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The impact of self-advocacy on the well-being of people with intellectual disability: An international programme of research



People 1st



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Research Brief

What is the problem?

People with intellectual disability remain one of the most excluded and under-served populations within society. They also experience significant and enduring health and well-being inequalities. The COVID-19 pandemic both exposed and exacerbated such inequalities. For example, in the UK, younger adults with intellectual disability were over 30 times (Public Health England, 2020) more likely to die from coronavirus than the general population. In Australia, the rate of hospitalisation with vaccine-preventable conditions for people with intellectual disability was three times higher than for those without intellectual disability (Weise et al., 2021). This is especially concerning given the slow vaccine roll-out in Australia.

Our research aims to understand how self-advocacy can help address these ongoing and pervasive inequalities, to support the greater inclusion of people with intellectual disability in society.

Subjective Well-being

- Refers to people's feelings and cognitive evaluations of their life (Diener, 2012);
- Can only be determined by the person under investigation and only takes into account the person's own feelings and evaluations of their life;
- High subjective well-being is a desirable outcome and key component of quality of life;
- Benefits one's health (Chida & Steptoe, 2008), income (Diener et al., 2002), work productivity (Oswald et al., 2015), and social behaviour (Aknin et al., 2011); is associated with more positive relationships.

Intellectual disability

Intellectual disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills, with;
- A reduced ability to cope independently;
- Which started before adulthood, with a lasting effect on development." (Valuing People. Government White Paper. 2001)

Self-advocacy

is 'a space in which people with intellectual disability can develop:

- Confidence;
- Skills;
- Leadership capacity;
- A collective identity, providing an essential foundation for grassroots activism' (Tilley, 2013, p. 470).

What we did about it

Study 1: Systematic Review of the Literature

"What difference does self-advocacy make to self-advocates' subjective sense of well-being?" utilizing the Dynamic Model of Well-being.

Well-being is understood in the Dynamic Model as 'flourishing': feelings of happiness, joy, contentment and satisfaction that are achieved when sufficient personal resources and positive external conditions are in place to enable good functioning and satisfaction of needs'.

The four key domains of the Dynamic Model are

- personal resources
- external conditions
- good functioning and satisfaction of needs
- good feelings day to day and overall).

Study 2: Interviews and focus groups with 54 self-advocates with intellectual disability

26 women and 28 men, 20 to 69 years old (an average of 42 years) Australia and the United Kingdom

What we found

Study 1

Our systematic review of the literature showed that participating in self-advocacy:

- Can make a difference to the subjective well-being of people with intellectual disability;
- Can change and improve people's external conditions (i.e., new and supportive social networks, opportunities for work and meaningful activity);
- Can also be seen to improve personal resources of people with intellectual disability, heightening self-esteem and increasing confidence;
- Appears to provide an environment in which people learn new skills and acquire new knowledge;
- Leads to a shift in self-concept following participation in a self-advocacy organisation;
- Helps people develop capacities to focus upon and celebrate their strengths;
- Supports people to have a more positive relationship with the label and experience of intellectual disability;
- Enables people to develop new and sometimes multiples identities, while simultaneously connecting individuals to a wider disability community (Tilley et al., 2020).

Participation in self-advocacy organisations does appear to have significant impacts on the subjective well-being of people with intellectual disability across the four domains of the Dynamic Model of Well-being.

Study 2

Our empirical research indicates that self-advocacy leads to tangible improvements in people's health and well-being. For example, our analysis demonstrates that self-advocacy:

- Supports better mental health, by improving people's self-esteem and confidence, reducing loneliness and isolation, and providing a new found sense of 'belonging';
- Helps people to make positive lifestyle changes to improve their physical health, and supports people to access healthcare;
- Facilitates the acquisition of new skills that people can draw upon in other parts of their life;
- Empowers people to 'speak up', to understand their rights and to have greater choice and control;
- Supports people to make significant changes in their lives, for example, in relation to housing or employment.
- Helps to build people's resilience, and supports people to take action, particularly in the face of sustained experiences of bullying and harassment.

The research also identified that many people with intellectual disability continue to experience bullying, abuse and harassment in their day to day lives. Self-advocacy groups provide a safe space for people with intellectual disability in what for many continues to be an otherwise hostile and intimidating environment.

Why does it matter?

- [The UN Convention on the Rights of Persons with Disabilities \(UNCRPD, 2006\)](#) clearly articulates the rights of people with disabilities to have full and effective participation and inclusion in society. While it has been ratified in 185 countries, people with intellectual disability continue to experience social exclusion.
- It is evident from our systematic review and empirical research that self-advocacy not only contributes to the health and well-being of people with intellectual disability, but enables them to experience social inclusion and belonging.
- It is imperative that statutory authorities, commissioners, and other funding bodies are aware of the profound impacts that self-advocacy has on people with intellectual disability to ensure that sufficient resources could be directed to supporting the development of self-advocacy in people with intellectual disability.

What next?

2020

- The University of New South Wales and Self-Advocacy Sydney investigated the development of online peer support and peer mentoring for and by people with intellectual disability. The study explored the impact of online peer support and peer mentoring on the social inclusion and well-being of people with intellectual disability.
- The Open University commissioned research to explore how self-advocacy groups in England were supporting people during the pandemic ([Rouse et al. 2020](#)). The impact of self-advocacy groups during the pandemic was found to be significant, wide-reaching, and in some instances, life-saving. The Open University is now undertaking funded research to explore the commissioning and funding of self-advocacy.

2022

- Joint application (UNSW and Open University) for the external funding.



About the Researchers



Iva Strnadová

Iva Strnadová, PhD, is a Professor in Special Education and Disability Studies at the University of New South Wales in Sydney, Australia. She is also Academic Lead Research at the Disability Innovation Institute at the UNSW. Her research aims to contribute to better understanding and the improvement of the life experiences of people with disabilities, especially people with intellectual disabilities. Combining research with advocacy is essential in her research program, which builds on supporting the self-determination (including self-advocacy) of people with intellectual disabilities, and is grounded in an innovative inclusive research approach. Further details are available at [Disability and me blog](#), Disability and me Facebook page, and Twitter @IvaStrnadova.



Joanne Danker

Joanne Danker, is lecturer in Special Education in the School of Education at the University of New South Wales. She specialises in the well-being of students with developmental disabilities (i.e., autism spectrum and intellectual disabilities), inclusive and special education, and enabling the voices of individuals with disabilities in research. Further details of her work can be found at <https://research.unsw.edu.au/people/dr-joanne-cherie-danker>.



Liz Tilley

Dr Liz Tilley, PhD, is a Senior Lecturer and Associate Head of School for Research in the School of Health, Wellbeing and Social Care, Faculty of Wellbeing, Education and Language Studies, The Open University. Her research interests are focused on the experiences of people with intellectual disabilities, particularly experiences of belonging; sexual and reproductive health; self-advocacy; ageing; capacity; and access to heritage. Liz has a particular interest in historical perspectives, ethics and participatory methods in applied health and social care research. For the past ten years Liz has co-chaired the Social History of Learning Disability Research Group at The Open University. Further details of Liz's work can be found here and you can connect with Liz on Twitter @liz_tilley24



Julie Loblinzk

Julie Loblinzk is a Board member at Self Advocacy Sydney, Inc. Her focus is on people with intellectual disabilities supporting themselves to speak up and be active in the community. Julie Loblinzk is also Adjunct Lecturer at the University of New South Wales Sydney. In her role she lectures to undergraduate and postgraduate students about topics such as self-advocacy and parenting with intellectual disability. She is also involved in inclusive research and is currently working with Prof Iva Strnadová on numerous research studies. Further details of Julie Loblinzk's work can be found at [Disability and me blog](#) and Disability and me Facebook page.



Alan Armstrong

Alan Armstrong was a self-advocate with BAROD Community Interest Company/ Carmarthenshire People First (United Kingdom). Very sadly, Alan died in February 2021, due to COVID-19. His death is a great loss to the self-advocacy and inclusive research communities.



Jan Walmsley

Professor Jan Walmsley is co-author of the most quoted publication on Inclusive Research (Walmsley and Johnson 2003) and has continued to work in this way and to publish with a variety of Disabled People's Organisations.



Michelle Tso

Michelle Tso is a PhD student at the University of New South Wales. Her PhD thesis is on the peer interactions of female high school students on the autism spectrum. She is supervised by Professor Iva Strnadová, Dr Sue O'Neill and Dr Joanne Danker. Her research interests are in inclusive and special education, and especially in supporting students on the autism spectrum to have increased well-being in the school environment and beyond. She is a research assistant on projects at the University of New South Wales (School of Education, and the Disability Innovation Institute). Further details of her work can be found at [Google Scholar](#).





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For more information

Requests for further information and/or media enquiries can be directed to Prof Iva Strnadová and A/Prof Liz Tilley for the Research Brief.

Special and Inclusive Education Research Group

Research into special and inclusive education aims to understand and respond to the needs of students with a lived experience of disability. An associated research team at UNSW – the Special and Inclusive Education Research Group (SIERG) – seeks to engage with the wider community of schools, people with disability, and service providers with the goal of improving the outcomes of people with disability at all stages of education.

SIERG membership is comprised of prominent researchers, higher degree research students, educators, and people with lived experience of disability. Much of this research is accomplished through participatory and inclusive research, action research, and community consultation.