Front Cover

Alison Wertheimer:

Making our voice heard:

Strengthening alliances between people who use services

King’s Fund Centre for Health Services Development

Community Living Development Team

Title Pages

MAKING OUR VOICE HEARD:

Strengthening alliances between people who use services

by

Alison Wertheimer

Report of a one-day seminar for those who use services for people with learning difficulties, physical disabilities or long-term mental health problems

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Setting the Scene

On 28 November 1988, a group of people who use services met to explore the ways in which it might be useful for service users to make links with each other, perhaps crossing the traditional boundaries between different types of disability. It was something of an innovative event, not only because services traditionally meet people's needs separately, according to the labels they are given ('learning difficulty', 'physical handicap', 'mental health problems') but because the hosts for the day - the King's Fund Centre Community Living Development Team - has also tended to organise its work within these separate groupings.

The day was led by John O'Brien from Atlanta, Georgia, who has considerable experience of working and talking with people who use services. He has been a major influence in helping people to ensure that services are designed around the people who use them and that those services help them to live a valued life in the community.

A word about the participants

A full list of participants appears at the end of this report. Everyone present had some stake in services - as users, as paid workers, or as individuals with a commitment to people with disabilities.

Although the group was quite small, people's experiences were many and varied.

> They included: being a patient in a psychiatric hospital, using a mental health day centre, being a user-representative on a local MIND group, president of a national self-advocacy organisation, being a member of a District Health Authority, being involved in consumer-led projects for people with physical disabilities, belonging to the Spinal Injuries Association (a national group), living many years in long-stay institutions, giving a consumer input to social work training courses on advocacy, spending years in an adult training centre, belonging to a self-advocacy group.

Setting the ground rules

We agreed at the beginning of the day that we would:

- try and really listen to what other people had to say
- , note our differences with other people - but not try and win them over to our own point of view,
- say what was on our mind and
- listen for the common themes which might emerge.

Establishing the agenda

After discussion amongst participants, it was agreed that the agenda would cover:

(1) Exchanging information about our agendas. What do we want?

(2) Looking at what gets in the way of achieving what we want. What are the barriers to achieving positive change?

(3) Thinking about what it is that works for us.

(4) What are the barriers that stop things working for us?

(5) What are some of our success stories?

(6) Identifying possibilities for action together. What are the issues? What possible strategies could we use? Are there differences between us which could hinder joint action? Are there disadvantages in collaboration - what are the possible obstacles on the way?

(7) Next steps after today.

Identifying our agendas - what do we want?

From a long ‘shopping list’, it was clear that people with disabilities wanted very normal things - they certainly weren’t asking for the moon. But the way they are treated at present - in the community and in service systems - means that often even these most basic wishes are not fulfilled; a decent home, a job, friends, leisure activities - none of these are very remarkable, but for disabled people to achieve them means many changes still have to be made.

…From the community:

Many of the problems which people with disabilities encounter, stem from other people’s attitudes and behaviour.

People with disabilities want to be treated as people first, not labelled 'the handicapped’ or ‘the disabled’. People with disabilities should be recognised as people with basic human needs - and rights.

The general public could be more understanding. 'Do they know what it’s really like for people who have our problems’? If they understood more about disability, people might get on better with each other.

Segregation of people with disabilities should be done away with - people should be treated as equals. Too often at present people with disabilities are segregated because of lack of access - they can’t get to places like shops, or further education colleges; sometimes they can’t even get outside their own front door.

…From services

The services we have now should be of a better quality, but we also need more of them - and that means more money being made available. Services need improving now, but we also want a better deal for future generations.

Sometimes people need to be somewhere safe when they are going through a crisis. At the moment this usually means going into an institution but they certainly aren’t places of safety. We want to see the institutions closed down.

Although no one is getting a particularly good deal from services at present, some people aren’t even getting a share of what’s available. People from minority ethnic groups, for example, are often excluded, particularly from services in the community.

We should do away with cheap labour at day centres. ‘What’s £4.20 a week for hours of work - it’s an insult!’.

What we want for ourselves…

More freedom and more power were high on the agenda. People wanted more control over their lives - 'the chance to make our own decisions, not having decisions made for you’.

We need to recognise that even if a group of people share the same label (e.g. 'person with mental health problems’), this doesn’t mean they all want the same things. Some people with mental health problems will decide that they want treatment, others may decide that they don’t.

One of the strongest messages from this part of the day was that people wanted above all, to be heard and understood by other people. It matters that people take you seriously ‘even though I may say or do strange things sometimes’. We need other people to talk to, to share difficulties with, to help us sort things out.

Everyone wants a home of their own and support for independent living. Some people have been denied that for most of their lives: ‘I’ve only been out of the “homes system" for five years’.

People want more money, and they want the jobs which can give them access to a better income. Developing co-operatives where people own and manage things for themselves was suggested as one way of creating jobs.

Getting consultation on the agenda

‘We want people to listen to us’ - this was said by many of the participants who felt that they were not being consulted about decisions which affected their lives.

Rather than having professionals working in services taking decisions over their heads, people with disabilities want to be properly consulted. This means learning how to work the system, acquiring skills like how to participate effectively in meetings. Sometimes people could learn as they went along - ‘learning by doing’ - but they also wanted the chance to learn specific skills which could help them participate more effectively in the planning and operation of services they used.

Summary

- We want to be consulted about the things which affect our lives.
- We want better, more flexible services which can give us any special help we need
- when we need it.
- We want the same things as everyone else - a home of our own, a job, and enough
- money to live on.
- We don’t want to be excluded from ordinary life. We want to be a part of it and to be
- accepted by the rest of society.
- We want to be listened to and we want other people to understand our lives and our experiences.

What are the barriers to achieving positive change?

A stake in services or a vested interest?

There are many people and organisations who have a vested interest in ensuring things stay as they are.

For example, charitable organisations may pay lip service to change, but can sometimes oppose it when it threatens them directly. Participants mentioned the example of one organisation which refused to change its logo despite criticisms from people with disabilities who find it demeaning and infantilizing. Unfortunately, if a logo seems to be helping a charity raise funds it may not want to change its image.

Sometimes there are commercial interests which can get in the way of change. Mental health service users may campaign against the over-prescription of tranquilizers but the pharmaceutical companies who manufacture them are unlikely to support a proposal which will reduce their profits.

Resistance to change

•Change causes pain for us; what we have causes pain, but change is personally painful'. Living with change is not easy; people with disabilities themselves may find change difficult.

People who work in services are often highly resistant to change; their jobs may be on the line but even if this isn't the case, demands for change always imply that what went before wasn't qood enough. There's an implied - and sometimes overt - criticism. Even where people working in services are trying to make changes, they are often isolated and can quickly become burnt out'.

Parents of people with disabilities often find change very hard to accept. It's frightening, it feels risky and 'letting go' of someone you've supported for years can be very hard. When parents are offered help, the chance to sit back and let other people take over some of the supporting, it can be hard to accept that help, particularly if you've always coped on your own.

Facing negative attitudes

Other people's attitudes can be the biggest barrier to change. Ignorance and negative attitudes feed into one another and people end up being treated like second-class citizens.

The media often portray people with disabilities in ways which are damaging and devaluing. Images are often conflicting. They show people as violent and dangerous on the one hand, andas helpless and childlike on the other. It’s not very often that the media shows people with disabilities as people with abilities - although one exception was the film Annie s Coming Out which was shown on television recently.

If people with disabilities were to stage mass campaigns how would the public feel about that?If all the roads round Parliament Square were jammed with disabled demonstrators would peoplenecessarily be sympathetic?

Because people with disabilities don't get much encouragement from other people this means they can end up feeling pretty negative about themselves. ‘The way we are treated means we don’t have much self-confidence and we have low expectations of ourselves’.

The way services treat people often leaves them feeling bad about themselves. ‘ We feel we’ve made a mess of our lives - it’s left us feeling angry and hurt’.

Lack of access can stop us going places

The lack of physical access can create some of the biggest barriers. People can’t get around to meet and talk with other service users; a lack of accessible public transport effectively keeps people with physical disabilities out of the community and when people demand more accessible transport their demands are always rejected on the grounds of expense.

‘Sometimes it’s like being in South Africa -it’s an apartheid system’.

People with disabilities are also excluded in less obvious ways. The welfare benefits system means that people are encouraged to be dependent, and to remain at home rather than go out to work.

Living in institutions can make it hard for people to go out and start making changes in their lives. ‘*You don’t know what life is like... you don’t have the confidence at first...it takes time.’*

They won’t even consult the experts

‘Trying to make changes is difficult when the people you need to negotiate with have (nearly) all the power. That means they don’t have to negotiate with you unless they want

to.’

'People with disabilities don’t even get fair access to the media - although it seems as though organisations for (not of) disabled people can get people in the media to listen to what they have to say. Why can’t we?’

People with disabilities are the experts on what it’s like to be disabled but professionals are still unwilling to learn from them; they’d rather go and find other “experts”. "My experience is devalued". Sometimes even non-professionals, with no direct experience of being disabled, get to be labelled as “experts” (e.g. if you write a book about some aspect of disability).

People employed in social services these days tend to have some experience in many different areas of social work but are often not trained to specialise; this means they often don’t know much about things like disability.

‘Why do people with no direct experience of disability have the audacity to tell me what to do ?'

Lobbying can be very hard work

People with disabilities can find it hard to get politicians - locally and nationally - to listen to what they are saying and to take notice of their demands. Politicians are part of the system too, and they can be pretty resistant to change.

Lobbying national government can be hard. ‘How do you get into the DHSS - it’s like a maze - so many desks!’

Even lobbying local politicians can be difficult. Local councillors are expected to be interested in very many different issues so it’s a problem to get them to come to meetings and hear the views of people with disabilities. Also they’re not very used to working with service users; usually it's the officers - the people employed in services - who they deal with.

‘Too much energy has to go into bending the system’.

Services can be a real headache...

Delays in getting services in the community started means that sometimes we have to wait a very long time before, say, we can move into our own homes.

Sometimes these delays occur because organisations are having financial problems. Some local authorities are being rate-capped by central government and this means expenditure is tight.

On the other hand, money sometimes gets handed out unexpectedly because there has been a public ‘scandal’ about services. However, that money doesn’t always go in the right direction; sometimes it gets spent on services which are not appropriate.

SUMMARY

The biggest barriers to change are:

- Resistance to change - by people in services, by parents and by the community at largebecause change is usually painful.
- Other people and organisations who have a strong vested interest in things staying just as they are.
- Other people’s negative attitudes which means people with disabilities end up not having very high expectations of themselves.
- Problems with access which means people with disabilities literally can’t get out there into the world and make changes.
- Professionals who reckon they are the experts on disability and refuse to talk to the real experts - people with disabilities.

What we’ve found works for us

During this part of the day, participants shared their experiences of some of the things which had empowered them, which had helped them to be better self-advocates, and to have more control over their own lives.

Self-advocacy and self-help

- Being personally committed to speaking for yourself.
- Forming self-advocacy and self-help groups like People First, and being able to meet in safe, comfortable places.
- Having opportunities to meet up with other self-advocates like at the recent People First International Self-Advocacy Conference in London.
- Learning skills which enable you to become a more competent self-advocate (e.g. how to chair meetings).
- Being given financial support for your group’s activities.
- Spreading the word by having a membership scheme and circulating a newsletter.
- Using the strength of your own experience...being yourself ...working in ways that suit you.

Building coalitions

- Forming national networks and coalitions such as People First, Survivors Speak Out, and British Council of Organisations of Disabled People.
- Finding a common language amongst the groups representing people with different disabilities - so that we’re all talking about the same things.

Infiltrating the system and improving services

- Getting into leadership positions in voluntary groups. ‘I’m a member of my local MIND management committee which has 50% users. It works well for me; it’s given me a lot of self-respect; it’s changed my life’.
- Taking part in qualifying and in-service training to put forward the consumer’s viewpoint.
- Getting money for services channeled directly to consumers, as in the Hampshire SOCS (Self-Operated Care Schemes).
- Identifying good practice and increasing people’s expectations of what is possible.
- Setting up small-scale examples of good practice.

- Identifying instances of bad practice and suggesting how things could be improved.
- ‘Being able to channel our anger constructively in ways that ensure people listen to us and treat our criticism constructively’.

Working positively with the professionals

- Finding professionals who will come and ask us what they should be doing - 'using the users helpfully’.
- Being able to form alliances between professionals who will work with us but not take us over.
- Having managers who spend time with people who use services.
- Professionals being given the time and space to really try and learn about what it feels like to be a service user.
- Giving users and professionals time to get to know each other in informal and non-threatening settings where they can talk openly.
- Professionals who will give paramountcy to the views of consumers.
- Being ‘allowed’ to make mistakes: ‘Not - one mistake and it’s all over’.

Influencing the community

- Talking to groups like young people on YTS schemes. Young people are often more receptive to what is being said.
- Being supported in our efforts to make changes by people who are not part of service systems and who are, therefore, conflict-free and independent (as with some advisers to self-advocacy groups).
- Getting issues relating to disability into the mainstream media - not just the specialist press and ‘special’ programmes. Getting radio or television coverage at peak listening/viewing times.
- ‘Being generally encouraged by other (non-disabled) people in what we are thinking, doing,and saying’.

Some success stories

Some participants described success stories. For example:

- A group of self-advocates with learning difficulties lobbied their local council in South London because they didn’t like being described as ‘mentally handicapped’. The Council agreed to their proposals and changed it to ‘people with learning difficulties’ - the group’s choice.

- * A local authority in outer London was planning to stop payments it made to people attending an adult training centre - even though they weren't getting very much money for their work anyway. After a protest, that decision was reversed.

To achieve more successes like these though, we need to learn:

- how to work political systems like in central and local government.
- how we can use the media so that our stories get press, radio and television coverage – and at peak time!
- what it is that makes some campaigns succeed and others fail. What do we do right and what are our mistakes?

SUMMARY

- Being active self-advocates
- Forming coalitions
- Infiltrating statutory and voluntary organisations.
- Forming positive alliances with professionals.
- Influencing the media and the community at large.

Possibilities for working together

During this part of the day we tried to answer several different questions:

- What are the issues we need to take on board in order to be able to work successfully together?
- Are there issues we could work on together?
- Would there be any disadvantages in adopting this approach?

What are the issues we need to take on board in order to be able to work successfully together?

Before we can work well together we need to understand our prejudices about other disabilities. ‘We don't want people with physical disabilities talking about ‘‘the mentally handicapped".

We share common needs such as housing, jobs, and accessibility but we will have to talk about whether we all want the same sort of housing, the same sort of work opportunities, and so on.Our needs may be the same but we will probably want to have those needs met in different ways.

Some groups have their own particular ‘philosophy’ - their own particular beliefs. People with physical disabilities may acknowledge the fact they are ‘disabled’, that they ‘have a disability’; on the other hand some people with learning difficulties don’t see things that way at all and would reject the idea that they are disabled. People will need to get together and talk about these differences.

Groups like People First or Survivors Speak Out will have to think about who it is they are representing. Do they just represent themselves or do they speak for all those with a similar experience of disability?

People with different disabilities have set up different types of groups. We will need to learn about these different models of organisation and how they operate.

The experiences of people with learning difficulties may be very different from those of people who have long-term mental health problems. It will be important to get to understand what those different experiences are - as well as what we share in common.

Are there issues we could work on together?

The first task may be to try and set some common agendas as different groups will almost certainly have different agendas. Working together doesn’t stop individual groups pursuing their own particular campaigns but to work together, some common objectives will have to be agreed.

Learning the skills of self-advocacy and campaigning are important and different groups could maybe get together and organise joint training for their members. We can learn from each other by sharing our skills and information.

We identified a number of specific issues which could become the focus of joint campaigns.

- The implementation of the 1986 Disabled Persons Act, and particularly those clauses which relate to advocacy (ss. 2 and 3) (Some of the organisations for people with disabilities have a joint campaign Act Now! Do we know what they have achieved?
- The need for more accessibility in the community. (We know there is a national Access Committee, set up by the government, and supporting local access groups - what else are they doing?)
- Some people with disabilities belong to trade unions. People in adult training centres may join the NUS and there is a special union for blind people.
- Using the media to campaign together on specific issues might have more impact than trying to get media coverage as individual - and smaller - groups.
-

Would there be any disadvantages in adopting this approach?

Even if we were able to understand each other’s experiences of disability better, the general public might get even more confused than they already are!

In the past we have usually had to compete with one another for limited financial resources.How would we cope with no longer being able to complain that ‘those other disabled people’are getting more than we are? And what would be the effect on the people who decide howmoney for services is spent?

If we were all to campaign together, everyone else might feel we were such a huge problem that they couldn’t do anything about it at all. On the other hand some people - particularly some groups of people with physical disabilities- already get a bad deal 'because there are too few of you to bother about’.

Working together would mean more meetings, more administration, and so on. Would all this extra time and effort be worth it? Are we sure there would be benefits to working this way?

SUMMARY

The possibility of strengthening our alliances means:

- Exploring our common ground
- Sharing our skills, information and experiences
- Identifying issues we could work on together
- Being aware of any disadvantages or difficulties in

The Next Steps

At the close of the seminar, people put forward their proposals for where we might go from here:

“I would like to find out more about groups like People First (a mental health service user).

“I’d like to meet up with other groups.”

“Some people aren’t represented here. We have no one with a visual impairment, or with hearing loss. We also don't have anyone from ethnic minority groups. In future, they should be included in this sort of meeting"

“We could have this sort of meeting at a local level - and this could lead to devising a local action plan.”

“It's early days yet so let's not stop talking!"

“I'd like more people to come to our People First meetings - some different faces - the chance to make new friends. ’’

”I’d like to know what people in other countries think about this and what they are doing. Let’s tell people about the People First international conference.”

“Let’s tell other people about what we’ve done here today.

Appendix

List of participants

PETER ASHE	Member, People First, Dorking, Surrey
PETER BERESFORD	Open Services Project, London
ROGER BLUNDEN	Programme Director, King’s Fund Centre
GARYBOURLET	President, People First, London and Thames
LESLEY BROWNE	Senior Policy Officer, RADAR
VIC ELLINGER	Camden MIND
BARRIE FIEDLER	Coordinator, Living Options Project, King’s Fund Centre
MELANIE GARDNER	Information Officer, Centre for Independent Living, Southampton
VALERIE LEWIS	Research Assistant, St. Bartholomew’s Hospital, London
CLIFFORD MOSS	Member, People First, Swindon, Wiltshire
THOMAS PIPPETT	Member, People First, Dorking, Surrey
JOAN RUSH	Senior Project Officer, King's Fund Centre
HELEN SMITH	Senior Project Officer, King’s Fund Centre
PETER SWAIN	Exeter Centre for Independent Living, Exeter, Devon
DIANA TWICHIN	Project Officer, King’s Fund Centre
ANDREA WHITTAKER	Project Officer, King’s Fund Centre
ILEANNE WILLIAMSON	Service user, Castleleigh Day Centre, Northwhich, Cheshire
LIZ WINN	Development Officer, King’s Fund CentreKing's Fund