



Self-Advocacy on the Map: Mapping and promoting the self-advocacy of people with learning disabilities and/or autism

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Background

Nearly 10 years of austerity (cuts) have seriously threatened the services and support for people with learning disabilities and/or autism. One area of great strength remains: self-advocacy. While threatened by cuts in funding, self-advocacy groups in the UK continue to support people with a learning disability and or autism and their families to improve their status as full independent and contributing citizens of their community. Our project sought to:

- Promote self-advocacy and its importance nationally.
- Identify, capture and document the work of self-advocacy groups across the country through the development of an online map.

Sunderland People First was established in 1994 and is celebrating its 25th Anniversary. We are now a user led Community Interest Company. Based in the North East of England, we have over 20 years of experience of working with services such as Sunderland City Council, Sunderland CCG, NHS England, Northumbria police and other voluntary sector organisations to drive forward positive change. We achieve this through consultation, co-production, promoting national and local campaigns and giving people a collective voice. We are also passionate about engaging with other self-advocacy groups across the country.



Sunderland focus group

Defining self-advocacy

The definition of self-advocacy that we have adopted for this project was kindly provided by Jenny Carter who is a self-advocate from the organisation Together All Are Able.

“Self-advocacy is where people with disabilities speak up for themselves. This doesn't need to be verbal communication the person can use other ways to communicate but communication is important to self-advocacy. Self-advocacy enables people to advocate for their rights needs and want they want explain to others what their rights are and enables people to stand up for their rights. Self-advocacy can be done with someone on their own or as part of a group.”

<https://rightfullives.wordpress.com/2018/12/22/guest-blog-jenny-carter>

Self-advocacy groups achieve an amazing variety of work in supporting people with a learning disability and or autism and family carers. Work designed and delivered by self-advocates is often more innovative and powerful because they are experts-by-experience who identify the issues and create meaningful solutions. In our own area of the North East & Cumbria this has included:

- Developing quality checking tools for health and social care providers based on standards created by people with a learning disability;
- Developing a regional Safe Place Scheme;
- Self-advocates leading the 'Stop People with a Learning Disability Dying Too Young' group that is having national influence on the LeDeR programme (The Learning Disabilities Mortality Review which is the first national programme of its kind aimed at making improvements to the lives of people with learning disabilities);
- Self-advocates working with health professionals to design and deliver a 'Be Cancer Aware' course for people with a learning disability.

Further resources on the impact of self-advocacy groups can be found here:

We are all citizens - <https://www.youtube.com/watch?v=ai5xcEMV2gg>

Human Activism - <http://ihuman.group.shef.ac.uk/portfolio/humanactivism-org>

Our research on self-advocacy

Sunderland People First wanted to find out how about the current reality for self-advocacy in the UK. We therefore consulted people with a learning disability and their families around their understanding of the term self-advocacy:

- We used Twitter, email and phone calls to contact all known self-advocacy groups in the UK.
- We presented a workshop at the 2018 National Self-advocacy Convention and three further workshops in Blackpool, Sheffield and Sunderland to learn from people with learning disabilities about how they understand self-advocacy.
- We devised and sent out an accessible questionnaire to all self-advocacy groups in the country to find about how they work, how they are funded, the impacts of austerity and the challenges they faced.

The challenges that self-advocacy has faced

Austerity has led to the loss of many self-advocacy groups. Those that are still running face continuous challenges with funding. As part of our workshop at the 2018 National Self-advocacy Workshop, we asked self-advocates from local areas to add a Green Dot to a UK map (to show existing groups) and a Red Dot (indicating groups that no longer run). The results were depressing:



These results support the work of the National Survivor User Network (2018) who found an alarming number of user-led and self-advocacy groups that have closed in their membership over the last few years.

And they back up the views of Becki Meakin, Shaping Our Lives manager, who told us: 'The growing pressure on voluntary and community sector organisations to secure funding is evolving into a fight for survival'.



Sheffield focus group

Mapping self-advocacy

The real risk to self-advocacy groups means that there is an urgent need to support and spread the word of self-advocacy. Therefore, drawing on the findings from our research, we have developed an online interactive self-advocacy map:

This map will be hosted on the Learning Disability England website. LDE are a membership organisation bringing together people with learning disabilities, professionals and organisations.



We are thankful to Jan Walmsley and Barod Community Interest group who had already started to develop a map of existing groups and have shared their English group contacts with us so that we can combine them with those we have collected. We will work with LDE to populate this map over the next couple of years. An exciting development of our work has been the take up of the Interactive Map in Malaysia; where United Voice (Kuala Lumpur) are currently developing their own to document self-advocacy groups in Malaysia.

Recommendations

- Ensure that all self-advocacy groups in the UK are represented on our online interactive self-advocacy map so that people with learning disabilities can identify and access a group near to where they live.
- Develop consistent and meaningful consultation so that policy-makers, professionals and service providers can learn about the real impacts of self-advocacy on the lives of people with learning disabilities.
- Link together self-advocacy with health and social care commissioning. Self-advocacy organisations across the UK have consistently shown how experts by experience are the best advisors about learning disability services.
- Promote sustainable business models for self-advocacy groups.
- Draw on co-production approaches to research – as evidenced by the Crook Fellows model – that put people with learning disabilities in the driving seat of research that has meaningful outputs.

References and further information

Further resources on the impact of self-advocacy groups can be found here:

<https://bit.ly/2Llunto>

Making Sense of Self Advocacy Today by Jan Walmsley:

<http://www.janwalmsleyassociates.com/file/janwalm/rtr-report-12-june-55555.pdf>

Jan Walmsley Associates (2019). A list of self advocacy organisations, and some thoughts about self advocacy.

<http://www.janwalmsleyassociates.com/a-list-of-self-advocacy-organisations-and-some-thoughts-about-self-advocacy>

Learning Disability England Website:

<https://www.learningdisabilityengland.org.uk>

National Survivor User Network (2018). User-led groups continue to close.

<https://www.nsun.org.uk/news/user-led-groups-continue-to-close>

Sunderland People First

<http://sunderlandpeoplefirst.com>

United Voice Malaysia

<https://www.unitedvoice.com.my>

