation and validation of qualitative data via a reference group, the project contributes to a methodology development in the area of participatory research. [ABSTRACT FROM AUTHOR]

Bjornsdottir, K., & Traustadottir, R. (2010). Stuck in the land of disability? The intersection of learning difficulties, class, gender and religion. *Disability & Society*, *25*(1), 49-62.

This article discusses the discrepancy between formal rights to full social inclusion and the lived experiences of young adults with learning difficulties. It draws on inclusive life history research in Iceland and employs intersectional theory to study the social participation of young adults with learning difficulties. In an attempt to understand the complex political, economic and ideological forces that hinder the actualisation of their formal rights the intersection of disability, class, gender and religion in the production and reproduction of existing social hierarchies is examined. The article demonstrates how the research collaborators resisted their devalued social construction and attempted to create and affirm themselves as competent social actors. [ABSTRACT FROM AUTHOR]

Brooks, M., & Davies, S. (2008). Pathways to participatory research in developing a tool to measure feelings. *British Journal of Learning Disabilities*, *36*(2), 128-133.

This article is about people with a learning disability doing research with therapists. It is about how we are learning to do research together. The research is trying to see if counselling and therapy helps people with a learning disability feel better. One way of doing this is to ask people questions about their feelings before and after counselling. We want to have some questions about how it feels living with a learning disability. Our group is talking about this. They have made a list of what they have said. They plan to ask other people if they agree. This research matters because people with learning disabilities are doing the research. They know what it is like living with a learning disability. They know what things that are important to them. They can help make a questionnaire that other people with learning disabilities will find easy to understand. The questionnaire should help people see how feelings can change over time. People with a learning disability, the experts of their own experience are increasingly involved in research. We will be discussing in this paper their centrality in the development of a psychological therapy outcome measure for people with learning disabilities. Their involvement needs to go beyond giving their views to being included in the whole research process. It is anticipated that such participatory research will help create a measurement tool that has greater meaning and validity for people with a learning disability. We are adapting clinical outcomes in routine evaluation 2013 outcome measure (CORE-OM) Evans et al. (2000, J Ment Health, 9, 247), the dominant psychotherapy outcome measure in routine use in the UK, for this purpose. However the existing four domains of CORE-OM (well being, problems/symptoms, functioning and risk) do not address some of the issues and feelings that impact on the lives of people with a learning disability. This we call the 'missing domain' and it is the focus of this present research. Within the Collaborative Research Group (CoRG) we are seeking to uncover the essential elements of this missing domain and convert them into items for a new domain. This article examines some of the issues involved in the complex interrelationship between the process of research and the outcome of research. [ABSTRACT FROM AUTHOR]

Dowse, L. (2009). ‘It's like being in a zoo.’ Researching with people with intellectual disability. *Journal of Research in Special Educational Needs, 9*(3), 141-153.

This paper introduces key debates in the contemporary practice of disability research and examines how these apply to conceptualising, designing and conducting research with people with intellectual disability. Specifically, it describes a collaborative action-oriented reflexive approach to researching the lived experience of people with intellectual disability in self-advocacy, offering a ‘reflective reprocessing’ of the methodological traditions, decisions, complexities and inadequacies of approaches to researching with such people. Emphasis on mutuality and the co-construction of research agendas, interpretative frames and meanings is a method that has rarely been seen in research practice in intellectual disability. The approach described enables a merging of the skills of the ‘researcher’ and the ‘researched’ to create a process of integrated inquiry and reflection. It promises the possibility of new forms of co-produced social knowledge about intellectual disability and self-advocacy, with explicitly emancipatory values and assumptions. [ABSTRACT FROM AUTHOR]

Flicker, S., Travers, R., Guta, A., McDonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health-Bulletin of the New York Academy of Medicine, 84*(4), 478-493.

National and international codes of research conduct have been established in most industrialized nations to ensure greater adherence to ethical research practices. Despite these safeguards, however, traditional research approaches often continue to stigmatize marginalized and vulnerable communities. Community-based participatory research (CBPR) has evolved as an effective new research paradigm that attempts to make research a more inclusive and democratic process by fostering the development of partnerships between communities and academics to address community-relevant research priorities. As such, it attempts to redress ethical concerns that have emerged out of more traditional paradigms. Nevertheless, new and emerging ethical dilemmas are commonly associated with CBPR and are rarely addressed in traditional ethical reviews. We conducted a content analysis of forms and guidelines commonly used by institutional review boards (IRBs) in the USA and research ethics boards (REBs) in Canada. Our intent was to see if the forms used by boards reflected common CBPR experience. We drew our sample from affiliated members of the US-based Association of Schools of Public Health and from Canadian universities that offered graduate public health training. This convenience sample (n = 30) was garnered from programs where application forms were available online for download between July and August, 2004. Results show that ethical review forms and guidelines overwhelmingly operate within a biomedical framework that rarely takes into account common CBPR experience. They are primarily focused on the principle of assessing risk to individuals and not to communities and continue to perpetuate the notion that the domain of "knowledge production" is the sole right of academic researchers. Consequently, IRBs and REBs may be unintentionally placing communities at risk by continuing to use procedures inappropriate or unsuitable for CBPR. IRB/REB procedures require a new framework more suitable for CBPR, and we propose alternative questions and procedures that may be utilized when assessing the ethical appropriateness of CBPR. [ABSTRACT FROM AUTHOR]

Garbutt, R. (2009). Is there a place within academic journals for articles presented in an accessible format? *Disability & Society*, *24*(3), 357 - 371.

This article addresses some of the difficulties inherent in disseminating emancipatory research findings in academic journals in a way that is empowering to people with learning difficulties in the UK. It calls for academics to challenge the editorial criteria of academic journals to consider accepting articles written in a more accessible style. It argues that from a social model point of view the products of the research, as well as the process, should be accessible to people with learning difficulties. It looks at what an accessible article is and why it is important, the editorial criteria of some academic journals, different models of presenting emancipatory research and suggests some innovative ways forward that highlight the need to ‘get involved’ in the world of people with learning difficulties and to consider accessible information as a rights-based issue. [ABSTRACT FROM AUTHOR]

Garbutt, R., Tattersall, J., Dunn, J., & Boycott-Garnett, R. (2010). Accessible article: involving people with learning disabilities in research. *British Journal of Learning Disabilities*, *38*(1), 21-34.

• This is an article that talks about our research about sex and relationships for people with learning disabilities. • It talks about how people with learning disabilities have been fully involved in the research. This is an article that talks about our research about sex and relationships for people with learning disabilities. [ABSTRACT FROM AUTHOR]

Goodley, D., & Moore, M. (2000). Doing Disability Research: activist lives and the academy. *Disability & Society*, *15*(6), 861-882.

The relationship between the academy and the disability movement is a problematic one. Disability researchers based in the academic world who align themselves with the social model of disability face contradictory aims and values in attempting to challenge dominant modes of research production in ways that signify the importance of the agendas of disabled people. It could be argued that research that involves people with the label of 'learning difficulties' creates further points of contention. In this paper we do two things. First, we re-present a paper given at a conference on the performing arts of people with 'learning difficulties', where the audience was made up of performers, workers, providers and researchers. This paper attempted to be accessible, theoretical, political and practical. Secondly, we reflect upon this paper in relation to seven points of analysis that emerge at the boundaries of disability politics and disability research. We argue throughout that real efforts must be made to bridge these boundaries in ways that augment disability theory and politics together. [ABSTRACT FROM AUTHOR]

Hollomotz, A. (2009). 'May we please have sex tonight?' People with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities, 37*(2), 91-97.

Everyone has the right to privacy and relationships. Some people who live in group homes are not allowed to be private with their partner. We will explain how this makes us feel. We will say what should change. Parts written in 'bold' font are in plain English. Read them to find out more. Many residential group settings for people with learning difficulties do not provide individuals with the private space in which they can explore their sexual relationships in a safe and dignified manner. Lack of agreed private spaces seriously infringes the individual's human rights. Many people with learning difficulties who lack privacy have no other option but to escape to isolated public or semi-private spaces to be sexually active. This places individuals at risk. It is suggested that self-advocacy driven policy guidance must be developed which must require residential services to review their practice to ensure that they accommodate residents' need for privacy, whilst supporting them to lead safe sexual relationships. [ABSTRACT FROM AUTHOR]

Hopkins, R. (2009). Making Research Live!. *British Journal of Learning Disabilities, 37*(4), 330-331.

• We have set up a group at our service who are doing research. • We decided on three things that were important to us to find out about: relationships, transport and holiday breaks, and personal social histories. • In this article we write about relationships. • We have shared stories, talked with other people and have made plays to get people to think about relationships and leaving home. • We have also gone on national radio to talk about this issue [ABSTRACT FROM AUTHOR]

Jurkowski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities, 46*(1), 1-11.

People with intellectual disabilities have few opportunities to actively participate in research affecting programs and policies. Employment of participatory action research has been recommended. Although use of this approach with people who have intellectual disabilities is growing, articles on specific participatory research methods are rare. Photovoice is a participatory method often used with underrepresented groups and is effective for engaging people with intellectual disabilities in research or program development. A literature review is presented for use with this population as is a description of Photovoice as a participatory research tool for engaging people with intellectual disabilities. An example of a participatory study among people with intellectual disabilities is provided. Benefits and challenges of employing Photovoice with this population are discussed.

Kellet, M., Aoslin, A., Baines, R., Clancy, A., ewiss-Hayden, L., Singh, R., et al. (2010). WeCan2: exploring the implications of young people with learning disabilities engaging in their own research. *European Journal of Special Needs Education, 25*(1), 31-44.

The concept of children and young people as researchers has started to gather momentum in response to changing perspectives on their status in society, recognition of their role as consumers and increased attention to children and young people's rights. There are early signs of a growing body of research studies undertaken by children and young people themselves. To date, this has included very little by young people with learning disabilities.1 Concepts of young people's participation and voice are thrown into sharper contrast for groups who sit on the margins of society. This paper reports research undertaken by a group of young people with learning disabilities exploring their experiences of youth democracy and meaningful participation in decision-making forums. The paper draws on theoretical frameworks of participation and voice; however, its primary focus is to celebrate and value research undertaken by these marginalised young people. [ABSTRACT FROM AUTHOR]

Knox, M., Mok, M., & Parmenter, T. R. (2000). Working with the Experts: collaborative research with people with an intellectual disability. *Disability & Society*, *15*(1), 49-61.

This paper reports on part of a wider study concerned with the collaborative efforts of an inquirer and six people with an intellectual disability, to develop a grounded theory explaining the processes by which these informants manage the relationships within their personal communities, The study was conducted through a series of in-depth interviews with each informant; a process characterised by information sharing, tentative theory development and elaboration, and informants' checking the accuracy of the emerging theory. This inductive approach allowed not only an insight into the lives of each informant, but recognised the informants' expertise in matters concerning their own lives and thus facilitated the emergence of theoretical elements of relevance to the informants themselves. The focus of the paper is on the collaborative or partnership approach adopted. The outcomes of the research partnership are detailed and implications drawn for the role of research in the lifestyles of people with an intellectual disability. [ABSTRACT FROM AUTHOR]

Kramer, J. M., J. C. Kramer, García Iriarte, E., & Hammel, J. (in press). Following through to the end: The use of inclusive strategies to analyse and interpret data in participatory action research with individuals with intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities.* Retrieved from http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2010.00602.x/pdf

Background: Scholars have called for research approaches that actively include and are driven by people with intellectual disabilities, but the process of inclusive data analysis has been scarcely documented in the literature. This paper demonstrates the process university researchers and a group of self-advocates used to analyse and interpret data collected during a participatory action research (PAR) project to increase the group's capacity for self-advocacy. Materials and Methods: University researchers presented numerical data in three visual formats for analysis. Seventeen People First members analysed and interpreted the data using a modified focus group approach. Results: All members participated in data analysis, but not all members participated in data interpretation. Members' interpretations suggest that the group felt an increased sense of empowerment and heightened awareness as a result of their increased capacity to run a meeting and involvement in the PAR cycle of action and reflection. Conclusions: Findings suggest that strategies such as visual representation of data, group analysis, and familiarity with data collection tools foster an inclusive process of analysis and interpretation. [ABSTRACT FROM AUTHOR]

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.

People labelled with learning disability are now more involved in research that is about them and their lives. When research about the lives of people labelled with learning disability gets published in journals the accounts are written by professionals or academics. Working and writing together is a good idea but we all need to decide on who is in control. Being in control of language often means being in control. 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. the six o'clock newsthis is thisix a clocknews thiman said nthi reasona talk wiaBBC accentiz coz yiwidny wahntmi ti talkaboot thitrooth wiavoice likwanna yooscruff. ifa toktabootthi troothlik wanna yooscruff yiwidny thingkit wuz troo.jist wonna yooscruff tokn.thirza rightway ti spellana right wayti tok it. thisis me tokn yirright way aspellin. thisis ma troothyooz doant nothi troothyirsellz cawzyi canny talkright. this isthe six a clocknyooz. belt up. Tom Leonard (1984). [ABSTRACT FROM AUTHOR]

McDonald, K., & Keys, C. (2008). How the Powerful Decide: Access to Research Participation by those at the Margins. *American Journal of Community Psychology*, *42*(1), 79-93.

How do those in power decide to include and exclude those at the margins from community life? We used simulated review of research vignettes to examine how researchers and members of Institutional Review Boards make decisions concerning the research participation of adults with and without intellectual disabilities. Results indicate that decision-makers are influenced by the disability status of the sample, characteristics of the research in which they are engaged, and their attitudes toward the research participation of adults with intellectual disabilities as well as their own relationship to the research process. For example, decision-makers may create situations that limit the self-determination of adults with intellectual disabilities and adults without disabilities within the research context, particularly when the research poses some risk of harm to participants. Implications for theory, action and research are explored. [ABSTRACT FROM AUTHOR]

Miller, E., Cooper, S.-A., Cook, A., & Petch, A. (2008). Outcomes important to people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 5*(3), 150-158.

An emphasis on the outcomes of health and social care services has become increasingly apparent within public policy in the United Kingdom. Alongside this, working in partnership has been a key theme, despite a relatively underdeveloped evidence base. Of central importance, however, must be whether directives toward partnership working are delivering improved outcomes, and in particular, the outcomes that are valued by service users. The authors describe a project that sought to identify the outcomes important to people with intellectual disabilities, and where possible, whether partnerships delivered these outcomes. The research was primarily based on interviews with service users and carers, and involved people with intellectual disabilities as both researchers and research subjects. The project categorized key outcomes in two categories (quality of life and process) and identified ways in which health and social care partnerships can deliver the outcomes service users want. If agencies are to deliver good outcomes to users, as increasingly emphasized in policy, this focus should accurately reflect the outcomes that users themselves define as important. [ABSTRACT FROM AUTHOR]

Milner, P., & Kelly, B. (2009). Community participation and inclusion: people with disabilities defining their place. *Disability & Society*, *24*(1), 47 - 62.

Disability-related public policy currently emphasises reducing the number of people experiencing exclusion from the spaces of the social and economic majority as being the pre-eminent indicator of inclusion. Twenty-eight adult, New Zealand vocational service users collaborated in a participatory action research project to develop shared understandings of community participation. Analysis of their narratives suggests that spatial indices of inclusion are quiet in potentially oppressive ways about the ways mainstream settings can be experienced by people with disabilities and quiet too about the alternative, less well sanctioned communities to which people with disabilities have always belonged. Participants identified five key attributes of place as important qualitative antecedents to a sense of community belonging. The potential of these attributes and other self-authored approaches to inclusion are explored as ways that people with disabilities can support the policy objective of effecting a transformation from disabling to inclusive communities. [ABSTRACT FROM AUTHOR]

Perry, J., & Felce, D. (2004). Initial findings on the involvement of people with an intellectual disability in interviewing their peers about quality of life. *Journal of Intellectual & Developmental Disability, 29*(2), 164-171.

There are relatively few examples of emancipatory research in which people with an intellectual disability become co-workers in the research process. The current study examined the feasibility of training someone with an intellectual disability to conduct quality of life interviews with peers. The extent to which response bias in a sample of 21 people with an intellectual disability varied according to whether interviews were conducted by a researcher or a person with an intellectual disability was also investigated Response bias was found not to be related to the characteristics of the interviewer. Amongst people Who responded without bias, responses were not tailored to interviewer characteristics. The study demonstrated that people with an intellectual disability can be trained and supported to be competent data collectors and to hold positions of responsibility in the research process. [ABSTRACT FROM AUTHOR]

Priestley, M., L., Waddington, & Bessozi, C. (2010). Towards an agenda for disability research in Europe: learning from disabled people's organisations. *Disability & Society*, 25(6), 731-746.

This paper addresses the challenges of building capacity for collaborative participatory research with disabled people's organisations in European countries. The paper presents initial findings from the project 'European Research Agendas for Disability Equality' (EuRADE), which seeks to build the capacity of civil society organisations to participate in future research collaborations in partnership with academic institutions. The findings draw on survey data identifying the research capacity, needs and priorities of 68 organisations in 25 countries and focuses, in particular, on responses from national or European level representative organisations of disabled people. The findings demonstrate a high degree of motivation and readiness for collaboration in academic research but raise concerns about the readiness of academic institutions to engage disabled people as equal partners within social model and rights-based approaches. Respondent organisations identified a wide range of research needs that raise challenges for collaborative responses from the academic community. In this way, the findings provide a basis for developing user-led agendas for European funded research within the emancipatory paradigm, and indentify important opportunities for new international research collaborations between activists and academics. [ABSTRACT FROM AUTHOR]

Rodgers, J. (1999). Trying to get it right: undertaking research involving people with learning difficulties. *Disability & Society*, *14*(4), 421-433.

This paper uses criteria defined by Zarb to describe research undertaken with people with learning difficulties, in the context of an emerging emancipatory paradigm. First, the paper addresses the question: Who controlled the research and what it was about? It considers consultation with people with learning difficulties, the influence of public service organisations and the ethical committee. Secondly, the paper evaluates how far disabled people were involved in the research process, and discusses issues relating to the inclusion of people with learning difficulties as respondents, obtaining informed consent and the involvement of carers in interviews. Finally, the paper discusses the questions: What opportunities existed for disabled people to criticise the research and influence its future direction? What happened to the products of the research? The role of a pilot study, opportunities to provide feedback and dissemination strategies are described. [ABSTRACT FROM AUTHOR]

Rodgers, J., & Namaganda, S. (2005). Making information easier for people with learning disabilities. [Article]. *British Journal of Learning Disabilities*, *33*(2), 52-58.

•Researchers worked with people with learning disabilities to make guidance on how to make information easier. They looked at books and papers and talked to people who had worked at making information easier.• One of the most important things they found out was that everyone who makes information for people with learning disabilities should work with people with learning disabilities to do it.• Everyone needs to keep working to find better ways to make information easier. Information is important for people with learning disabilities to make changes that will make their lives better. This paper begins with a discussion of what we mean by easy information. It then describes the methods employed in a project to create guidance on making information easier for people with learning disabilities. Researchers and people with learning disabilities worked together to interview information providers about approaches they had used and to carry out a literature review. Draft guidance was written and tested with a range of groups and individuals. Key findings from the project were the necessity of a clear aim when planning information, the need to consider carefully the best format or media for sharing your message and most importantly, to work with your intended audience when creating information. The paper goes on to discuss the importance of making information appropriate for all sections of the community, including people from Black and minority ethnic groups. [ABSTRACT FROM AUTHOR]

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. [ABSTRACT FROM AUTHOR]

Tierney, E. (2009). Supporting rights through research: development of a national research strategy for intellectual disability the national federation of voluntary bodies research strategy 2008–2013. *British Journal of Learning Disabilities, 37*(4), 323-325.

•The UN Declaration on Rights for persons with Disabilities says that people with disabilities should be included in things that concern them. •The National Federation of Voluntary Bodies in Ireland has been planning what research it will carry out in the future. •We involved people with intellectual disabilities, service providers and families in helping us to make our plans. [ABSTRACT FROM AUTHOR]

Tuffrey-Wijne, I., & Butler, G. (2009). Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis. *Health Expectations*, 13, 174-184.

Background: People with learning disabilities have been included in research as co-researchers since the 1990s. However, there is limited literature about the processes of involving people with learning disabilities in the more intellectual and analytical stages of the research process. Aims: To examine the potential contribution of people with learning disabilities to data analysis in qualitative research. Methods: This article is a reflection on one research experience. The two authors include one researcher with and one without learning disabilities. They each describe their experience and understanding of user involvement in analysing the data of an ethnographic study of people with learning disabilities who had cancer. The researcher with learning disabilities was given extensive vignettes and extracts from the research field notes, and was supported to extract themes, which were cross-compared with the analysis of other members of the research team. Results: The researcher with learning disabilities coped well with the emotive content of the data and with the additional support provided, he was able to extract themes that added validity to the overall analysis. His contribution complemented those of the other members of the research team. There were unexpected benefits, in particular, in terms of a more reciprocal and supportive relationship between the two researchers. Conclusion: It is possible and valuable to extend involvement to data analysis, but to avoid tokenism and maintain academic rigour, there must be a clear rationale for such involvement. Extra support, time and costs must be planned for. [ABSTRACT FROM AUTHOR]

Young, A. F., & Chesson, R. A. (2008). Determining research questions on health risks by people with learning disabilities, carers and care-workers. British *Journal of Learning Disabilities*, 36(1), 22-31.

• We did a study to look at the way research questions were developed by people with learning disabilities, their carers and care-workers. • Everyone thought of questions for helping people with learning disabilities be healthy. • There were six main research questions. Everyone voted for their top question. • The study showed that people with learning disabilities and carers can describe research questions that they feel are important. Also they can decide which ones are the most important to study. Here we describe the process by which research questions were developed for reducing health risks for people with learning disabilities. A participatory approach was used to give service users and carers a clear voice in deciding questions, thereby setting the research agenda. Audio-taped interviews and focus groups were used. Forty people (20 service users, 10 carers, 10 care-workers) were recruited and gave consent for interview. Interviews incorporated scenarios and these were used to describe two different types of health risks (i) those relating to lifestyle, and (ii) those associated with unrecognized illness. Participants were invited to specify a research question for each scenario. A total of 78 questions were identified, and from these, six key themes emerged. The themes were validated using three separate focus groups (service users, carers, care-workers). From this process six final questions encompassing participants' key research concerns were produced. Questions were resubmitted to participants for prioritizing, using a postal voting system (75% response rate). The research clearly demonstrates that people with learning disabilities and carers can identify and prioritize research questions they consider significant for improving health. [ABSTRACT FROM AUTHOR]