

## ADVOCACY FOR A CHANGE

### BEST PRACTICE IN ADVOCACY FOR ADULTS WITH LEARNING DISABILITIES

#### **Abstract:**

*This paper describes a model of best practice in the provision of advocacy activities and services. This best practice model was developed over a long period of time where advocacy work was extended and expanded from the provision of case-based and citizen advocacy to the co-production of group, peer and case-based advocacy provision and projects. This involved iterative evaluation and innovation of different, more extended forms of group and peer - advocacy. Also the model takes into account the work of advocacy providers and current trends in advocacy, social work and social support. Successful advocacy, that both improves the lives of people and influences how institutions behave towards users, is a long and complex process – especially where the individual(s) who needs advocacy has additional or complex needs. This paper models advocacy and change for and with people as a process of 12 steps.*

*Practitioners and organisations involved in any kind of advocacy, social work or other community services will find the model helpful in providing a synthesis of the processes one needs to go through to facilitate successful change and improvement through advocacy. The paper includes a description of the change model and illustrations its effectiveness with three case studies. This work has lessons for social work and community support practice.*

#### **Advocacy as change and improvement in well-being:**

Brighton and Hove Speak Out's work supporting people with learning disabilities aims to achieve *change* at several levels. Change in the person - i.e. *internal change* so that people feel good, feel able to flourish and have the capacity to participate - is a step-by-step process. This change model is developed from both the psychology and social work literature and the practice experience and evidence from Speak Out's work. Speak Out has managed to take people through many change steps. This can be a long term and complex process to achieve with clients, often taking lots of effort and support to facilitate small changes and help people take very gradual steps.

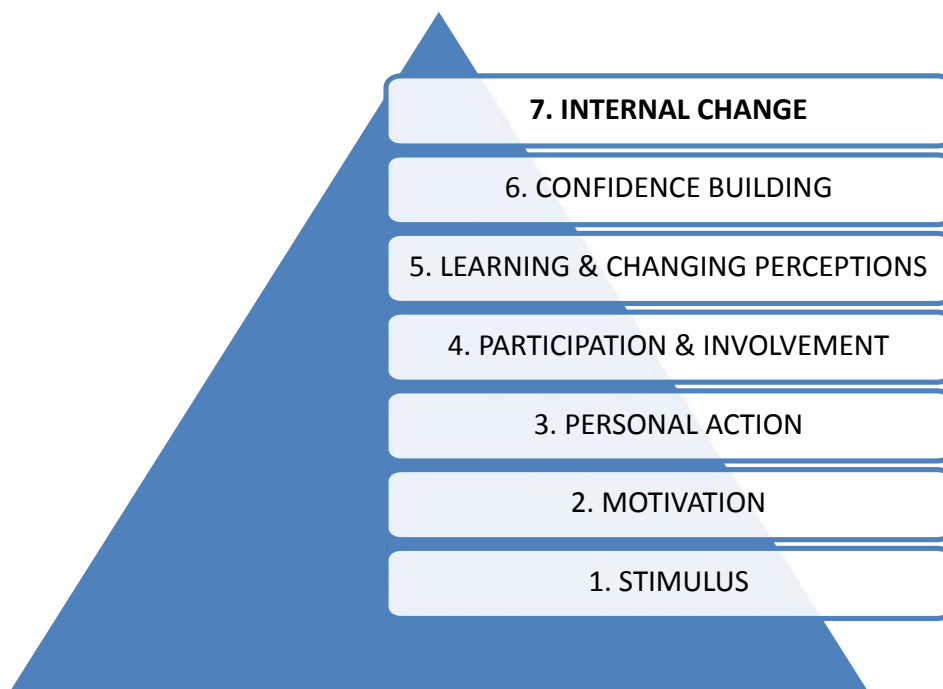
First of all, people need a reason to want to make any kind of change. Change emerges in response to day-to-day experience and emerges as a response to a negative or positive stimulus. For instance, PWLD might feel lonely or isolated or feel that their rights are not being upheld. Positive wants or needs to, say, connect in the community, socialise, learn, enjoy things or participate are also stimuli.

Stimulus can lead to motivation and a desire to take action, do something or change something. Regular participation and action leads to the person learning – i.e. perceptions about themselves or the situation around them change as new experience and new learning is absorbed. These steps enable confidence to be built and developed.

There is an understanding now that personal change and development is driven significantly by *building confidence*. Confidence building and confidence building measures, tasks and experiences are the basic, under-pinning methods of achieving change and improvement for people. For instance psycho-therapeutic work or using tools such as Outcomes Star or Patient Activation Measures all involve building confidence as the key currency to helping people to make positive changes. In fact one of the first of these progression and personal development tools that was developed in the third sector was called ‘Catching Confidence’.

Conversely a lack of confidence hampers change and personal development and leaves people caught in cycles of limitation and risk-aversion. Negative stimuli such as poor relationships or self-reinforcing feelings of loneliness leave people stuck, frozen and unable to make change. It takes considerable efforts and skilled intervention to help PWLD change and develop, building confidence and capability each step of the way.

#### **CHANGE MODEL– internal change, personal change, steps 1 to 7**



The ongoing, tenacious and innovative work of Speak Out enables change and development to happen at the *personal level*, in groups and more broadly through action taken in the community (more about his later). Through a varied package of advocacy and group-based activity PWLD have the opportunity to be supported and make improvements in their lives individually and collectively as well as make friends and extend their participation more widely.

### **CASE STUDY ONE: Personal change and improvement in wellbeing**

#### **One-to-one Case Advocacy - a Journey**

Sarah is young woman with a mild learning disability and mental health needs who came to speak out in her early 20's. She wanted advocacy support to help her think about becoming more independent and maybe moving out from her family home to live in the community. Sarah suffers from anxiety and at the time was facing issues around everyday life at home. Sarah was supported by an issue advocate from Speak Out to start mapping what was important in her life and think about her hopes and aspirations. Together they made contact with the Council and a social worker was allocated. Sarah then started to look at some possible supported housing options. 'I looked at some houses but didn't want to live there, so I decided to stay at home. My advocate helped me understand that I had choice'. Sarah's advocate also helped her find out about activities in the community. She joined a local arts organisation, took a cookery course and later started drumming lessons. At one point the situation at home changed and Sarah needed some support to access respite care.

'When you have an advocate you feel like you have someone on your side, someone who's outside of things who really listens to you and is there for you. It makes a difference - I felt that things were moving for me'

Over the years Sarah has stayed in touch with Speak Out. She sometime attends a drop-in in her neighbourhood where she can meet up with others: 'I see friends and have a cuppa. Sometimes people talk about their problems - we help each other.'

She took part in a 'Train the Trainer Course' run by Speak out and has worked alongside Speak Out staff to deliver disability awareness training for Council services. Sarah has become an experienced public speaker, speaking at events including arts conferences and a local advocacy conference. She has also become member of Speak Out's Governance Board and contributes to planning the future direction of the charity and its work. She has become skilled in user-involvement and helps others to become involved users too.

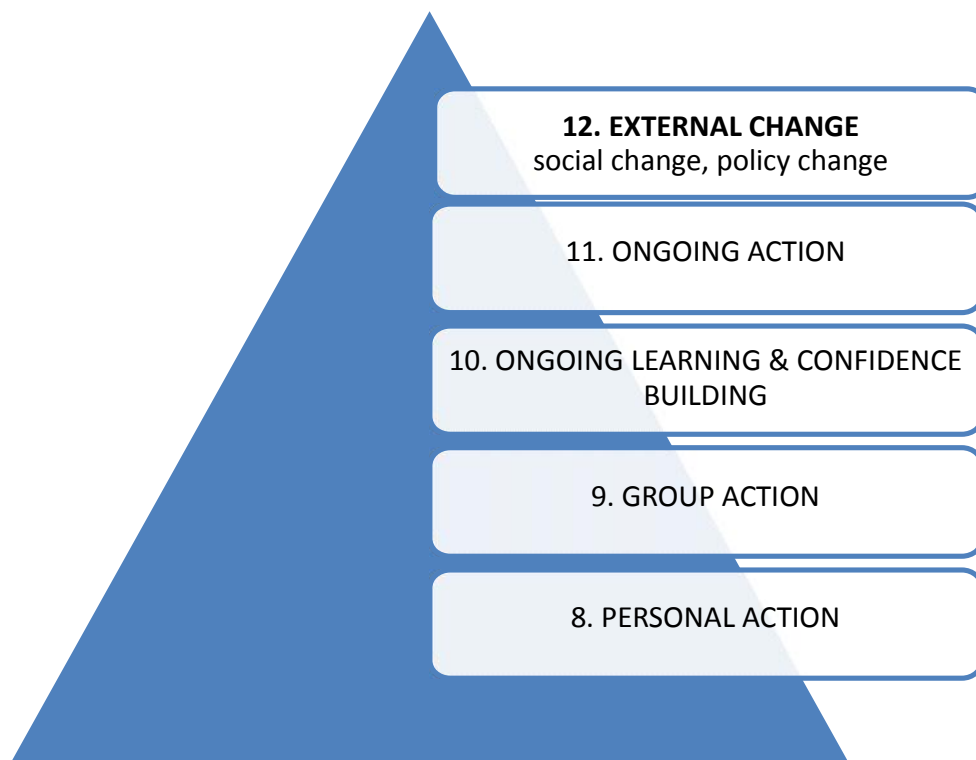
'Without Speak out I feel that my world would be invisible and things would not have changed for me'.

**With this case example we can see a life improved and changed and opportunities for Sarah opened up hugely. Wider opportunities became possible to access once her immediate and complex issues were attended to and changes made for the better.**

## Group advocacy and changing others:

*Changing external situations* requires both *personal action* - people trying to change and improve what is happening around them and to them - as well as *group action*. Achieving external change needs people to come together confidently and purposefully to take action and build their confidence and capability together. Ongoing work is required to make changes in other people, institutions and policies. It does not come easily or quickly.

## CHANGE MODEL– external change steps 8 to 12



Speak Out's work is managing to use a variety of skilled methods and processes to facilitate:

- ) **Personal change and development for individuals** – e.g. case-based advocacy work, participation in social groups, learning groups or volunteering
- ) **Change in the way PWLD are treated** – e.g. with doctors and other health professionals, social workers and public services

- J **Change in peoples' circumstances** – e.g. improving benefits, housing or care and support packages, resources or conditions
- J **Change at an external level** – e.g. raising awareness of PWLD needs and requirements say with transport providers or at a higher policy level with local authorities of government

## **CASE STUDY TWO: Group and Community Change, stage two**

### **Group advocacy for young people with learning disabilities**

The 'Power Group' was started as a user-led self-advocacy group for people aged 16-25 with a learning disability. The remit of the group from our perspective was always very open but we imagined that it would be a place where young people would be able to get information; build confidence and communication skills; and discuss and explore issues important to them in a confidential, safe, parent/support worker free environment. From the outset the group members were involved in directing the content of the group. We started with 3 people who clearly stated that they simply wanted a space to talk.

In the early days, we spent a lot of time 'playing', jumping around on bean bags, throwing balls/ Frisbees as a way to build links and break the ice. Gradually and naturally the time we spent playing diminished and the time spent talking increased. Group numbers increased, usually young people referred by parents, usually stating that the young person was isolated, bullied or shy.

We have seen people learn self-advocacy skills and confidence to speak up in a group. For example one young woman initially was worried about the over friendly nature of another member, she felt unable to deal with this issue herself or even have the issue dealt with directly so the facilitator had to talk about ground rules to the whole group with the hope that it would stop the behaviors. Months later, this young woman was able to tell the person directly when she felt uncomfortable, she was also able to support other people in the group with many of their issues.

We have often seen group members facilitate the group themselves, referring other members to the group rules etc. One member began by having a support worker in another room waiting for the 2 hours, by the time he left (due to age) he was able to sit with the group and participate in the group. Some members have developed sophisticated user-involvement and co-production skills and capabilities.

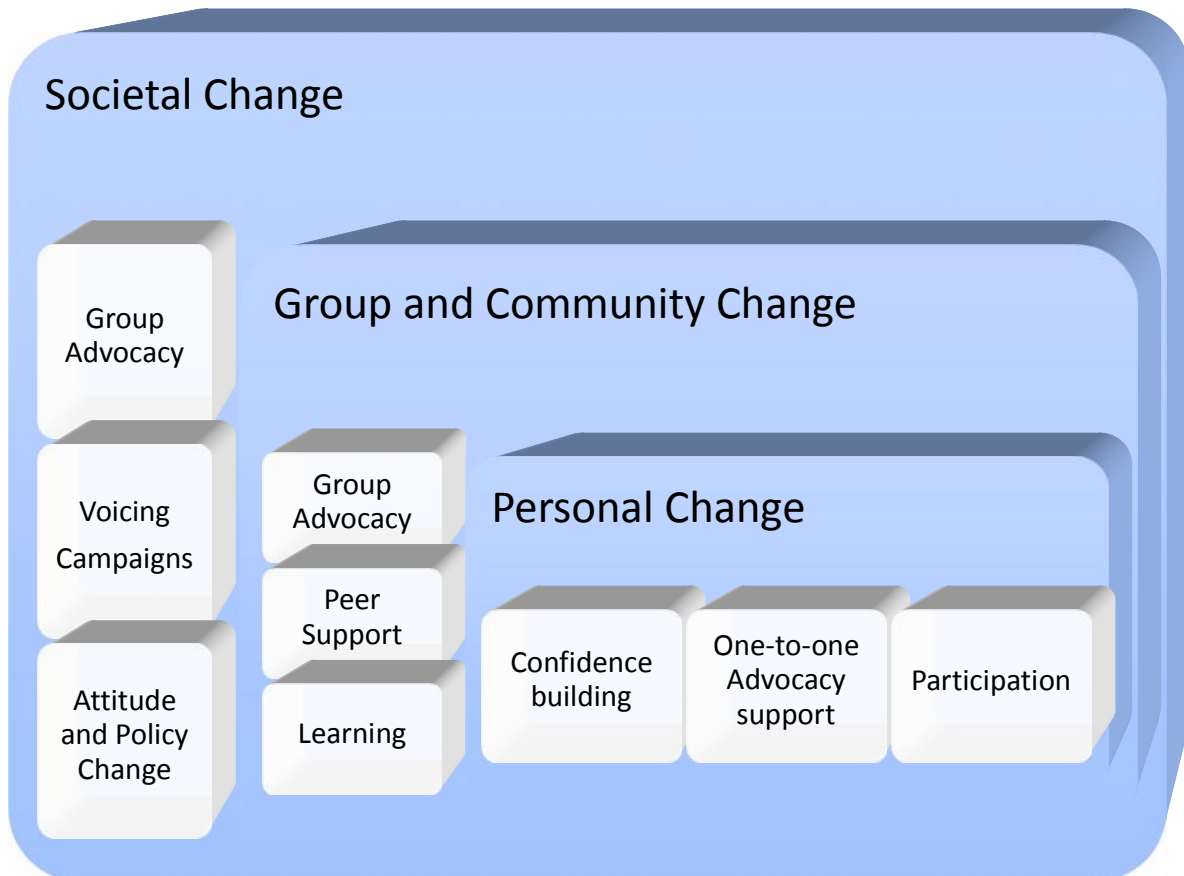
Sometimes external speakers come to the group to talk about issues like employment, contraception, or first aid. One group member has been involved in outreach, recruiting other members to the group.

**With this case study we can see that change and improvement is happening on a wider scale; peers are supporting and helping each other whilst positive social networks are also being forged that tackle the loneliness and isolation so often reported by PWLD. This peer-support and group advocacy is a second stage activity as people need to take steps to address personal issues or problems with bias and discrimination before feeling able to fully participate in a group.**

Though Speak Out has no control over external change by others it has achieved positive results in improving how PWLD are treated. The combination of ways of involving PWLD and working with them makes the difference in the ability to achieve significant and complex change.

Providing a drop-in social space; 1-to-1 advocacy support; group activities; social campaigns; and peer support all go towards achieving change. Speak Out is able to achieve positive change and development by providing a rich and diverse package of activities, services and interventions. The change process for individual PWLD, groups of PWLD and society is all related and connected as shown in the diagram below.

## Change through advocacy



As the model above shows there is a relationship between change at the personal level, group level and wider community level. Apart from anything else one type of advocacy tends to lead to another, or at least reveals the need to work at the next level up. For instance repeated advocacy *cases* of say difficult problems with care homes, doctors or bus companies in how they deal with PWLD prompts a necessity for *cause advocacy* or *class advocacy* that deals with the issues in the wider community attempting to change the actions and policies of others for the wider benefit of people with learning disabilities. PWLD who are often isolated or socially excluded need to take steps to make changes at the personal level in order to participate in group advocacy or group-based learning.

### **CASE STUDY THREE – Society-Level Change, stage three**

#### **Being Heard in Government Group (BHIG) - Campaigning/Awareness raising/ Impact**

The BHIG group started in 2013 as a result of people reporting that they were worried about cuts to their services. We started as a one issue group – understanding more about the local budget setting process and how this would affect people with learning disabilities but the group developed into one with a wider remit of understanding the process of, and involvement in, democracy.

We started to attend council meetings and saw the impact this had on decision-makers in the city, who commented on how unusual it was to see members of the public engage in the way we were engaged.

The group felt very strongly that they wanted to campaign against the cuts to their services and joined in demonstrations. They used social media to engage local media and politicians in debate and, as a result, were invited guests at public debates and rallies. Also we have worked with other campaigning groups such as Disabled People Against the Cuts to ensure that the view point of people with learning disabilities is included in their campaigns.

We worked with the UK Parliament Outreach team to run a course on how democracy works and how people can get more involved.

Once the election came around in 2015 the group thought it was important to encourage as many people with learning disabilities to get involved in having their say so BHIG worked with all local political parties to develop accessible information for people with LD, we held accessible hustings, and worked with our partner organisations: Grace Eyre Foundation, Frances Taylor, Southdown Housing and Mencap. We worked with the Council's democratic services department to ensure that people with learning disabilities had opportunities to enrol themselves on the voting register. We worked not only with parliamentary candidates but also local councillors to ensure that people understood the local issues that they could vote on. Subsequently we have organised a number of accessible events providing opportunities for PWLD to engage with their local politicians in a meaningful way.

As a direct result of the ongoing work and the relationships built over the years we were approached by The Cabinet Office and invited to meet Chris Skidmore MP, then the Minister for Democracy, as part of his fact finding tour investigating the issues for marginalised people and their involvement in democratic processes.



In the lead up to this meeting, members of the group did a small research project finding out about the experience of people with LD in local elections and we produced a report, which we gave to the Minister. He discussed with us our recommendations and took them to the All Party Parliamentary Group meeting and they helped inform the Committee's Report on Democracy in the UK.

On the back of the ministerial visit we were invited to join the All Party Parliamentary Group for Learning Disabilities at The Houses of Commons.

Our visit from Chris Skidmore highlighted the importance of being heard in the political sphere. Clearly the visit made an impression on the Minister, he sat in a group of 10 people with LD who were all engaged, experienced and expert in political debate and had informed opinions and it had a very positive effect much more widely on people with learning disabilities too. Members said how empowering it was to feel like they had been listened to. People told us how proud they were that their work had brought them to this stage.

In the four years that the group has been running we have seen members grow skills and confidence in public speaking, in advocacy, both on an individual level and in terms of advocating for other people. One member who will talk about having "dark thoughts" due to her fears around the current political/ economic climate can now talk openly about those in terms of sharing her fears and campaigning to make positive change around the same issues. People from the group made a film, sharing their thoughts and dreams which was shown as a trailer at a local, mainstream cinema all week during learning disability week. See the film 'Speak Out Being Heard' here – the film is packed with facts and experiences about living with a learning disability: <https://www.youtube.com/watch?v=FFvK4uMubpE&feature=youtu.be>

Group members have made links with local media outlets and fostered those relationships independently.

The group is about to embark on a larger piece of research about a subject raised in one of their meetings, members watch the news and make notes to share with the group.

**Here we find the process of group advocacy taken a stage further – affecting change in institutions so that they engage, listen and perform better. Of course the advocacy group has no control over whether institutions like local authorities, government or health services make changes. What is certain with this case is that these institutions are changing their attitude and listening better.**

## **Advocacy and changing lives – ‘case’, ‘cause’ and ‘class’**

Supporting people and achieving change through advocacy can take several forms. Usually the starting point is individual *case* advocacy that helps individual clients be heard, make their case or confront poor service or discrimination. The more that individual case-based advocacy is provided, the more that the provider can observe certain problems that repeatedly present themselves where a collective *cause advocacy* approach might reap more benefit. For instance Speak Out’s Being Heard in Government Group has enabled PWLD to be more involved in democracy and campaign on issues such as cuts to local services and welfare. Here also *class advocacy* has been developed too where PWLD in general are being represented with their needs being articulated in order to promote change in societies attitude and approach.

Cause and class advocacy was an original foundation activity of social work recognising the need for people with particular needs, characteristics or disadvantages to be heard and for institutions to learn better how to engage with them. This kind of advocacy support has become too marginalized in social work and community services and needs to be extended and developed in order to better align people’s needs with public service provision.

## **Conclusions**

Practitioners need to help people make changes in their lives by addressing the things that motivate them, taking care to help people take action and build confidence in manageable ways, step-by-step. Extending advocacy, support and social care provision to more group-based activities helps people to support each other and build strong, caring and effective social networks. Advocacy services and provision can be more effective if, through for instance research and social campaigns, they can take on and advance cause and class issues that repeatedly affect wider groups of people in society. Advocacy and support services naturally have to deal with the *consequences* of inadequate services or bias and discrimination by providing good casework and seeking remedies for individuals. However they also need to work *back to the causes* of these problems in the first place, and help groups of people to represent their interests and articulate problems and solutions.

## **Acknowledgements and contact details**

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