



Self-advocacy and the promotion of citizenship

For over thirty years self-advocacy has a key mechanism through which people with learning disabilities can agitate for recognition as full citizens [1]. We used a host of different strategies to find out what people with learning disabilities think of self-advocacy [2]. They told us that self-advocacy involves:

- 'Campaigning for things that we are passionate about fighting for our rights';
- 'Provides help and advice for people who are having problems with their life';
- 'Helping other people with learning disabilities to speak up'.
- 'Being a self advocate has given me more confidence at meeting new people and helped me get a job and also live on my own';
- 'Coming to my advocacy group has helped be to have more confidence in my ability to live on my own, and be a part of the community'.

Without self advocacy:

- 'I would be lost without my advocacy service. They have given me a lot of advice around benefits and letters to help me understand what they are about';
- 'I would lose my friends that I have made';
- 'I do not know what I would do without my self-advocacy group'.

We found that:

- Relatives, friends and supporters of people with learning disabilities felt equally supported by self-advocacy groups;
- Often people with learning disabilities are the people best placed to make decisions about the lives of other people with learning disabilities;

- Self-advocacy groups take many forms. Some are based in services, others in residential homes and many others in the community;
- Self-advocacy promotes resilience of people with learning disabilities and their families;
- The cuts have led to the closure of numerous self-advocacy groups which leaves many people with learning disabilities and their families isolated and lonely in the community;
- Self-advocacy groups can be viewed as Big Society in practice but require financial and human support of society;
- Many self-advocacy groups have expertise around person centred planning, community living and employment that service providers and policy makers can learn from

Key messages

- While the government has promised no new cuts to disability benefits, people with learning disabilities are living with the realities of an austerity welfare state, which threaten their day to day existence;
- The last 50 years has witnessed the global growth of the self-advocacy movement. This is a political movement set up by people with learning disabilities so that they can collectively agitate for their rights;
- This movement has helped push politicians and policy makers to ratify the United Nations Convention on the Rights of Disabled Persons;
- Our research has uncovered worrying decreases in the amount of funding that self-advocacy groups can access and has collected many stories of groups folding in a time of austerity;
- Commissioners need to recognise that people with learning disabilities are differentially precarious in a time of austerity and to organise advocacy tenders in ways that do not exclude self-advocacy groups supporting people with learning disabilities;
- They must recognise that as statutory services are cut, self-advocacy services are becoming the first line support for people who do not meet the thresholds for statutory

support, without having been given any extra resources to match the increase in demand;

- The impact of the Care Act (2014) on delivery of statutory services and disabled people's lives should be carefully monitored;
- Self-advocacy groups constitute a crucial element of civil society for people with learning disabilities therefore funding to self-advocacy services should not be cut.

Background

The government remains committed to improving the life chances of disabled people. The United Nations Convention on the Rights of People with Disabilities, to which the UK government is a signatory, sets out the rights of disabled people in relation to rights to independence, to make choices and to a home and family life. Self-advocacy groups have a thirty-year history of promoting the rights of people with learning disabilities. Self-advocacy promotes psychological, health and social well-being benefits for the individuals involved, enables community participation through providing sources of information and support and promoting the wider rights of people with learning disabilities in the local, regional and national communities

Self-advocacy organisations have responded to the challenge of reduced funding streams for their advocacy work by developing their own business markets and forms of enterprise; expanding their roles through the provision of training to health, social care and other professionals. In a time of austerity people with learning disabilities still experience stigma, marginalisation and abuse. It is vital that the work of self-advocacy groups is supported, not eroded.

Evidence

Our research explored the contemporary community living experiences of people with learning disabilities in a time of austerity drawing on qualitative research undertaken between 2013-15. The research demonstrated that:

- Self-advocacy is flexible offering unique bespoke services to individuals;

- Self-advocacy supports individuals through crisis (e.g.: problems with benefits, hate crime and housing);
- Self-advocacy is a collective endeavour offering mutual support to people with learning disabilities;
- Self-advocacy groups employ person centred approaches to support their members through friendship circles, self-advocacy groups are tackling loneliness and promoting interdependence within the lives of people with learning disabilities;
- Self-advocacy groups are disabled people user-led organisations and are uniquely well-placed to represent the concerns of people with learning disabilities;
- The number of self-advocacy organisations for people with learning disabilities is steadily declining and has been over the last decade;
- Fewer and fewer people are able to engage in self-advocacy, this is particularly the case for people with learning disabilities living in care homes or supported living arrangements;
- Self-advocacy services are diversifying and expanding their offer to include training and support services in addition to their traditional self-advocacy work but this is not enough to fill the gap left by shrinking local authority funding;
- As fewer people with learning disabilities are qualifying for statutory support, more and more people are being referred by practitioners to voluntary funded self-advocacy services – demand is increasing at a time when resources are dwindling;
- People with learning disabilities are concerned about the impact of the implementation of the Care Act 2014 including rising thresholds for accessing statutory services;
- Numbers of people attending self-advocacy meetings are falling;
- There are fewer opportunities for self-advocacy groups to meet together to discuss shared concerns;
- Block commissioning of generic advocacy services prevents self-advocacy organisations from tendering for local authority funded advocacy contracts;
- Employment opportunities for self-advocates within the movement are also reducing.

Conclusion

More than thirty years on, self-advocacy services continue to do vital work in promoting the rights of people with learning disabilities. Currently, such services are under severe pressure and threat of further decline. There is an urgent need to review the practices that are denying self-advocacy groups access to funds. Worryingly, the current period of austerity in Britain threatens to reverse the political gains made by the self-advocacy movement for people with learning disabilities over the last thirty years.

In a time of austerity, people with learning disabilities still experience stigma, marginalisation and abuse. It is vital that the work of self-advocacy groups is supported, not eroded.

References

[1] Dan Goodley (2000). *Self-advocacy in the lives of people with learning disabilities*. Buckingham: Open University Press.

[2] Banister, P., Bunn, G., Burman, E., Daniels, J., Duckett, P., Goodley, D., Lawthom, R., Parker, I., Runswick-Cole, K., Sixsmith, J., Smailes, S., Tindall, C. & Whelan, P. (2012). *Qualitative Methods in Psychology: A research guide*. 2nd Edition, Open University Press.

For more news and research on the impact of the cuts on people with learning disabilities - and information and resources for surviving austerity – visit humanactivism.org.