

Learning Disability in the Community: Problems, Solutions and Advocacy

This report is published by Speak Out and Jim Simpson in order to shed light on two things:

- how people with learning disabilities are disadvantaged
- how advocacy services, working with individuals and groups, can alleviate and solve some of these problems and issues

Speak Out is a long established Learning Disability organisation that has pioneered different ways of supporting people with learning disabilities using advocacy, social campaigning, training and support.

This paper describes the picture of people with learning disabilities in society and reviews and presents some findings from various research studies. People with learning disabilities (PWLD) face considerable disadvantages. These disadvantages are often brought about by how services are organised or how society operates, quite separate from any intellectual disability or impairment that individuals might have. For instance PWLD get poorer health services and less access to jobs and education. So often treating PWLD differently can be the wrong kind of different that prevents them from being able to participate in society on an equitable basis and denies equal access to services and opportunities.

Advocacy services and groups help PWLD to have their voices heard; speak up about their needs and wants; and do whatever can be done to make sure that PWLD get the services they need; the benefits they are entitled to; and the support that they require. Advocacy constructively challenges bias and enables discrimination to be reduced.

In Speak Out's case advocacy and other related support work produces activities in the community that are of wider benefit to PWLD such as a regular social groups; training social care providers; activity groups such as drop-in socials and cooking groups; and social campaigns like getting PWLD and politicians together in elections or influencing public policy on social care provision.

Contents

1. Summary
2. Introduction
3. Equity and fairness:
 - Population
 - Independence and choice
 - Bullying and victims of crime
 - Health
 - Mental Health
 - Sexual health
 - Criminal justice system
 - Demand for Care support and Cuts in Services
4. Advocacy delivers:
 - How different kinds of advocacy help tackle problems of social disadvantage
5. Service provider solutions:
 - What service providers can do to address problems, and initiate 'equitable practice'
6. Acknowledgements and contact details

1. Summary

Adults with learning disabilities face much harder lives than other people. They have to contend with low incomes, discrimination and poorer public services, whilst their learning disability is supposed to afford them access to better services in order to achieve some acceptable level of equality.

PWLD (people with learning disabilities) are significantly disadvantaged by society and its attitude and approach – intentionally or not. Society in general and public institutions or businesses can at least start to address these problems in some simple ways, such as providing easy-read materials or training their staff effectively.

Over a million PWLD have, on average, shorter lives, less education, little access to employment and their benefits and support services are being substantially cut. Advocacy and support activities in the community and the voluntary sector are addressing these problems including through advocacy input. This report highlights ways that advocacy work makes a difference to people's lives providing simple yet powerful ways of building community and redressing inequality.

2. Introduction

This research report introduces information about the learning disabled community nationally and gives information and insight into some of the issues that affect them. One response and solution to the difficult disadvantages and problems that people with learning disabilities have to contend with is good advocacy work on a short term and long term basis; with individuals; in groups; peer-to-peer; and through social lobbying, publicising of issues and campaigns.

The report contains broad research evidence and the national picture illustrated with advocacy work responses to these problems.

3. Equity and Fairness – the Evidence

People with learning disabilities have as much right to public services and a good life as anyone else in society. If, for instance, they are not getting good health services then their health is at risk. If they are able and keen to work yet find it more difficult to find a job then any discriminatory or bias hiring practices need to be changed. The evidence below examines some of the inequities that PWLD have to deal with.

Population:

These are some statistics on the population of PWLD (1):

- There are an estimated 1,191,000 people with a learning disability (LD) in England, or 2.5% of the population
- More men and boys than women and girls have an LD: 286,000 children (180,000 boys, 106,000 girls) age 0-17; 905,000 adults aged 18+ (530,000 men and 375,000 women), of whom 189,000
- 21% are known to learning disabilities services

(1) Emerson, E., Hatton, C. et al *People with learning Disabilities in England 2011*, Learning Disabilities Observatory/Department of Health [Online] 2011; Available from:http://www.improvinghealthandlives.org.uk/securefiles/150521_1836//IHAL2012-04PWLD2011.pdf [Accessed May 21st 2015]

Independence and choice:

Promoting choices and independence are two key principles that underpin the government white paper Valuing People. Under the guise of a choice-based approach some people with learning disabilities are, at times, presented with a pre-arranged menu of choices and not necessarily items on the menu that PWLD would necessarily choose first. Such tokenistic choice-making has implications for the development of personal autonomy. It is arguable that a lack of control in respect to mundane choices is disempowering and leads to learned passivity (2). Such learned passivity and public service driven dependency contradicts the goal of independence and can act against it rather than advance it.

According to the Foundation for People with a Learning Disability 7% of PWLD have a job. This compares with 1 in 2 disabled people generally. Yet at least 65% of PWLD want to work. Of those PWLD that do work, most only work part-time and are low paid (1).

Recognising the importance of PWLD being allowed to take risks and supporting PWLD to become more involved in all aspects of society is extremely valuable in terms of societal equality. PWLD are often marginalised and socially isolated. Literature around the experiences of PWLD exposes how many are in a 'relationship vacuum', where the majority of their relationships are with professionals and they lack the opportunity to make meaningful relationships with others in society (3).



SPEAK OUT'S 'HUB' DROP IN BRINGS PEOPLE TOGETHER

The Hub is a regular drop in – a social space where PWLD come together and support each other. People bring along all kinds of issues – letters they don't understand, debt, health-care problems and medication being stopped. Out of the hub groups and projects are formed, new friendships are formed and people grow in confidence. Participants feel part of something and less isolated or lonely.



The hub helps the whole community by helping PWLD articulate their collective voice and learn things together from cooking to social campaigning; voting and electoral participation to health improvement and public transport.

Just 1 in 3 PWLD have taken part in some form of education or training (1). At least half of all adults with a LD live in a family home - meaning that many don't get the same chances as other people to gain independence, learn key skills and make the same kind of choices about their lives as others who are living independently or with supported living (1).

75% of GPs have received no training to help them treat PWLD (1) , highlighting the need for advocacy as a way of representing PWLD to ensure their voices are heard, and effecting a cultural change within healthcare services.

Less than a third of PWLD have some choice about who they live with, and less than half have some choice over where they live (1). This lack of freedom and choice undoubtedly affects PWLD ability to feel connected, and their overall sense of satisfaction with their lives.

- (1) Mencap. *Facts about Learning Disability*. Mencap. 2015
- (2) Hollomotz, A. Are We Valuing People's Choices Now? Restrictions to Mundane Choices Made by Adults with Learning Disabilities. *British Journal of Social Work*. [Online] 2014; 44;1: pp234-251. Available From 10.1093/bjsw/bcs119 [Accessed 18th April 2015]
- (3) Bowey, L. McGlaughin, A. Assessing the Barriers to Achieving Genuine Housing Choice For Adults with a Learning Disability: The Views of Family Carers and Professionals. *British Journal of Social Work*. [Online] 2005; 35;1: pp. 139-148. Available From 10.1093/bjsw/bch167 [Accessed 18th April 2015]



THE VOICE OF PEOPLE WITH LEARNING DISABILITIES

Being Heard in Government is one group run by Speak Out. It managed to get local politicians and constituency candidates to listen to the voice of PWLD. This was part of a campaign to involve PWLD in the election and influence policies.

Also at the *Have Your Say* debate talking about government cuts people in our BHIG group spoke passionately about the effect cuts have on people with learning difficulties. A film included Rohan, Hannah, Katie and Ian speaking on behalf of the BHIG group.



Another excellent film about democracy also featured Speak Out

<https://www.youtube.com/watch?v=VVHNXabvQFk>



Bullying and victims of crime:

People with disabilities are at increased risk of violence. Mencap's end hate crime campaign, 'Stand by Me', suggested that as many as 9 out of 10 PWLD had been a victim of hate crime and bullying (1). Consequently, PWLD fear of being active in society is perpetuated, leading to protective behaviour such as staying in, and avoiding social situations where opportunities for personal growth and social participation are afforded. This leads to even further marginalisation and isolation, and therefore PWLD becoming an even more 'hidden' group in society.



OUT AND ABOUT, SAFE AND SOUND

Speak Out's advocacy supports individuals who have been bullied or victims of crime. Our group advocacy, drop-ins, information and advice helps PWLD to be out and about, making friends and flourishing. Speak Out also runs campaigns to help places and spaces become more open and learning disability friendly. The Safe Places Scheme asks organisations and businesses to be safe places for people with learning disabilities when they are out and about, get lost, scared, or are bullied. Thumbs up is about getting local businesses and services to promise to follow the 10 tips for good support for people with learning disabilities. When a service joins they get advice on good support. Over 150 organisations have joined the Thumbs Up scheme including Moksha Café, Prince Regents Leisure Centre and Brighton and Hove Buses.

A recent systematic review suggested that adults with disabilities were at a higher risk of violence than non-disabled adults, being approximately 1.5 times more likely to be a victim of violence (2).

Most PWLD are treated as 'different'. They do not have the same control over their own lives as the rest of society and face challenges and prejudice every day. Often decisions are

made about PWLD, and their lives, without them being consulted. Within professional systems they lack a voice, and services are not tailored to their needs (1)

References-

- (1) Emerson, E. Roulstone, A. Developing an Evidence Basis for Violent and Disablist Hate Crime in Britain: Findings From the Life Opportunities Survey. *Journal of Interpersonal Violence*. [Online] 2014; pp1-19. Available from 10.1177/0886260514534524 [Accessed 18th April 2015]
- (2) Hughes, K et al., Prevalence and Risk of Violence Against Adults with Disabilities: A Systematic Review. *The Lancet*. [Online] 2012; 379; 9826. pp 1621-1629. Available From 10.1016/S0140-6736(11)61851-5 [Accessed 18th April 2015]

Health:

Everyone relies upon a health services and social care to be there when they need it. We expect the NHS and Local Authorities to provide services on the basis of need and to guarantee equal access to mainstream services or access to more services if and when health or care support needs become greater.

People with Learning Disabilities are 2.5 times more likely to have a health problem than other people – particularly in the areas of obesity and respiratory disease (1). It is not clear how far the severity and life-long limitations of these conditions is caused and exacerbated by unequal access to health care. However there is significant evidence that PWLD have fewer health checks and they have a shorter life-span.

PWLD die significantly younger than people without Learning Disabilities. All other things being equal PWLD should live longer where their learning disability does not directly impact upon morbidity and mortality which, in the majority of cases, learning disabilities do not have a significant impact. In many respects also PWLD have healthier lifestyles with less exposure to the biggest causes of premature death – alcohol, smoking and substance misuse.



ADVOCACY FOR HEALTH AND WELL-BEING

Speak Out's advocacy supports individuals who are struggling with many different issues related to health and getting proper care, support and treatment. For instance we supported a woman who was dealing with cancer risk that she did not understand and other clients who were not having medications managed properly. PWLD often don't feel listened to and don't have sufficient health checks related to the rest of the population.

Speak Out runs health groups too such as the good food, nutrition and cooking group featured on the left.

A confidential enquiry into the premature deaths of people with LD by the Norah Fry Research Centre found that PWLD, in England and Wales, are two and a half times more likely to die before the age of 50. The enquiry sought to review the sequence of events leading to the deaths of 247 adults and children who had a Learning Disability, the enquiry found that almost half of the deaths of PWLD were avoidable, furthermore what is shocking that over a third of those 'avoidable deaths' might have been avoided by good quality healthcare. The enquiry found that PWLD are often not believed when describing their symptoms and families of PWLD felt that professionals did not listen to them.

Significantly more PWLD experience difficulties in having their illnesses diagnosed and treated. The inquiry found all aspects of the provision and coordination of care of PWLD was worse than the group without Learning Disabilities that they were compared with (2).

Taking these statistics into account, the Learning Disability Observatory estimates this to be more than 1200 premature deaths a year (3). In 2007, a Mencap report into NHS care for PWLD exposed 'institutional discrimination', these statistics show there is much progress still to be made as the discrepancy is much too high (4).

(1) Disability Rights Commission, *Equal Treatment: Closing the Gap- A Formal Investigation into Physical Health Inequalities Experienced By People With Learning Disabilities and/or Mental Health Problem*, <http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf> [Online] 2006; [Accessed 21st May 2015]

(2) Blair, P., Fleming, P., Heslop-Hoghton, M., Marriott, A. Russ, L. *Confidential Enquiry into the Deaths of People with Learning Disabilities*. Norah Fry Research Centre. Report Number: 2, 2012

(3) Emerson, E., Baines, S. *Health Inequalities & People with Learning Disabilities in the U.K.* Learning Disabilities Observatory. Report Number: 1, 2010

(4) MENCAP, *Death by Indifference*. MENCAP. Report Number 1, 2007

Mental health:

There is evidence that PWLD have a higher prevalence of mental health issues and illness than those in the general population. The Foundation for People with Learning Disabilities has been offering guidance and information on mental health needs in a recent series of publications. Research into the experiences of PWLD accessing support for their mental wellbeing, discovered that PWLD were commonly only defined and assessed by their learning disability, and therefore they did not receive adequate mental health support. Secondly, the information provided was not accessible or in a format they could understand. When they felt down, they were not believed, listened to or supported. People with LD wanted more control around their mental health (1).

People with Learning Disabilities are three times more likely to develop poor mental health than the general population. The Foundation for People with Learning Disabilities showed

that PWLD are continuing to struggle to access mental health support and services. They also identify that many barriers still exist, and stand in the way of people with a dual diagnosis being inclusively and appropriately supported. The report also identified that timely access for mental health services; which is imperative, is even worse for PWLD, compared to that of the general population (1) .

(1) Koulla-Burke, C. *Feeling Down, Improving the Mental Health of People with Learning Disabilities*. Foundation for People with Learning Disabilities. Report Number:1, 2014

Sexual Health:

The WHO (World Health Organisation 2006) definition of sexual health states ‘the sexual rights of all persons must be respected, protected and fulfilled’ (1)The sex education programmes offered to PWLD focus on ‘protection’ a ‘prevention’, with little attention given to supporting people to develop healthy, positive sexual relationships

The pervasiveness of negative, paternalistic or fearful attitudes potentially shape the way in which information and support are provided to both children and adults with LD about sexual relationships. PWLD are more likely to experience sexual abuse than their non-disabled peers (2) and there is evidence to suggest that often low levels of knowledge about sexuality and relationships can impede their recognition of abusive situations, therefore understanding of practical information about safer sex and the development of positive attitudes to sexual expression is imperative for PWLD (3)

Reviews into sex education programmes for PWLD found a disappointing lack of attention given to supporting individuals to engage in programmes which seek to promote the development of healthy, positive sexual relationships and here, the lack of attention given to strategies such as the involvement of peer educators and self-advocates in providing an important link to the lived experience o PWLD (3).

(1) World Health Organisation (WHO), *Defining Sexual Health, Report of a Technical Consultation on Sexual Health*. WHO, Report Number: 1, 2002

(2) Hughes, K., Bellis, M., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mikton,C., Shakespeare, T. & Officer, A. Prevalence and Risk of Violence Against Adults with Disabilities: A Systematic Review and Meta-Analysis of Observational Studies. *Lancet*, [Online] 2012; 379;9826, pp. 1621-9. Available from 10.1016/S0410-6736(11)61851-5 [Accessed 12th April 2015]

(3) Schaafsma,D., Kok, G., Stoffelen, J., Curfs, L. Identifying Effective Methods for Teaching Sex Education to Individuals with Intellectual Disabilities: A Systematic Review. *Journal of Sex Research*, [Online] 2014; pp 1-21. Available from 10.1080/00224499.2014.919373 [Accessed 5th April 2015]

Criminal Justice System:

A study into the experiences of PWLD in the Criminal Justice (CJ) system published in the British Journal of Learning Disabilities found that PWLD lacked support, information and faced social isolation. The study which looked at prevalence studies in the UK illustrates how PWLD are consistently over-represented; through the use of psychometric testing a figure close to 30% was ascertained (1).

There are many factors which contribute to the over-representation of PWLD in the CJ system, and the higher rates of recidivism, and these relate to their often poorer life circumstances; lower rates of education and employment, poverty, lower socio-economic status, lack of support and social isolation than the general population. PWLD enter the CJ system with disadvantages that make accessing their rights and engaging with opportunities to assist them to leave the system, and not return extremely difficult (1).

Through research and examination of studies of first-person accounts of PWLD, and their experiences, many themes emerged. Firstly, PWLD were bewildered by their experience of the CJ system, many did not understand the process, they did not understand why they had been arrested, under interrogation by the police many did not understand the questions they were being asked, and that anything they said may be used as evidence against them. The second theme was the lack of support; whilst in custody there was no-one to talk to or answer basic questions. Thirdly, the research highlighted the linked theme of social isolation for individuals transitioning to the community after incarceration, from the research it is clear they were placed in situations where their legal and human rights were not always respected.

Therefore the need for practical measures to change this, as well as effective advocacy is the key to ensuring that the rights of PWLD are respected within the CJ system as well as in other contexts such as the health and care systems and to create a situation where 'hopelessness' is not the defining feature of peoples' lives, through helping them to access the resources they need to create a better life (1).

(1) Hyun, E. , Hahn, L., & McConnell, D. Experiences of People in the Criminal Justice System. *British Journal of Learning Disabilities [Online] 2014; 42:4: pp 308-314. Available From 10.1111/bld.12076 [Accessed 14th April 2015]*

Demand for Care and Support; Cuts in Services

Demand for support activities amongst people with learning disabilities is growing whilst publicly funded provision is being cut. Cuts are hitting PWLD harder than other people whilst their needs are greater. Cuts in benefits support, care support, and day-based provision is happening more and more, whilst the number of people with learning disabilities is set to expand more than other population groups.

Research commissioned by Mencap shows that 7 out of 10 families caring for someone with profound and multiple learning disabilities have reached or come close to 'breaking point' because of a lack of short break services.

29,000 adults with a LD live with parents aged 70 or over, many of whom are too old or frail to continue in their caring role. In only 1 in 4 of these cases have local authorities planned alternative housing.

A Local Authority example – Brighton and Hove:

An Independent review of LD services for Brighton and Hove (B&H) took place in October 2014, in order to inform the future commissioning and provision of services of adults with LD. In B&H there are an estimated 5,053 adults aged 18 or over with LD, of whom 1065 are estimated to have moderate or severe LD (1).

In the year 2013/14, there were 1138 adults with LD registered with a B&H GP Practice and 786 people received Social Care Services provided or funded by B&H City Council. The majority of services are services in the independent sector, funded mainly through the Community Care Budget. The independent sector provision makes up 72% of the social care budget. The Council faces significant financial challenges in the coming years, with increasing demand yet reducing resources, to meet need. The Learning Disability Review highlights This issues:

'These are unprecedented times for Adult Social Care- difficult challenges exist alongside great ambitions to promote personalised services that support individuals and their families to live fulfilling and independent lives in their communities' (1)

B&H has seen an increase in the demand for all services and the JSNA estimated that there would be a 12% increase in the number of people with a severe or moderate disability by 2030 (2).

There is evidence in some areas that PWLD don't understanding the proposed cuts in services bringing into question the effectiveness of consultation processes. For instance the aspiration of 'independence' and independent living has become tainted. Some PWLD are trying not to use the term independence and see it as a threatening word that can be used as a reason for cutting services.

(1) Health & Wellbeing Board, *The Outcome of the Learning Disability Review & A Good, Happy & Healthy Life*. Health & Wellbeing Board, Report Number:1, 2015

(2) JSNA. *Brighton & Hove JSNA 2014*. JSNA, Report Number: 1, 2014

4. Advocacy delivers!

Advocacy empowers people, upholds their human and civil rights, and ensures that their voices get heard and that they have control over their lives. Advocacy aims to:

- Support people to state their own needs

- Speak on behalf of people who cannot speak for themselves
- Ensure that people have information they need to make informed choices or decisions
- Take up an issue or a complaint on behalf of someone or a group of people
- Provide independent support that is objective and non-judgemental

Advocacy activity can be delivered in groups; with individuals; through representation; through campaigns; short term; and longer term.

Advocacy has helped change and improves lives in many fields such as: Health care; social care; mental health; transport; access to services; leisure and sports; benefits entitlements; employment and education and many more.

The Role of Advocacy

Research by British Institute of Learning Disabilities (BILD) looked at the experiences of PWLD as members of a self-advocacy group. The research indicates that PWLD felt their lives had improved and were more fulfilled as a result of being part of the self-advocacy group. The BILD stressed that it was important that people knew how self-advocacy groups helped PWLD.

The findings of the study were as follows

- Being a member of a self-advocacy was found to enhance the personal lives of participants
- Empowerment occurred for the participants' both at an individual and collective basis
- Members felt more confident to speak up and assert one's rights
- This change in self-concept occurred when members gained new roles and responsibilities that gave them a feeling of status, as well as friendship and support
- There are strong links between empowerment, choice and self-advocacy as each offer responsibilities for people with LD to exert control over their lives

From the research many positive themes emerged which the research categorised based on the information the participants provided.

Through the self-advocacy group a sense of 'asserting self' occurred, participants' reported that they felt supported and comfortable to express their views and opinions. Through the group a process of individuals sharing experiences with their group created the opportunity for showing mutual support among members.

Affecting Change-

The process of being involved in affecting change appeared to be as important to the participants' as the effect of change itself. For example thinking about the position of PWLD in society and what could be done to affect change.

Decision Making- The opportunities the group provided for them to make choices were demonstrated by their greater sense of self-determination and autonomy in their lives.

Role of Members-

Participants' developed a sense of status emanating from the involvement with their self-advocacy group. The findings of the participation group indicated that the self-advocacy group helped to foster and increased level of confidence and self-esteem among all members.

Involved and participating-

The impact of group membership on personal lives indicated that participants felt more empowered. The opportunities presented to participants to meet with other groups, attend and speak at conferences, participate in training courses for developing self-advocacy skills, and learn about their rights and entitlements contributed to their personal development. They also had a greater sense of personal identity, 'it made me more aware of who I am'. Expanded social networks through self-advocacy groups creates opportunities for people with LD to develop friendships and to expand networks outside of support services.

Helping Others-

It is the collective response of the group that ensures that others, who cannot speak for themselves are represented. It was apparent from the study that interdependence existed among members whereby some members were able to draw on the skills and abilities of others in the group when the need arose (1).

A number of research projects have identified the benefits of advocacy. PWLD report feeling increased respect from professionals when an advocate is present, gain increased understanding of services and value the provision of emotional support from advocates. Advocacy can help to empower people with learning disabilities, reducing feelings of individual inadequacy and developing self-confidence, self-identity and culture. The research also identified the wide array of scenarios where there was a need for advocacy in the context of PWLD

-Advocacy support was often needed to make choices and decisions on a daily basis, and when it came to making more major and complex decisions such as where to live, relationships and finances.

Advocacy support could also be needed when dealing with services as PWLD and family members could find meetings and health appointments stressful and feel under pressure to agree with service providers.

People with complex needs or communication needs might need specific advocacy support, and some people might prefer someone to represent them at a meeting.

Advocacy for people with complex needs was seen as an important area for development as the numbers of people coming into services with complex needs is increasing

Advocacy could be needed to improve communication and resolve issues between people with LD, families and services

The need for advocacy is not static as an individual's advocacy needs can change over time, as a person has more life experiences and develops confidence

Support workers felt that particular issues needed specialist advocates: sexuality, bereavement, financial abuse, transitions and healthcare (2)

- (1) Gilmartin, A. & Slevin, E. Being a Member of a Self-Advocacy Group: Experiences of Intellectually Disabled People. *British Journal of Learning Disabilities*. [Online] 2010; 38;1: pp.152-159. Available From 10.1111/j.1468-3156.2009.00564 [Accessed 18th April 2015]
- (2) Chapman, M et al. Speaking Up About Advocacy: Findings From a Partnership Research Project. *British Journal of Learning Disabilities*. [Online] 2012; 40;1: pp71-80. Available From 10.1111/j.1468-3156.2011.00688.x [Accessed 18th April 2015]

5. Service provider solutions:

Here are some suggestions and effective ways that services providers, businesses and employers can help to improve biases, differences and inequalities:

1. *Ask, initiate and listen:* consultation and conversation with PWLD will help to improve services. Asking people what they think and how they feel a service or activity could be improved.
2. *Easy Read Information:* Provide simple and jargon free information about the service or activity. This is useful for all sorts of purposes.
3. *Target Groups, Target Users:* Identify carefully who the target people are and how you might reach them. For instance PWLD who are diabetic or/and overweight or PWLD who are not visiting their GP surgeries.
4. *Target Initiatives:* Try and redress disadvantage through specific projects and initiatives like a feedback campaign on public transport or in doctor's surgeries.
5. *Use advocates, be-frienders, help agencies and appropriate adult where they are available:* Make the best use of helpful and skilled people already connected to PWLD whilst making sure that they are appropriately articulating the views, needs and experiences of PWLD.
6. *Test impact:* test out the impact of certain policies and procedures before they are put in place to make sure that they will reach and help PWLD.
7. *Measure impact, before and after:* assess the impact that mainstream services are having on particular people and groups especially vulnerable groups.
8. *Train Staff:* Even with a small training input staff can deliver services and activities better to PWLD.

9. *Review Equalities Impact:* Some policies and procedures might be both unwittingly discriminatory excluding particular groups, disproportionately harming certain groups or simply not reaching target groups. Equalities Impact Assessment is required to check out the impact of policy and procedure.
10. *Test out real choices:* Find out if PWLD have any real choices about the services they get and are entitled to. Check too if choices are the ones that PWLD would typically make.

6. Acknowledgements and contact details

Report compiled by Jim Simpson and Samantha Sohota
Published by Speak Out and Jim Simpson Consultancy

Contact details:

Speak Out

West Werks
41-43 Portland Road
Hove BN3 5DQ

Email: info@bhspeakout.org.uk
Web: <http://www.bhspeakout.org.uk>
Telephone: 01273 421921

Jim Simpson

Jim Simpson Consultancy

Email: jim@jimsimpsonconsultancy.co.uk
Web: <http://www.jimsimpsonconsultancy.co.uk>
Telephone: 01273 303108