Self-Advocacy and people with intellectual/learning disabilities

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| Authors | Title, Journal, Date | Abstracts | Comments |
| Feldman, M. A. ; Owen, F. ; Andrews, A. ; Hamelin, J. ; Barber, R. ; Griffiths, D. | Health self-advocacy training for persons with  intellectual disabilities  Journal of Intellectual Disabilities  2012 | Background People with intellectual disabilities (ID) have unequal access to health care. While systemic efforts are addressing health inequalities, there remains a need to demonstrate that persons with ID can increase their health self-advocacy skills. Method A randomised control design with up to 6-month follow-up was used to evaluate the 3Rs (Rights, Respect and Responsibility) health self-advocacy training program for persons with ID (n=31). Training involved teaching participants to recognise and redress health rights violations in the context of respect and responsibility. Training materials included PowerPoint slides and interactive video scenarios illustrating health rights, respect and responsibility problem and non-problems. Two-hour training sessions were conducted twice a week in a group format where participants played a game and answered questions. Results The health rights training group made significantly more correct responses on post training and follow-up tests than the control group. Training effects generalised to untrained scenarios and in situ health interviews. Conclusions The results of this study suggest that persons with ID can learn complex skills related to health self-advocacy. More research is needed to improve in situ generalisation. | Very scientific, not much interest in empowerment |
| Daignault, J | The Riot Self-Advocacy Survey | Abstract only |  |
| J. Caldwell | Leadership development of individuals with  developmental disabilities in the  self-advocacy movement  Journal of Intellectual Disabilities 2010 | Background Exploring the life stories of leaders in  the self-advocacy movement can expand our knowledge  about leadership development of individuals  with developmental disabilities. A better understanding  of this process may assist with supporting  the movement and leadership development of youth  with disabilities.  Methods In-depth qualitative interviews were conducted  with 13 leaders in the self-advocacy movement  within the USA in order to explore their life  stories. Purposeful sampling contributed to a  diverse sample of leaders. A grounded theory  approach led to the identification of major themes  and factors associated with their leadership  development.  Findings Four major themes emerged: (1) disability  oppression and resistance; (2) environmental supports  and relationships; (3) leadership skills; and (4)  advanced leadership opportunities. Findings have  conceptual and practical relevance for future interventions  and research. | Strong paper with relevance for today. Need to develop younger leaders especially pertinent |
| Sian Anderson and Christine Bigby | Self‐Advocacy as a Means to Positive Identities for People with Intellectual Disability: ‘We Just Help Them, Be Them Really’  JARID  2017 | Background Stigma attached to having an intellectual  disability has negative implications for the social  identities and inclusion of people with intellectual  disability.  Aim The study explored the effects of membership of  independent self-advocacy groups on the social identity  of people with intellectual disability.  Method Using a constructivist grounded theory  methodology, semi-structured interviews were  conducted with 25 members of six self-advocacy groups  which varied in size, resources, location and policy  context: two based in the Australian states of Victoria  and Tasmania and four in the UK.  Results Collegiality, ownership and control by members  characterized groups. They gave members opportunities  for paid or voluntary work, skill development and  friendship which contributed to their conﬁdence and  engagement with life. Possibilities for new more positive  identities such as being an expert, a business-like  person, a self-advocate and an independent person were  opened up. Self-advocacy is an important means of  furthering social inclusion of people with intellectual  disability. | Good evidence for why self advocacy matters. Concrete contributions to both well being and employment |
| Rachel Clarke  Glenbourne Unit, UK  Kelly Camilleri  University of Exeter, UK  Lois Goding | What’s in it for me? The meaning of involvement in a self-advocacy group for six people with intellectual disabilities | Background: This article explores the experiences of six people with intellectual disabilities in the context of a self-advocacy group, identifying the benefits and difficulties of being part of the group. Materials and Methods: Six adults with intellectual disabilities were interviewed about their experiences. Each individual took part in two individual and two group interviews. The transcripts were analysed using thematic analysis. Results: Analysis revealed four themes, namely, being part of the group, self-esteem, self-determination and empowerment. Conclusion: Being part of the group is central to the experience of self-esteem, self- development and empowerment. Responses allow the exploration of the interrelationship between individual, group and community. Consideration is given to models of disability and the evidence base in relation to personal and political outcomes of self-advocacy. Links are made with developing a sense of self, self-determination, interpersonal learning and building resilience. Implications for practice are discussed. | More emphasis on well being as a consequence of belonging to a self advocacy group (UK) |
| David Henderson and Christine Bigby | ‘We Were More Radical back then’: Victoria's First Self-Advocacy Organisation for People  with Intellectual Disability  Health and History  2016 | This article is concerned with exploring the historical development of Reinforce, the oldest self-advocacy organisation for people with intellectual disability in Victoria. In particular, it considers how governmental indifference, as well as ad hoc funding and support, has hindered the growth of the organisation and, more generally, the growth of the self-advocacy movement in Victoria. By obtaining a deeper understanding of the input from the policy makers, professionals, and supporters working in the field of intellectual disability, we can begin to comprehend some of the reasons for the comparatively slow development of self-advocacy in this country. | Relevant for the DRILL bid |
| Ann-Louise Davidson | A Collaborative Action Research about Making Self-Advocacy Videos with People with Intellectual DisabilitiesSocial Inclusion 2015Canada | This article presents the results of a collaborative action research conducted with people living with intellectual disabili-ties (ID) who were going through a community integration process. To be successfully integrated into a community, they need to develop basic life skills as much as they need to learn to use mobile technologies for authentic interactions (Davidson, 2012) and to be self-advocates online (Davidson, 2009a). This study used the Capability Approach pioneered by Sen (1992) and Nussbaum (2000), which focusses on what people can do rather than on their deficiencies. I recruit-ed a group of eight people with ID who wished to set goals, engage in developing new capabilities, share their goals and act as models for others with ID who want to learn to live on their own. In this article, I examine the process of develop-ing self-advocacy videos with mobile technologies using the Capability Approach and I analyze the inventory of capabili-ties collected through this study. I provide recommendations for intervention through mobile technologies with the long term-goal of helping people with ID to become contributing citizens. I discuss the innovative action research methodology I used to help people with ID become self-advocates and take control of the messages they give through producing their own digital resources. | One of those projects which portrays self advocacy / empowerment as a gift from above. |
| Jan Walmsley | An investigation into the implementation of Annual Health Checks for people with intellectual disabilitiesJournal of Intellectual Disabilities2012 | This project, conducted during 2010 by a researcher working with a self-advocacy group, investigated the implementation of Annual Health Checks (AHCs) for people with intellectual disabilities in Oxfordshire, where only 26.1 percent of AHCs were completed in 2009–10 (national average 41 percent). AHCs were introduced in England in 2008 as a response to findings that people with intellectual disabilities have significantly worse health care than other groups. GP practices are financially incentivized to offer AHCs. This study found that slow progress in implementing AHCs was attributable to: uncertainty over who was eligible; limited awareness in general practices about the legal duty to make ‘reasonable adjustments’ to facilitate access; limited awareness of AHCs and their potential benefits amongst carers and adults with intellectual disabilities; and in some cases scepticism that AHCs were either necessary or beneficial. The article also explores the benefits of undertaking this project in partnership with a self-advocacy group. | This is about an inclusive research study conducted by a self-advocacy group. |
| Magnus Tideman & Ove Svensson | Young people with intellectual disability—The role of self-advocacy in a transformed Swedish welfare system  Cogent Social Sciences 2017 | A growing number of young people in Sweden with intellectual disability have organized themselves during the last 15 years in self-advocacy groups for socializing, empowerment, and expressing opposition to the norms and attitudes in a society that labels them as disabled. At the same time, the Swedish welfare system has transformed dramatically with processes of far-reaching individualization, closure of the major institutions, decentralization of responsibility from the state to local governments, and an emerging welfare market where service users are turned into customers. The aim of this article is to analyse and discuss the significance of self-advocacy in the new welfare context. Data were collected over a period of more than 10 years using repeated interviews with members of two self-advocacy groups and participation observations. Findings suggest that participation in self-advocacy groups opens up members for increasing health and well-being through new roles and identities, and it strengthens their control over everyday life. Support is still needed, however, but in new ways; otherwise, the restrictions of the institutions will simply be reconstructed in the new welfare system. | Very relevant for LDE |
| Therése Mineur, Magnus Tideman and Ove Mallander | Magnus Tideman & Ove Svensson (2015) Young people with intellectual disability—The role of self-advocacy in a transformed Swedish welfare system, International Journal of Qualitative Studies on Health and Well-being, 10:1, DOI: [10.3402/qhw.v10.25100](https://doi.org/10.3402/qhw.v10.25100) | Self-determination and the ability to express opinions and preferences are fundamental to all people. Some people with intellectual disability no longer accept a subordinated role as disabled and new self-advocacy groups have evolved. The aim of this study was to analyse the meaning and importance of engagement in a self-advoca- cy group for self-advocates daily life and identity. An interpretative abductive approach was used to analyse data from interviews with 26 self-advocates from six self-advocacy groups in Sweden in relation to the theoretical concepts; recognition, social capital, culture capital and self-determination. The key finding is that the vast majority of the participants experienced a changed self-perception, as more skilled, social and confident people, depending on group affiliation, their personal engagement and positions within the group. The conclusion is that self-advocacy is important for daily life and identity of people with intellectual disability. The self-organized movements indicate an important change in society and the results are of importance not only for the target group but for shaping future support and treatment from society of people with intellectual disability. | As above, shows relevance of self advocacy to modernised welfare systems |
| Elizabeth Tilley | Management, Leadership, and User Control in Self-Advocacy: An English Case StudyMental Retardation 2013 | This paper presents findings from a qualitative research project on an English self-advocacy organization. In light of recent political and economic developments that have threatened the sustainability of a number of self-advocacy groups for people with intellectual disability, I seek to  explore how one particular organization managed to survive and grow. In particular, the paper explores themes of management, leadership, and user control, linking these to external perceptions about self-advocacy organizations. The organization in my study developed an ‘‘interdependent’’ governance model based on key organizational roles for nondisabled advisors and self-advocates,  which proved popular with external funders. Despite the organization’s notable achievements, its success raises questions for the wider self-advocacy movement, notably how leadership capacity can be developed among self-advocates. | Interesting study of Talkback in Bucks |
| [Rohhss Chapman](https://onlinelibrary.wiley.com/action/doSearch?ContribAuthorStored=Chapman%2C+Rohhss) | An Exploration of the Self‐Advocacy Support Role Through Collaborative Research: ‘There Should Never be a Them and Us’ | Background The role of the support worker in self‐advocacy groups for people with intellectual disability is pivotal in setting the scene for empowerment. However, despite the growing importance of the role, it has attracted very little scrutiny. Method The study developed an inclusive team approach working alongside researchers labelled with learning difficulties. Emphasis was placed on making all aspects of the research cycle accessible to the team. A variety of qualitative methods were used. Results Despite supporters’ allegiances to disability equality and their emphasis on reflexivity, many crucial aspects of organizational practice and support remained hidden. However, an emerging shared narrative about the potential of people first implied the possibility of increased collaboration. This was evidenced in some of the groups. Conclusions Where problematic practice was discussed, supporters were open to developing alternative approaches. Acknowledging members contributions alongside the work of their supporters helped nurture more collaborative relationships. Accessible Abstract A lot of accessible methods were used to find out what was happening. Much support work is hidden away and not listed by organisations. The supporter role is very complex where supporters are managed by members. Supporters may find ways to hold on to power even when they say they try not to. There were some good ways seen for members and supporters to work together fairly. The writer talks about working in a team with researchers with learning difficulties. The study concludes that we can all learn from each other. |  |
| Ann Gilmartin, and  Eamonn Slevin, | Being a member of a self‐advocacy group: experiences of intellectually disabled people | A phenomenological methodology was used to explore the lived experiences of  belonging to a self-advocacy group for people with intellectual disabilities. Thirteen  persons with intellectual disabilities who attend three self-advocacy day centre  based groups in a city in the west of Ireland were the sample identified for the study.  Changes affected by self-advocacy group membership occurred in the day centres  the self-advocating participants attended. In addition being a member of a selfadvocate  group was found to enhance the personal lives of the participants.  Empowerment occurred for the participants’ both at an individual and collective  basis. The evidence produced suggests that opportunities should be provided for  adults with an intellectual disability who are not attending day services to join selfadvocacy  groups in a community setting as there were clear benefits identified in  this study from group membership. A recognition that service providers need to  take on board the value that can result from self-advocacy groups was apparent. The  need to conduct larger scale studies over larger geographical areas and longitudinal  research in this area is highlighted. |  |
| Ove Mallander Therese Mineur, David Henderson, Magnus Tideman | Self-advocacy for people with intellectual disability in Sweden – organizational similarities and differences | Self-determination and the ability to express opinions and preferences are fundamental to all people. Self-advocacy (SA) among people with intellectual disability (PWID) presents opportunities for them to develop skills to have a say and influence changes in their local environments. The aim of this article is to explore and understand organizational similarities and differences of SA groups for PWID in Sweden by focusing their structures and activities. Within the theoretical framework of Resource-Dependency and New Institutional Perspectives, data from six Swedish SA groups belonging to two different national organizations, have been analyzed. Factors such as affinity and expectations show limited differences, while power distribution, rules and the role of support persons point to greater diversity. However, good relations within the local organizational field seems to be essential to maintain strong SA for PWID. |  |
| Rob Greig | Can self-advocacy impact upon culture? | Purpose – The purpose of this paper is to provide a commentary on the preceding article “Changing  organisational culture: another role for self-advocacy”.  Design/methodology/approach – The paper suggests that self-advocacy has the potential to be  a significant influence on organisational culture, but questions whether self-advocacy’s current funding  regime and limited focus on outcomes makes this possible.  Research limitations/implications – This issue is identified as one where further research would be  beneficial.  Practical implications – If organisations are to use self-advocacy as a route of cultural change, it is  suggested that attention will need to be given to issues of independent funding, management change  objectives and whole system change.  Originality/value – If evidence were generated to support the belief that self-advocacy can impact on  organisational culture, the consequences for how society and services behave towards people with learning  disabilities could be significant. |  |
| Miller Robin | Changing organisational culture: another role for self-advocacy? | Purpose – Improvements in organisational culture are a common recommendation of enquiries into system  failure and an aspiration of policy. The purpose of this paper is to explore an initiative to change culture in a  low-secure service through the introduction of a self-advocacy group.  Design/methodology/approach – An independent evaluation was carried out by a university research  team. A theory-based methodology was deployed with qualitative data gathered through observations,  interviews and focus groups.  Findings – Culture change was reported by senior managers and clinicians in relation to the transparency  of the service, decision making regarding resources, and engagement of patients in redesign.  Self-advocacy group members reported a different relationship with senior management which in turn  enabled greater influence in the organisation. Achieving these impacts relied on independent and skilled  external facilitation, support from senior managers, and a calm and democratic atmosphere in the  meetings. Ward staff were kept at an arms-length from the group and were less certain that it had made  any difference to the way in which the ward operated.  Research limitations/implications – The research was only based in one organisation and the impacts of  the initiative may vary with a different local context. Research in a wider sample of organisations and  culture change initiatives will provide greater insights.  Practical implications – Self-advocacy groups can lead to organisation culture change alongside  benefits for individual group members but require funding, external and independent facilitation, and  organisational endorsement and support.  Originality/value – This paper adds to the limited literature regarding culture change in secure services  and services for people with |  |
| Caldwell, Joe | Disability Identity of Leaders in the Self-Advocacy Movement | Life stories and perspectives of leaders in the self-advocacy movement were explored to enhance knowledge about disability identity formation. In-depth qualitative interviews were conducted with 13 leaders in the self-advocacy movement. Five major themes emerged: (a) resistance-claiming personhood and voice; (b) connection with disability community; (c) reclaiming disability and personal transformation; (d) interconnection with broader disability rights movement; and (e) bond with social justice and interdependency. |  |
| Jan Walmsley and The Central England People First History Project Team | Telling the History of Self-Advocacy: A  Challenge for Inclusive Research | Background This paper tells the story of Central England  People First’s (CEPF) History Project.  Method This was an inclusive research project, owned  and controlled by members of CEPF which sought to  chart its 21-year history, 1990–2012.  Results It illustrates both the strengths of such a project  and some of the challenges.  Conclusion It concludes that using inclusive research  methods enabled the story to be told, but that it was  less successful in addressing questions about why the  organization grew and prospered in the 1990s, only to  struggle in its later years, and what this tells us about  the conditions which enable self-advocacy to flourish.  The paper was collaboratively written by the CEPF  History Project team and an academic ally. Different  fonts differentiate the contributions, although it is  acknowledged that lots of the ideas were shared. |  |
| Rohhss Chapman & Liz Tilley | Exploring the Ethical Underpinnings of Self-advocacy Support for Intellectually Disabled AdultsEthics and Social Welfare2013 | Self-advocacy organisations support people in a wide range of political activities, alongside providing key social networks. The emergence of formalised self-advocacy for intellectually disabled people marked an important cultural shift. These groups soon became associated with the pursuit of social change and the attainment of rights. The role of the self-advocacy support worker, working together with self-advocates, has been pivotal. However, studies have shown there has been concern over the relationship between self-advocates and those who advise or support them. Both parties are aware of the potential tensions of supporters teaching people skills to take control, to manage their workers, whilst, perhaps inadvertently, assuming a powerful position in the relationship. This interesting paradox hints at ethical complexities inherent in the role. A key challenge facing these support workers is how they can support their employers to run successful organisations, without ‘taking over’. Using material from both Chapman and Tilley's research of self-advocacy organisations in the UK, this article problematises some key ethical issues within the role. |  |
| Thomas G. Ryan, Sarah Griffiths | **Self-advocacy and its impacts for adults with developmental disabilities** | The following review of literature illuminates self-advocacy from a North American transformational learning perspective via meaningful impacts, which arise for adults with developmental disabilities, as well as various communities and their members. For adults with developmental disabilities, increased leadership capabilities and the evolution of new self-concepts continue to be powerful examples of the impact of self-advocacy. For communities, a more prominent voice and personable research within the academic community, increased awareness for some boards and committee members, and the acknowledgement and support of local or online community members are broad examples of the impacts self-advocacy has on us. |  |
| Carli Friedman | Self-Advocacy Services for People With Intellectual and  Developmental Disabilities: A National Analysis | Self-advocacy plays an important role in facilitating the empowerment of people with intellectual and developmental disabilities (IDD), and helps people with IDD develop the skills necessary for the participant direction of services. The purpose of this study was to examine Medicaid Home and Community Based Services (HCBS) 1915(c) waivers across the nation to determine how states  were utilizing self-advocacy services for people with IDD. Findings revealed approximately half of waivers provided self-advocacy services; however, less than .01% of waiver spending was projected for stand-alone self-advocacy services. States need to expand the provision of self-advocacy services  for people with IDD in order to strengthen their ability to direct their waiver services and exercise their rights. | Highly instrumental use of self advocacy. Might be worth some thinking about  US |
| Krist ́ın Bjo ̈rnsdo ́ttir and Ingo ́lfur A ́sgeir Jo ́hannesson | People With Intellectual Disabilities in Iceland: A Bourdieuean Interpretation of Self-Advocacy  IDD  2009 | There are many barriers to social participation in Iceland for people with intellectual disabilities. This article builds on qualitative research with young adults with intellectual disabilities. The purpose of this article is to develop an approach where the struggles over the meaning of social participation of people with intellectual disabilities are seen as social strategies. In the article, the authors suggest that people with intellectual disabilities are carving out a space where intellectual disability is gaining higher social status. They also posit that people with intellectual disabilities use several social strategies in the emerging field of self-advocacy for the purpose of improving their social position. Thus, the article contributes to a new social understanding of disability and how people with disabilities gain authority over their lives and experiences. | A little fanciful for my tastes |
| [Suzie Beart](https://onlinelibrary.wiley.com/action/doSearch?ContribAuthorStored=Beart%2C+Suzie)    [Gillian Hardy](https://onlinelibrary.wiley.com/action/doSearch?ContribAuthorStored=Hardy%2C+Gillian)    [Linda Buchan](https://onlinelibrary.wiley.com/action/doSearch?ContribAuthorStored=Buchan%2C+Linda) | Changing Selves: a Grounded Theory Account of Belonging to a Self‐advocacy Group for People with Intellectual Disabilities JARID 2004 | **Purpose** To explore the experience of belonging to a self‐advocacy group for people with intellectual disabilities, and how membership of such a group impacts on individual members.  **Methods** Eight people with intellectual disabilities, who belonged to a self‐advocacy group for at least 6 months, were interviewed about their experiences of membership. A grounded theory approach was used to generate and analyse the interview data.  **Results** A model of the impact of belonging to a self‐advocacy group for people with intellectual disabilities on individual members' self‐concept is developed. The model proposes that participants' self‐concept changes as a result of group membership and that this process of change involves six key categories: joining the group; learning about and doing self‐advocacy; becoming aware of group aims and identity; experiencing a positive social environment; identifying positive change in self‐concept and seeing the future of self and group as interlinked.  **Conclusion** Membership of a self‐advocacy group for people with intellectual disabilities changes the self‐concept of participants. The processes surrounding these changes have important implications for self‐advocacy groups both, in recruitment and in supporting group members. | About identity primarily |
| Strnadova, Johnson, & Walmsley | ".. but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities?  JARID  2018 online publication  Australian data | A policy commitment to social inclusion has brought about some positive changes in the lives of people with intellectual disabilities; yet many also continue to experience social isolation, poverty and abuse. The authors introduce a framework for belonging from the literature and then present a study exploring the views of people with intellectual disabilities about belonging. These are discussed in relation to the framework identified from the literature. Three focus groups with 24 participants with intellectual disabilities were conducted in New South Wales and Victoria (Australia). The authors used inductive content analysis to identify four meanings of belonging: (i) belonging in relation to place, (ii) as being part of a community, (iii) as having relationships and (iv) as identity. Also discussed are commonly experienced barriers to belonging identified by participants. Implications for policy, service provision and practice are discussed. | Illustrates value of self advocacy to combat isolation, cement friendships, provide a sense of belonging |
| Carli Friedman • Catherine K. Arnold • Aleksa L. Owen • Linda Sandman | ‘‘Remember Our Voices are Our Tools:’’ Sexual Self-advocacy as Defined by People with Intellectual and Developmental Disabilities  Sex and Disability  2014 | This exploratory study examines how people with intellectual and develop- mental disabilities (IDD) define and experience sexuality in the context of their identities as self-advocates. Using nominal group technique this study found self-advocates descri- bed sexual self-advocacy as relating to knowing and respecting themselves, respect for others, choices, speaking up, having their rights respected, getting information, healthy relationships, and interdependence. They also explained facilitators that would increase their sexual self-advocacy such as expanding access to information and sexual health services, removing systemic barriers, educating others, increasing access to counseling, and developing opportunities for sexual expression. The significance of the study is the expansion of research on sexual self-advocacy by bringing the sexuality and self-advocacy literatures together, reinforcing the value of people with IDD as legitimate sources of information about their own experiences, and providing a sustainable and accessible research method for working with people with IDD. |  |
| Susa, J ; Susa, M | From parent advocacy to self advocacy: How one family does it! | Journal Of Intellectual Disability Research, 2000 Jun-Aug, Vol.44, pp.479-480 |  |
| [Nonnemacher, Stacy L](https://search.proquest.com/indexinglinkhandler/sng/au/Nonnemacher,+Stacy+L/$N?accountid=12763); [Bambara, Linda M](https://search.proquest.com/indexinglinkhandler/sng/au/Bambara,+Linda+M/$N?accountid=12763). | "I'm Supposed to Be In Charge": Self-Advocates' Perspectives on Their Self-Determination Support NeedsIntellectual and Developmental Disabilities 2011 | In this qualitative interview study, we explored the perceptions of adults with intellectual disability regarding interpersonal or social supports needed to express their own self-determination. Specifically, 10 adults, all members of a self-advocacy group, were asked to discuss their understanding of the term self-determination and ways in which support staff have either supported or inhibited their selfdetermination. Ten themes characterizing supportive and impeding staff actions were identified. The need for greater exploration of environmental and social influences on self-determination is emphasized. |  |
| Andrew Power  Ruth Bartlett  Edward Hall | Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity  2016 | Whilst personalization offers the promise of more choice and control and wider participation in the community, the reality in the United Kingdom has been hampered by local council cuts and a decline in formal services. This has left many people with intellectual disabilities feeling dislocated from collective forms of support (Needham, 2015). What fills this gap and does peer advocacy have a role to play? Drawing on a co-researched study undertaken with and by persons with intellectual disabilities, we examined what role peer advocacy can play in a context of reduced day services, austerity and individualized support. The findings reveal that peer advocacy can help people reconnect in the face of declining services, problem-solve issues and informally learn knowledge and skills needed to participate in the community. We argue that peer advocacy thus offers a vital role in enabling people to take up many of the opportunities afforded by personalization. | Illustrates role of self advocacy when welfare state retreats |
| Patsie Frawley & Christine Bigby | Reflections on being a first generation self- advocate: Belonging, social connections, and doing things that matter  JIDD  2015 | Background Despite good policy intentions, people with intellectual disability continue to be socially excluded. Social geographers suggest the potential of self-authored spaces as catalysts for social inclusion. One such space, self-advocacy, is commonly perceived as part of a political movement for social change rather than a vehicle for social inclusion of its members. This paper investigated what involvement in self-advocacy has meant to long-term members of a self-advocacy group in Victoria, Australia.  Methods In-depth interviews were conducted with 12 self-advocates about their reflections on involvement in the group. These data together with the commentary of 5 self-advocates during interviews with 18 self-advocacy supporters about their recollections of involvement in the group were transcribed and analysed thematically. Findings Through their involvement in self-advocacy, members of the group had gained a sense of belonging, social connections, and purposeful occupation, which included paid project work, lobbying, and organisational leadership and management.  Conclusions This study suggests that self-advocacy groups can be places that foster social inclusion, potentially offering “membership” of an exclusive group, a wider social movement and of mainstream society. | About belonging again |
| Aleksa Owen, Katie Arnold, Carli Friedman and Linda Sandman | Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities  Qualitative social work  2016 | People with intellectual and developmental disabilities must often advocate for them- selves in many facets of life, including sexuality. Because of this, sexual self-advocacy is an important concept to develop and apply to policy and practice. This paper provides a conceptualization of sexual self-advocacy, a view of sexuality formulated by adults with intellectual and developmental disabilities that is closely tied to the values of the Self- Advocacy Movement. In describing the study process, this paper also puts forth the Participatory Action Research method, Nominal Group Technique, as an accessible method for gaining insight from adults with intellectual and developmental disabilities. The choice of Nominal Group Technique as a research method was motivated by several factors. Nominal Group Technique served to counterbalance many of the poten- tial research difficulties when working with people with intellectual and developmental disabilities, including the need for understandable, inclusive, and participatory ways to access data from people with intellectual and developmental disabilities, and addressed the topic of sexual self-advocacy that is important to people with intellectual and developmental disabilities. |  |
| Steve Mcnally | A survey of self-advocacy groups for people with learning disabilities in an English region  Journal of Learning Disabilities 2002 | This is the first of two articles which report the rationale for and the planning, execution and analysis of a postal survey of self-advocacy groups in the English midlands. It considers some key literature on previous studies of self-advocacy groups. Ethical considerations including informed consent and confidentiality are explored. The researcher gained approval from various research ethics committees in the planning of the study. It is important that approval was secured prior to gathering data from potentially vulnerable individuals. This may be seen as paradoxical because a cornerstone of the self-advocacy movement is for people to make their own choices and decisions, including informed consent to participate in a research project. This article discusses the design and piloting of an illustrated questionnaire and letter of invitation to participate in the study. Methodological issues in conducting out-research, including remote postal work, with people with learning disabilities are also examined. |  |
| [Dryden, Eileen M.](https://primoa.library.unsw.edu.au/primo-explore/search?query=creator%2Cexact%2CDryden%2C%20Eileen%20M.%20%2CAND&tab=default_tab&search_scope=SearchFirst&sortby=rank&vid=UNSWS&mode=advanced&offset=0)  [Desmarais, Jeffrey](https://primoa.library.unsw.edu.au/primo-explore/search?query=creator%2Cexact%2C%20Desmarais%2C%20Jeffrey%20%2CAND&tab=default_tab&search_scope=SearchFirst&sortby=rank&vid=UNSWS&mode=advanced&offset=0)  [Arsenault, Lisa](https://primoa.library.unsw.edu.au/primo-explore/search?query=creator%2Cexact%2C%20Arsenault%2C%20Lisa%2CAND&tab=default_tab&search_scope=SearchFirst&sortby=rank&vid=UNSWS&mode=advanced&offset=0) | Effectiveness of IMPACT:Ability to Improve Safety and Self‐Advocacy Skills in Students With Disabilities—Follow‐Up Study Journal of School Health  2017 | BACKGROUND: Research shows that individuals with disabilities are more likely to experience abuse than their peers without  disabilities. Yet, few evidenced-based abuse prevention interventions exist. This study examines whether positive outcomes  identiﬁed previously in an evaluation of IMPACT:Ability were maintained 1 year later.  METHODS: A survey measuring safety and self-advocacy knowledge, conﬁdence, and behaviors among special education  high-school students was administered 12 months post-training. Paired samples t-tests were used to compare baseline to follow  up and postsurvey to follow up and repeated measures analyses were conducted to test the effect of time across the 3 time  points (baseline, post, and 1-year follow up) (N = 47).  RESULTS: Follow-up study participants had a range of disabilities, just over half were boys, and most were either black or  Latino/Hispanic. Difference between scores at baseline and follow-up for all the measures of interest represented gains from  baseline. Statistically signiﬁcant post-training improvements in participants’ safety and self-advocacy knowledge and conﬁdence  were maintained 1-year later.  CONCLUSIONS: These results provide additional support for the case that IMPACT:Ability is a promising safety and  self-advocacy training program for diverse groups of students with disabilities.  Background: Research shows that individuals with disabilities are more likely to experience abuse than their peers without disabilities. Yet, few evidenced-based abuse prevention interventions exist. This study examines whether positive outcomes identified previously in an evaluation of IMPACT:Ability were maintained 1 year later. Methods: A survey measuring safety and self-advocacy knowledge, confidence, and behaviors among special education high-school students was administered 12 months post-training. Paired samples t-tests were used to compare baseline to follow up and postsurvey to follow up and repeated measures analyses were conducted to test the effect of time across the 3 time points (baseline, post, and 1-year follow up) (N = 47). Results: Follow-up study participants had a range of disabilities, just over half were boys, and most were either black or Latino/Hispanic. Difference between scores at baseline and follow-up for all the measures of interest represented gains from baseline. Statistically significant post-training improvements in participants' safety and self-advocacy knowledge and confidence were maintained 1-year later. Conclusions: These results provide additional support for the case that IMPACT:Ability is a promising safety and self-advocacy training program for diverse groups of students with disabilities. | Another interpretation of self advocacy is that it can strengthen coping mechanisms for specific purposes. This is an example |
| Marie-Sol Reindl  Mitzi Waltz  Alice Schippers | Personalization, self-advocacy and inclusion: An evaluation of parent-initiated supported living schemes for people with intellectual and developmental disabilities in the Netherlands  JID  2016 | This study focused on parent-initiated supported living schemes in the South of the Netherlands and the ability of these living schemes to enhance participation, choice, autonomy and self- advocacy for people with intellectual or developmental disabilities through personalized planning, support and care. Based on in-depth interviews with tenants, parents and caregivers, findings included that parent-initiated supported housing schemes made steps towards stimulating self- advocacy and autonomy for tenants. However, overprotective and paternalistic attitudes expressed by a significant number of parents, as well as structural constraints affecting the living schemes, created obstacles to tenants’ personal development. The study calls for consideration of interdependence as a model for the relationship of parents and adult offspring with disabilities. The benefits and tensions inherent within this relationship must be taken into consideration during inclusive community building. |  |
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