



Tipping Point User Involvement Project

Report

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1 Introduction

This report presents the findings of a survey of disability organisations and three case studies. The survey asked disability organisations about the involvement of disabled people, current and past service users in a range of activities. The case studies investigated the processes of developing user involvement, the process of change, and the principles of good practice in user involvement.

The broad aims of the project are to influence all disability organisations to increase the degree of control by disabled people. The project aimed to achieve this through developing tools for change based on the experience of disabled people. The research element has begun to identify some of these tools.

Tipping Point was set up by RADAR to promote involvement of disabled people in disability organisations and in particular RADAR member groups. The aims of Tipping Point are to:

- Identify user-centred user involvement / control activity
- Identify, develop and share why user-centred user involvement / control is important from a disabled person's point of view
- Identify what works for managers and trustees
- Identify different motivations for developing user involvement / control
- Identify methods for implementing user involvement / control at different levels and for different activities and in different situations
- Clarify and develop criteria for defining user-centred user involvement / control
- Develop tools for change based on the experience of disabled people

2 Methodology

The Tipping Point survey was designed and delivered by researchers from the Centre for Institutional Studies, at the University of East London with input from RADAR and an advisory group of disabled people. Key elements of the project are described below.

Questionnaire design

A draft questionnaire was designed by the researchers. This was piloted by four organisations that were recruited to assist with the project at RADAR's annual conference in October 2005.

Feedback from these organisations and the advisory panel resulted in a radical redraft to improve the accessibility, clarity and ease of completion of the questionnaire. Organisations and panel members who had taken part in the pilot were invited to comment on the redraft before the researchers finalised the survey.

The questionnaire pack included a covering letter and stamped addressed envelope. The covering letter invited people to contact UEL if they had any special requirements for the questionnaire.

Most of the organisations included in the 48 usable responses were able to answer most questions in the survey.

Sample and response rate

RADAR provided their membership list as sample for the survey. This list was supplemented by suggestions from members of the advisory groups and the researchers. 48 organisations responded representing a response rate of 14%.

Organisations responding varied in terms of size, area and services provided (see profile of organisations overleaf).

The data in this report should be used to explore the range of activities and experiences across disability organisations rather than to draw precise quantitative conclusions about user involvement across the wider population of disability organisations.

3 Profile of organisations

Responses came from a wide range of organisations in terms of size, function and area.

Turnover

The highest turnover was in excess of £158 million and the lowest was an organisation who stated that they have no annual turnover.

Table 1: Turnover

Range	Size	Number of organisations
£10M+	Large	1
> £1M, < £10M	Medium large	5
>£100K <£1M	Medium	21
£100K or less	Small	16
Total		43

Coverage and establishment

The majority of organisations are local. Seven organisations cover the London area and the rest cover wide range of different areas, from Cumbria to Dorset.

Table 2: Geographical area represented

Area	Count
Local	27
Regional	9
National	11
International	1
Total	48

Table 3: How long has your organisation been established?

Time	Count
Less than 5 years ago	3
6-15 years	13
16-25 years	12
26 years of more	20
Total	48

Services provided

The most common function of participant organisations is advice and information (43 of the 48 organisations). This is followed by the number providing self-help services (24), advocacy (23), campaigning (22), and recreational activities (23).

Table 4: Functions of organisation

Type of services		Count
Direct services	Accommodation	8
	Personal care	6
	Health services	5
	Advice and information	43
	Advocacy	23
	Recreational activities	20
	Training or support with employment	12
	Self help	24
Other functions	Campaigning	22
	Umbrella/ second tier	9

Functions mentioned by several respondents which do not fit into the above categories included training services and transport.

21 respondents stated that they would be interested in assisting further with the Tipping Point project, for example by helping the researchers to consult with service users and staff at their organisations.

4 Findings: The involvement of disabled people through governing bodies, individual membership and employment and volunteering

Composition of governing body

42 respondents gave a profile of members of their governing body, indicating how many are current services users, past services users, disabled people who have not used the organisation’s services and others who do not fall into these categories. Responses account for 430 members of governing bodies in 42 organisations. The average number of people on the governing bodies is nine.

Current service users account for just over a third (35%) of members of governing bodies, whilst past service users account for just over a fifth (22%). This means that in total well over half (57%) of those on governing bodies have direct experience of their organisation’s service. The second largest category is ‘other’. This indicates that around three in ten of those on the governing bodies represented are non-disabled people. The final group is disabled people who have no experience of the organisation’s services; this group accounts for just over one in ten (12%) members.

15 of the organisations’ governing bodies do not include any current service users, and 16 do not include any past service users. Seven organisations do not have past or current service users on their governing bodies. However, only one organisation does not have any disabled people at all on their governing body.

Figure 1: Composition of governing bodies

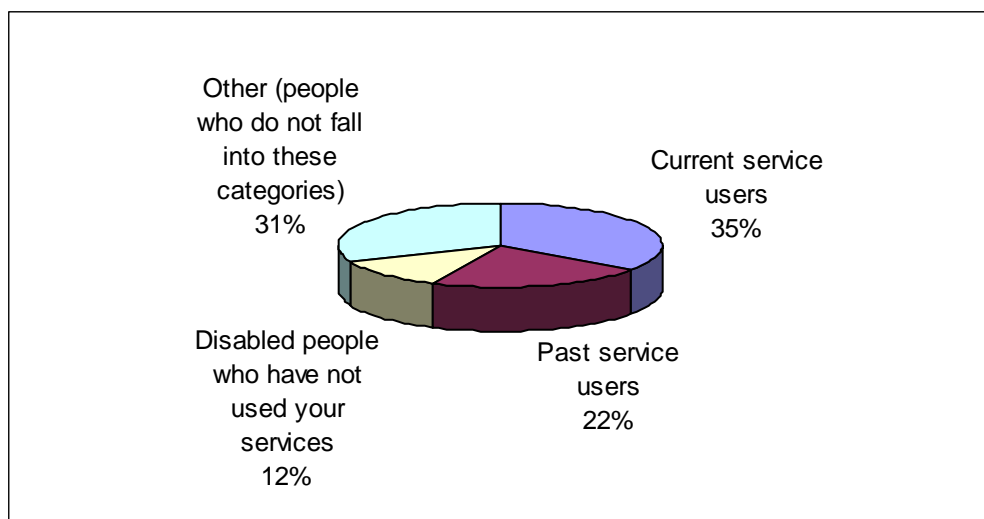


Table 5: Composition of governing bodies

	Number	Percent
Current service users	152	35
Past service users	95	22
Disabled people who have not used your services	50	12
Other (people who do not fall into these categories)	133	31
Total	430	100

Respondents were asked to indicate whether the proportion of disabled people and services users on the governing body is affected by constitution, formal policy or target, and informal policy or target. Six in ten (60%) of the 48 organisations indicated that the number of disabled people and service users on the board is influenced by their constitution. A quarter (25%) of organisations have formal policies or targets to ensure disabled people and services users are represented on the governing body. An example of formalised policy and targets was described by one organisation:

- 'Our constitution states that 'The Management Committee shall consist of not less than three and not more than 12 members of whom not less than 51% shall be disabled people.'

Slightly more organisations (29%) have informal policies or targets that affect the composition of the governing body. Generally organisations have either formal or informal policies and targets, although two respondents selected both of these options.

The most popular method of recruitment to governing bodies across 48 organisations was 'selection by election' (60%). A similar proportion of organisations (58%) have a system of nomination to the governing body by service users or members. Sizeable minorities of the organisations represented have members of the governing body selected by existing members (38%) and selected by staff (17%). All 48 organisations selected one or more of the methods. 19 of the 32 organisations that have members of the governing body nominated by service users or members also have elections to make appointments.

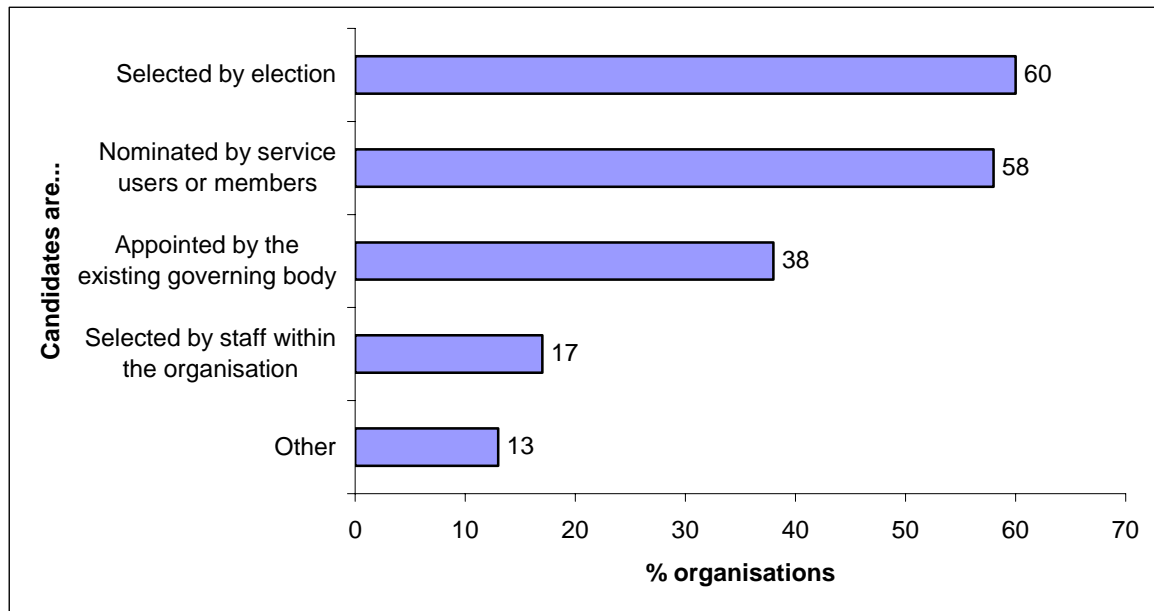
Other responses often referred to informal selection procedures:

- 'Whoever is prepared to be involved and able to enhance the organisation'
- 'Expressions of interest'

Other open comments about how governing bodies are recruited include:

- 'By recommendation'
- 'The council run it, they advertise for specific skills (must be disabled people)'
- 'People are appointed by council'

Figure 2: How are people recruited to your governing body? (Respondents could select more than one option)



39 respondents made a comment about the recruitment of disabled people to their governing body. Key themes in responses were comments about:

Specific, sometimes informal and/or localised, methods of recruitment:

- 'We ask clients and people we meet who appear to have the skills or aptitude we need, who are disabled'
- 'Informal support by Manager and Chairman. Often clients of the organisation become interested and volunteer'
- 'Vacancies are advertised to all our members. Anyone interested is then invited to attend the next meeting as an observer. If they are then happy to join us they are co-opted at the next meeting'

Ease of recruitment:

- 'We have never had trouble recruiting - only with selection of suitably skilled candidates. We provide a full induction programme and candidates 'shadow' for six months, before formally signing up to the board'

- 'We have a very flourishing and active membership from which members put themselves forward. For the last 3 years we have had 16 applications for ten posts'
- 'We advertise through services and newsletters. We find it difficult to recruit young disabled people, and disabled people from Black and Minority Ethnic Associations'

Ways of making board membership accessible or attractive to disabled people:

- 'Disabled people on the Board of Directors are supported by the provision of accessible transport, expenses and large print documentation if required'
- 'Face-to-face encouragement publicising need for representation of disabled people on Board (is included in) articles in our newsletter'
- 'We encourage disabled people to apply to the governing body as it assists understanding as to the needs of our organisation'

Individual membership

33 of the 48 organisations responding (72%) have individual membership options. The organisation with the largest membership has over 13,000 members and the smallest just 20.

Members of organisations are current and past service-users, disabled people who are not past service users, professionals, carers, interested individuals, and other disability organisations and groups.

Employment

Respondents were asked what proportion of staff at different levels within the organisation are disabled and what proportion are current or past service users. Staff were both paid staff and volunteers; two organisations only employed volunteers.

In total 15% of all the staff represented in the questionnaires are disabled and 5% of staff and volunteers are service users or past service users. This varies greatly across organisations.

Figure 3 shows that at the higher end of the scale one in ten (11%) of organisations only have disabled employees. In total, over four in ten (43%) of organisations represented have workforces where more than half of staff are disabled. At three in ten organisations less than a quarter of staff are disabled although only 3% do not have any disabled staff.

Six in ten organisations do not employ any current or past service users. In 28% of organisations over half of staff are service users or past service users.

Figure 3: % of all staff who are disabled

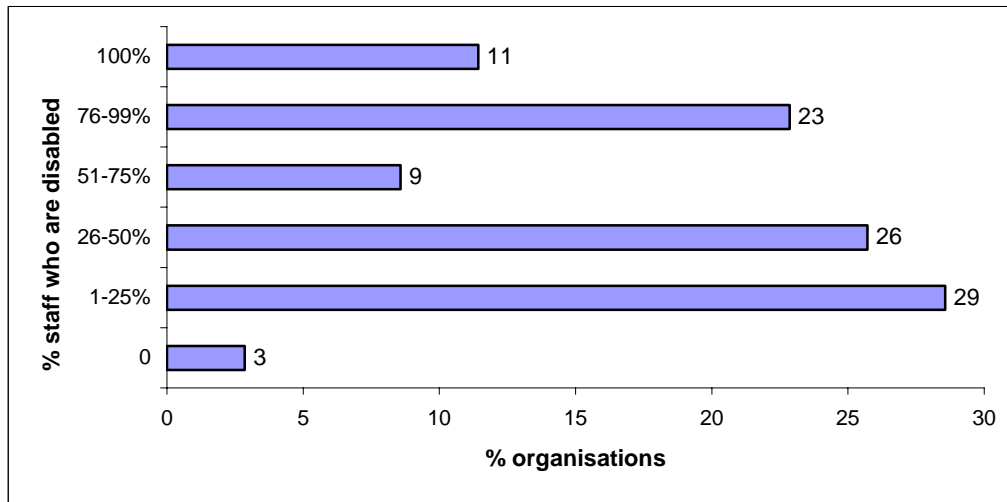
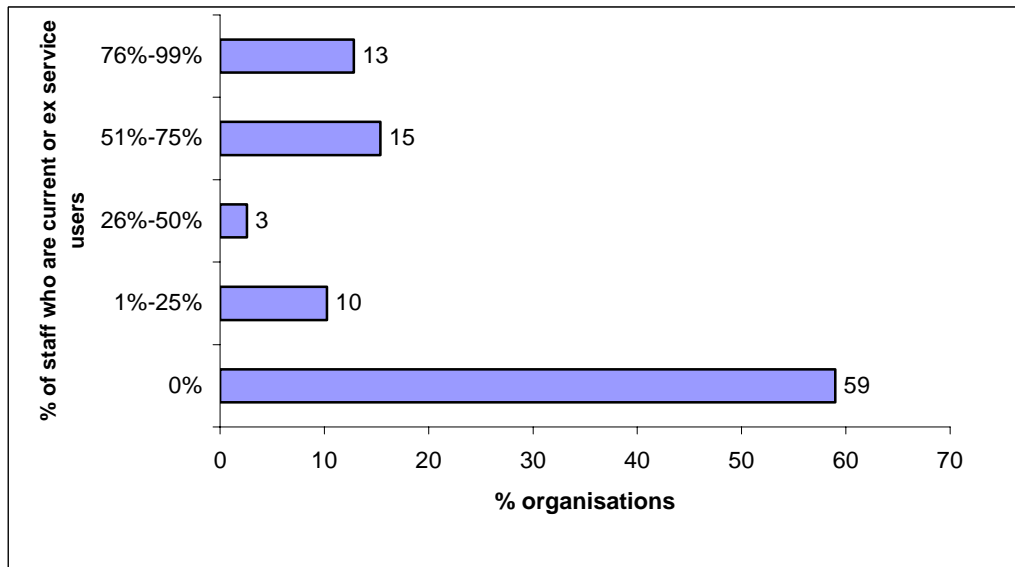


Figure 4: % of all staff who are current or past service users



The organisations that have a high proportion (75-100%) of senior staff who are disabled or current or past service users only have between one and five senior employees.

39 respondents made a comment about the employment of disabled people. Responses are themed below:

General statements about working practices and attitude and culture around employing disabled people

- 'We provide flexible hours where we can, and are positive about employing disabled people - there are no barriers or attitudes to support provided as long as we get the 'expert' we need. We have no quotas or targets for employing disabled people.'
- 'All office staff, volunteers and trustees are disabled people.'
- 'Employing people with a learning disability is one of our five key priorities over next 3 years. In the last year there have been a number of initiatives.'
- 'We have a commitment to increase the number of visually impaired staff.'

Adverts and promotion

- 'Encouraged through adverts, where we advertise and seek disabled people from our membership.'
- 'We advertise all jobs in areas that are accessible to disabled people.'
- 'No targets or quotas. Database of disabled people may be notified of posts.'
- 'Our Ads say 'Personal experience of living with a disability would be an advantage'.'

Recruitment practices (beyond advertising)

- 'Our recruitment processes encourage applications from disabled people and this is monitored on a regular basis. Our positive approach to employing disabled people is an important element of our overall Equal Opportunities Policy'
- 'We do not discriminate for or against. Based on suitability for role first. Would only add we encourage people in work to declare disabilities but do not insist. We would offer any reasonable support to gain or maintain employment and seek appropriate input from outside sources.'
- 'Our job adverts always encourage applications from disabled people and disabled people always get an interview'
- '...Regard having personal experience of disability as an additional asset.'
- 'We provide application packs in requested (formats). We advertise in appropriate disability media'

Accreditation

- 'We are Investors in People and a Two Ticks employer.'
- 'We are proud to be accredited as a Positive about Disability employer.'

Key findings and issues

The involvement of disabled people through governing bodies, individual membership and employment and volunteering

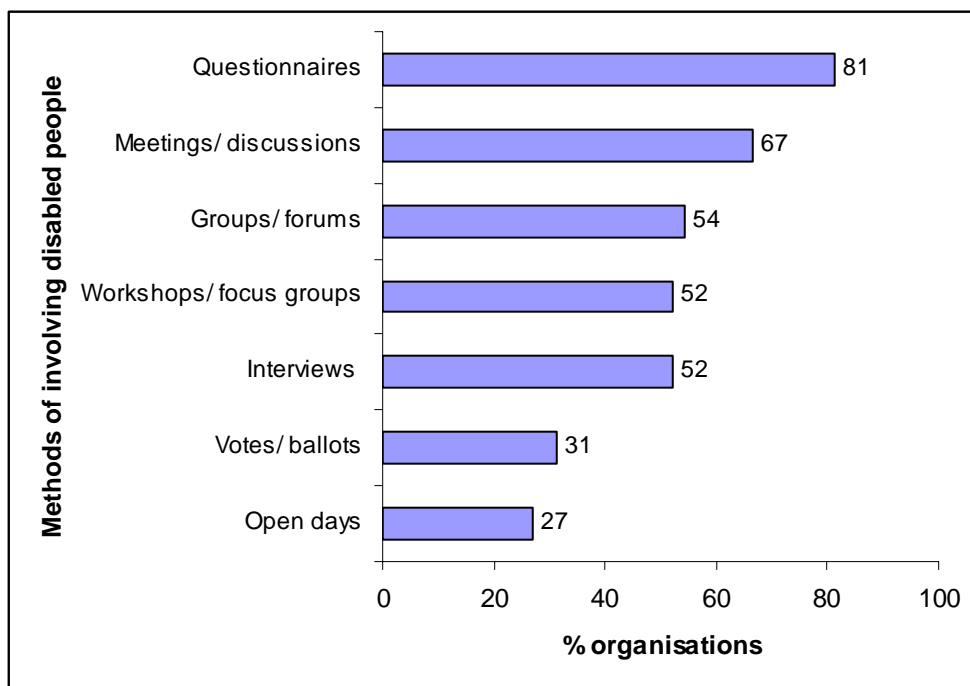
- Membership of governing bodies is a key vehicle for user involvement in disability organisations.
- Nearly six in ten (57%) of those on the governing bodies of participating organisations have experience of receiving service from the organisation. There are a minority (7) of organisations with no current or past service users on the governing body and one governing body does not have any disabled members.
- 60% of organisations have constitutions which ensure that there are disabled people on their governing bodies. A quarter have formal targets and three in ten have informal targets.
- Organisations described a range of methods for ensuring that the governing body represents service users or members.
- Seven in ten organisations have individual membership options. The largest sub section of members for most organisations is current service users followed by past service users and disabled people who do not receive services from the organisation.
- 15% of all the staff represented in the questionnaires are disabled and 5% of staff and volunteers are service users or past service users. This varies greatly across organisations.
- Over four in ten (43%) organisations represented have workforces where more than half of staff are disabled including one in ten (11%) where all employees are disabled.
- The presence of disabled people on governing bodies is important but does not provide any evidence of the experiences or influence of disabled members on governing bodies.
- Findings from this section confirm that the role of disabled people as members of governing bodies, members of organisations and as employees are important mechanisms of user involvement.

5 Findings: Methods and responsibility for user involvement

Respondents were asked to indicate which methods, from a list of seven, they have used over the last year to involve disabled people in decision-making. On average respondents selected three methods. Seven organisations use all the methods listed.

All methods listed were used by more than a quarter of organisations. The most widely used method of involvement is questionnaires (81%), followed by meetings and discussions (67%). Over half of organisations use groups and/or forums (54%) and similar proportions (52%) use workshops, focus groups and/or interviews.

Figure 5: Which of the following methods has your organisation used to involve disabled people in decision making?



Respondents were asked to describe any other methods of involvement they had used over the last year.

Four respondents mentioned involvement through newsletters including 'feedback through our magazine', 'newsletter requests' and 'feedback via our monthly newsletters'. Three mentioned involvement via the Internet: 'website forum and questionnaires on website' and 'four message boards on our website'.

Three examples of informal methods were given, 'One to one conversations encourage people to become trustees or volunteers', 'Informal contact, word of mouth is the best way to find things out in this area' and 'informal discussions'. Two organisations mentioned their Annual General Meetings and one mentioned an Annual Review.

Other examples included involvement via campaigning and research: 'users have engaged in groundbreaking research in assistive technologies and ergonomics', 'disabled learners present their experiences to statutory and voluntary agencies through skill's conferences and events and publications'.

Of 43 respondents, 56% (24) organisations stated that they have staff with specific responsibility for user involvement as part of, or all of, their job.

Staff responsible for user-involvement included the chair and vice-chair, directors, managers, co-ordinators, officers, advisors and project workers. This demonstrates that user-involvement can be the responsibility of any, if not all, staff in an organisation.

Nine organisations gave usable data about their budget for user involvement. This is shown in Table 6. Open comments about what user involvement budget is spent on included the following: 'twice yearly consultation with service users', 'subsidised social events/training, travel and meeting expenses, staff costs, refreshments, national and international meetings'.

Table 6: Money allocated to user involvement

User involvement budget	Annual turnover	User involvement budget as % of annual turnover
£1,000,000	£8,000,000	13
£50,000	£100,000	50
£38,000	£2,889,322	1
£30,000	£5,100,000	1
£21,000	£225,000	9
£8,000	£2,100,000	0.4
£3,800	£66,000	6
£262	£250,000	0.01

Respondents were invited to make an open comment about responsibility for user involvement in their organisation. These comments demonstrate the importance and priority given to user involvement in organisations and user involvement being a way of working and a principle which is realised beyond the allocation of responsibility to a few specific roles. Examples of responses are as follows:

- 'We have it uppermost in our minds to seek the views of members.'
- 'It is the responsibility of all managers and all departments to involve and engage users, to improve services and increase potential for independent living.'
- 'The Manager undertakes twice yearly evaluations with service users and reports the outcomes to the Board of Trustees, who use this information to develop the service(s).'
- 'We try and make 'user involvement' an integral part of every staff member's job as it's a big part of the ethos, culture and constitution of our organisation.'
- 'Trustees and management staff give user involvement a very high priority.'
- 'Funding streams do not allow for this role. Currently in negotiation with local authority to fund designated role.'

Key findings and issues

Methods of and responsibility for user involvement

- The most widely used method of involvement from a list of seven provided is questionnaires, with 81% of organisations having used this method in the last year. This is followed by meetings and discussions (67%). Over half of organisations use groups and/or forums (54%) and similar proportions (52%) use workshops, focus groups and/or interviews.
- Respondents described a range of vehicles for methods of involvement, including newsletters, the internet and informal communication and feedback mechanisms.
- Of 43 answering, 56% (24) of organisations stated that they have staff with specific responsibility for user involvement as part of, or all of, their job.
- Organisations are using a wide range of methods to facilitate user involvement. This information provides useful context for an exploration of experiences of the user involvement methods described.
- These methods are particularly important for those service users and members who do not want to, or are unable to, be involved as staff volunteers and members of governing bodies.

6 Findings: Evaluating user involvement

In the ‘evaluating user involvement in your organisation’ section of the questionnaire respondents were asked to give their opinion as to how their organisation is performing in various aspects of user involvement.

The questionnaire stated that researchers understand that this information is subjective and suggested that respondents may like to consult staff and service users about their responses.

60% of respondents feel that seeking feedback to monitor and evaluate services is a strength area. Just 11% think this is a weak area for their organisation. Half of respondents feel that the collection of members and/or service users views for use in policy and campaigning is a strength area for their organisation, although nearly 20% see it as a weak area. The results are slightly less positive for systematically informing service users about significant changes that occur in their organisation, with 44% saying it is a strength area and 10% a weak area. When it comes to systematically collecting service users’ views before making significant decisions, 42% felt they were strong, and 21% weak.

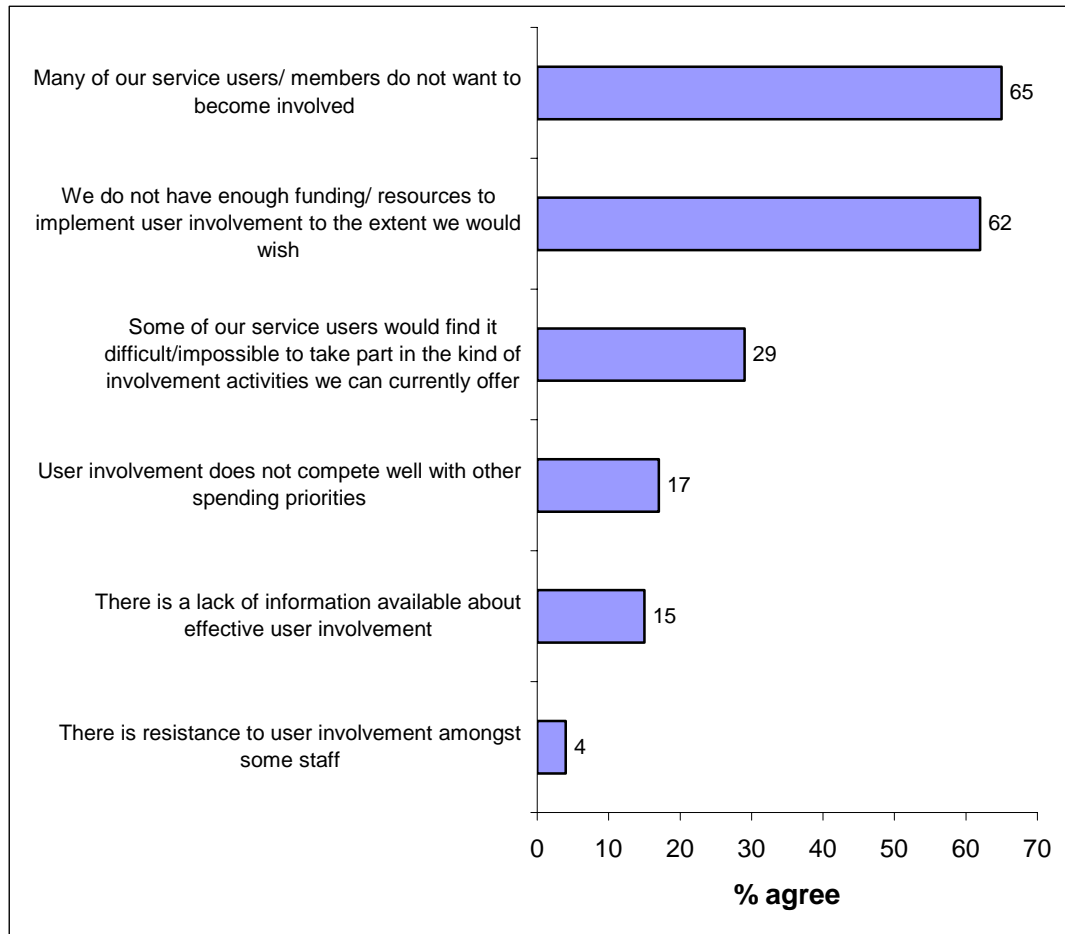
Areas attracting less positive responses were about members and/or service users becoming involved in evaluation and monitoring through paid employment and volunteering. 34% of respondents rate their organisation as strong in terms of involvement as evaluators or researchers and 23% rate their organisation as weak. Just 23% rate their organisation as strong in terms of providing opportunities for employment and volunteering, but 27% rate their organisation as weak in this area.

Respondents were next asked whether, or to what extent, they face each of six problems, or barriers to involvement. The results can be seen in Figure 6.

65% agreed that ‘many of our members and/or service users do not want to become involved’. Whilst 62% agreed that their organisation does not have the resources to implement user involvement to the extent that they would like. This raises the question of whether there is a relationship between an organisation’s spend and the keenness, perceived or otherwise, of users to get involved.

29% of respondents agreed that some of their users would find it difficult or impossible to take part in the kind of involvement activities that they can currently offer. Very few, just 4%, saw a resistance to user involvement amongst staff.

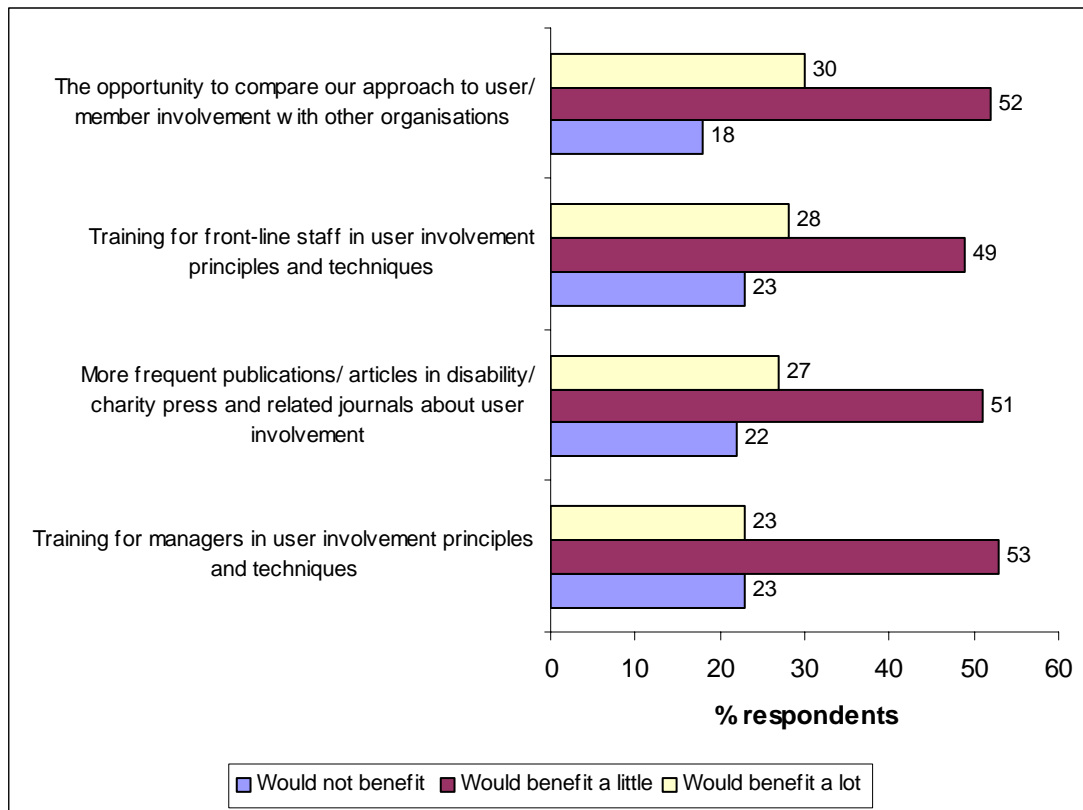
Figure 6: How much do you agree or disagree that the following are challenges or barriers to implementing user or member involvement?



Respondents were then asked how much their organisation would benefit from a range of assistance relating to user involvement. Responses were similar for each of the services. Between just under a quarter (23%) and just under a third (30%) feel that their organisation would benefit a lot from each of the following:

- 'The opportunity to compare our approach to user and/or member involvement with other organisations.'
- 'Training for front-line staff in user involvement principles and techniques.'
- 'More frequent publications and articles in disability and charity press and related journals about user involvement.'
- 'Training for managers in user involvement principles and techniques.'

Figure 7: Which, if any, of the following services would your organisation benefit from?



Respondents were asked to describe other support or services that their organisation would benefit from in terms of implementing user involvement.

Several respondents indicated practical support:

- 'Examples of feedback forms etc. Templates to use for communications. New ideas.'
- 'Ways to show 'added value' of user involvement.'
- 'More funding to do an extensive survey.'

Several respondents mentioned constraints around money and time:

- '£ £ £ - We have the expertise not the money!'
- 'More realistic financial support from local authority.'
- 'The difficulty is finding the time, when the demand for our services is constantly rising. It is one of our founding principles, but it is really tough managing to deliver services under increasing pressure whilst supporting facilitating disabled staff and volunteers.'

Key findings and issues

Evaluating user involvement

- 60% of respondents feel that seeking feedback to monitor and evaluate services is a strength area. Just 11% think this is a weak area for their organisation. Half of respondents feel that the collection of members and/or service users views for use in policy and campaigning is a strength area for their organisation, although nearly 20% see it as a weak area.
- Areas attracting less positive responses were about opportunities for members and/or service users to become involved in evaluation and monitoring as researchers or evaluators and opportunities via paid employment and volunteering.
- 65% agreed that ‘many of our members and/or service users do not want to become involved’. Whilst 62% agreed that their organisation does not have the resources to implement user involvement to the extent that they would like. This raises the question of whether there is a relationship between an organisation’s spend and the keenness, perceived or otherwise, of users to get involved.
- One in three (29%) respondents agreed that some of their users would find it difficult or impossible to take part in the kind of involvement activities that they can currently offer.
- Very few respondents perceive a resistance to user involvement amongst staff (4%).
- A perceived low level of interest in user involvement could reflect problems with current methods of facilitating involvement or preconceptions about what involvement entails.
- The accessibility of involvement activities is likely to be a key issue for future work.

7 Case Studies

Methods

It was decided to focus the resources available on smaller organisations because these make up the majority of RADAR’s membership. Three sites were chosen from those that had responded to the survey and had also expressed a willingness to participate in further research.

We used purposeful sampling based on the following criteria: reported experience of involvement of disabled people already; geographical spread; evaluated themselves as implementing good practice in some areas of involvement (derived from survey); and annual total expenditure of under £1m per annum.

Each of these organisations was contacted by email and telephone to check their willingness to take part. One of the initial selections was not used because it was very small and its service users were located across a rural area and had infrequent contact with the organisation. Each organisation was sent the case study plan that gave clear instructions about what was expected and each was visited once.

During the visits we conducted interviews with a cross-section of members, users, volunteers, trustees and paid staff. The table below gives the number of people interviewed in different categories for each of the sites.

In this report the three organisations have been given fictitious names to preserve anonymity.

Table 7: Analysis of interviewees by role and disability

	WAD (Westborough Association of Disabled People)	NTDIC (Northern Town Disability Centre)	SEAD (South East Association of Disabled People)
Service users/members	5	6	3
Volunteers	3	6	2
Daff	5	1	1
Trustees	1	1	2
Disabled people	7	6	3
Non-disabled people	2	1	1

Note: some interviewees had more than one role, for example they could be both a volunteer and service user.

Case Study 1

WAD – Westborough Association of Disabled People

The organisation

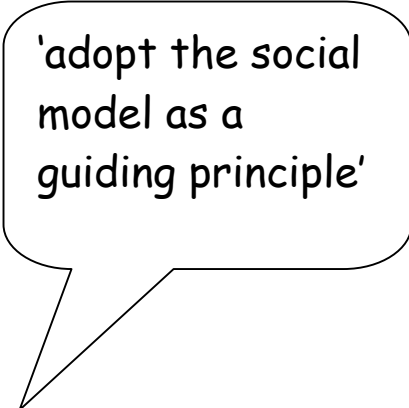
WAD provides a variety of services for disabled people in Westborough. The services include: an information and advice service; an advocacy service; a welfare rights service; a young people's service; a personal assistants' agency; and training and consultancy to other organisations. WAD is also very involved in influencing local and national policies and services aimed at disabled people. There are groups for women, volunteers, parents and young people.

Westborough is an inner city area with a population of 214,000. Within the area 17% of the population are disabled or have a long term health condition.

WAD presents itself as an organisation run by and for disabled people. It operates from offices in a community building which also accommodates other voluntary organisations and a community café.

WAD is a company limited by guarantee and a registered charity. The annual expenditure is just over £600,000. There are 11 office based paid staff, of whom all except one are disabled. The personal assistants' agency has around 45 people registered who provided assistance to 42 disabled service users in 2004-05. There are six volunteers who work in the office, all of whom are disabled. A personal assistant is employed within the office to support the staff and volunteers.

WAD was set up in the mid 1970s by some 'nice ladies' from a nearby suburb. However, some of the members of the organisation were disabled activists and 'took it over'. Although another version of events was that a transfer of power was mutually agreed. Part of the resulting changes were for the organisation to adopt explicitly the social model of disability as the guiding principle for what the organisation should do and how it should be run.



'adopt the social model as a guiding principle'

Why involve disabled people?

'The people with the most direct experience and understanding of need are ourselves' (senior staff member).

The chair of trustees sees WAD very clearly as an organisation 'of' disabled people rather than an organisation 'for' disabled people.

'It's a membership organisation where they are consulted. We get to know what local people want. The board is 100% disabled people so we could make decisions ourselves, but it is good to check with local members'.

'It's a vital thing really – historically we had non-disabled people making decisions about the welfare and needs of disabled people, and some charities still do'.

These statements by the chair and a senior staff member represent a practical interpretation of WAD's mission which is: 'to be a major force for positive change in society's perception of disabled people, to support human rights for disabled people and to be a source of empowerment for disabled people living in Westborough'.

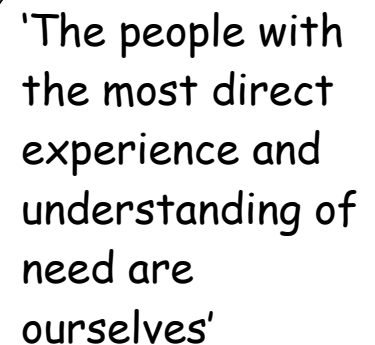
Involvement in services

All services are accessible by telephone, email and on a drop-in basis. These services are delivered by trained staff who are supported by volunteers.

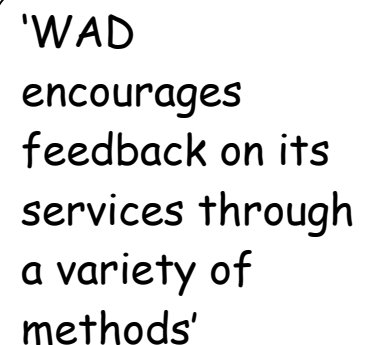
The personal assistants' agency has to maintain certain standards which are regulated by the Commission for Social Care Inspection and include requirements relating to user involvement. WAD has scored highly on 'user focused services' in its two most recent inspections.

WAD encourages feedback on its services through a variety of methods and feedback received is collated into an annual report.

Staff and volunteers feel that they have a good rapport with service users because they are disabled people themselves.



'The people with the most direct experience and understanding of need are ourselves'



'WAD encourages feedback on its services through a variety of methods'

WAD is also able to respond to newly identified needs. WAD staff and members have developed a close working relationship with the local authority's Neighbourhood Services Directorate. This included providing consultation on policy, Equality Impact Assessments and Equality Monitoring Reviews, particularly in relation to housing. As a result of participation in these meetings it emerged that there was a need for disabled people who were experiencing hate crime, harassment or domestic violence, to have representation through an advocacy service. WAD worked with Neighbourhood Services to develop a service to respond to their needs.

The Director of WAD aims to balance getting feedback from service users through informal communication with more formal methods. All service users are invited to be members of WAD. This does not cost individuals anything and is a way of keeping in touch and offering opportunities for involvement.

Involvement in governance and staffing

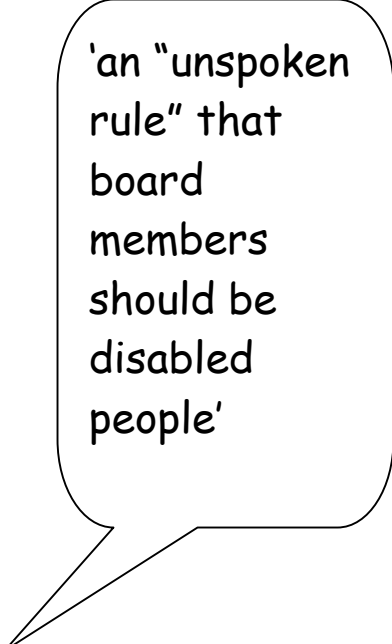
All the members of the board of trustees are disabled people. The chair and director of WAD were uncertain about whether the current constitution stated what percentage of the board of trustees should be disabled people. However, they were both very clear that there was an 'unspoken rule' that the elected members of the board of trustees should be disabled people.

The constitution has provision for co-opted members who could be non-disabled and also the local authority can nominate a member who could be non-disabled people although they have not exercised that right for some time.

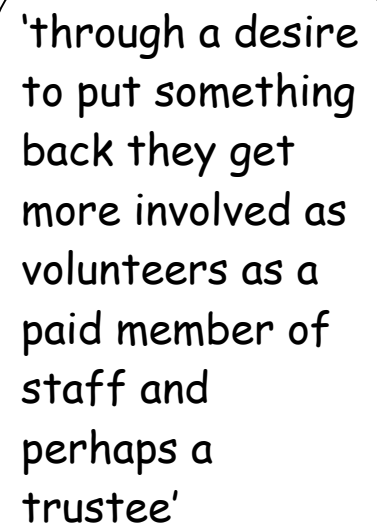
A review of the constitution is underway and will examine these areas to bring the written document in line with practice and expected future needs.

The Director sees involvement of WAD's members as important and also views the whole population of disabled people in the area as part of WAD's wider constituency.

The trustees and staff who are responsible for making strategic decisions consult face to face with members through an annual strategy day.



'an "unspoken rule" that board members should be disabled people'



'through a desire to put something back they get more involved as volunteers as a paid member of staff and perhaps a trustee'

Trustees are recruited from the membership of the organisation. Posts are advertised through services and newsletters. It has proved difficult to recruit younger people and people from black and minority ethnic communities.

Some trustees have expressed concern about finding people who are willing and able to be trustees. So the organisation is exploring how it can broaden its pool of active members who take part in a variety of ways such as attending local authority forums or volunteering.


Some trustees have followed an informal career path within WAD. Starting as service users, through a desire to 'put something back' they get involved as volunteers, as a paid member of staff and perhaps afterwards a trustee.

This pattern of multiple roles and ways of being involved can lead to problems in some instances. The current chair reported that WAD had had difficulties in the past with an office based volunteer who was elected as a trustee. Once elected 'they are perceived differently by staff and other volunteers'.

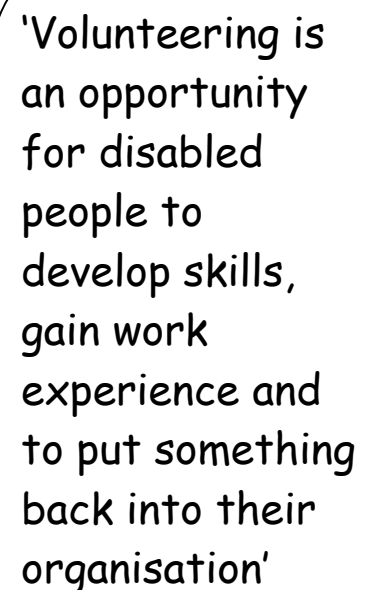
Members who have been services users have a strong relationship with the organisation. The chair believes that many users have a strong desire to put something back because contact with WAD has a big impact. In his case 'it turned my life around - by introducing me to the social model'.

Offering volunteering opportunities for disabled people in WAD has multiple aims. It contributes to the work of the organisation and delivering services. Additionally, it is an opportunity for disabled people to develop skills, gain work experience and to put something back into their organisation. One volunteer said that going to his local day centre was 'totally boring – you just sat around'. At WAD he says he meets 'different sort of people with all sorts of disabilities who are not talking about disability all the time'.

Another volunteer wanted to get out more after she left rehabilitation following an accident. A friend who was supporting her at home became a personal assistant through the WAD agency and so she knew about the organisation as a service user. She experienced months of



'It turned my life around - by introducing me to the social model'



'Volunteering is an opportunity for disabled people to develop skills, gain work experience and to put something back into their organisation'

delay when she approached another organisation looking for volunteer work. She found that WAD dealt with her application professionally and speedily, and is still with them 10 years later.

WAD provides highly flexible arrangements for employees that ensure it attracts and retains high quality disabled staff in most posts. WAD selects candidates on the basis of the best person for the job. Just one out of the total of 11 staff is not disabled.

Involvement in external policy

WAD receives many requests to take part in policy development locally and nationally through consultations, forums, surveys and research.

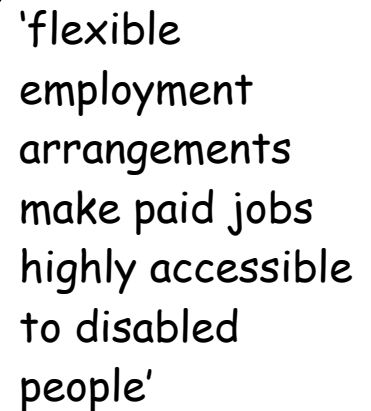
At present WAD receives specific funding from the local authority social services department for the core and the welfare rights service, and from Neighbourhood Services for the advocacy service. However, WAD has no formal agreement to receive funds from other Directorates to participate in consultation and policy making. When WAD receives requests for expert input on access issues they now ask for a minimum fee and travel expenses.

When the request is for more in depth advice or training on disability equality issues or practice then WAD offers a professional service and charges fees and expenses to its clients. This service brought in over £5000 in 2004/05 and over £8000 the year before.


Although the requests for representatives are addressed to WAD the director is keen to point out that disabled people who participate in local forums speak for themselves. She is currently advertising amongst members to increase the pool of willing people because 'it is inappropriate that the same 20 people are asked over and over again'.

The target is to have a pool of 40 to 50 people who are prepared to do things for WAD and externally with other bodies such as the police, health service and the council.

WAD runs focus groups for various organisations to help them find out what disabled people think of their services or plans. WAD's future intention is to request a small charge



'flexible
employment
arrangements
make paid jobs
highly accessible
to disabled
people'

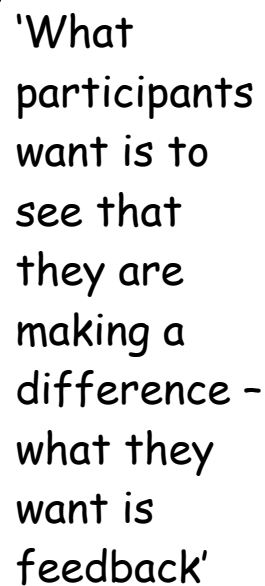


'We ask for
information
in accessible
formats'

for this, so that participants may be provided with refreshments, and a token of thanks for giving up their time. But, the Director points out that:

'People do not do it for the money and the lunch, that is just a thank you; what they want is to see that they are having an effect, making a difference – what they want is feedback'.

The Director believes that WAD succeeds because of the 'gentle nature of its campaigning' and as a result has developed links throughout the council, with hospitals and the police.



'What participants want is to see that they are making a difference - what they want is feedback'

Case Study 2

Northern Town Disability Information Centre

The organisation

NTDIC is an information and advice centre for disabled people in a northern town of 130,000 people. It operates from an accessible shop-front office with training room. There are also three groups for members, these are: men's health, women's and amputee support. A counselling service is provided by three trained counsellors.

A disability awareness training service has been developed and is delivered by disabled people to organisations in all sectors.

There is an Access/Plans group which works with the local authority to review accessibility of proposals. Members take part in social activities, including sport and outdoor pursuits.

NTDIC has 4 paid staff, 1 of whom is disabled. 30 disabled volunteers deliver all of the services. The organisation is a registered charity and company limited by guarantee. The annual expenditure is around £255,000.

NTDIC was set up in 1996 in an inaccessible basement on the edge of the city. It was an initiative of disabled people and organisations such as a county disability group. The city council had an active equal opportunities unit at that time with an officer for disability equality who supported its inception. In 1997 a new manager was appointed who led a process of relocating and developing the organisation.

Why involve disabled people

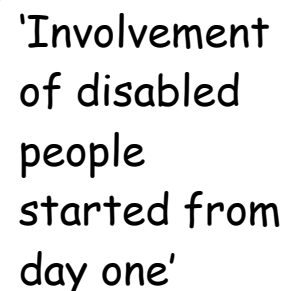
'Involvement of disabled people started from day one'.

NTDIC has always been run by and for disabled people. It was set up on the basis that it should be 'user-led'.

The organisation's services are all aimed at disabled people. As the manager puts it, disabled people are 'our customers'



'All of the services are delivered by 30 disabled volunteers'



'Involvement of disabled people started from day one'

and 'involvement is embedded' in every aspect of the work because 'it makes sense' and 'it makes it easier'.

NTDIC has built a reputation locally as an important resource and a focus for disabled people and other agencies. This reputation is partly based on its unique position as 'the only disability organisation in the city that is run and controlled by disabled people'.

Involvement in services

The core information and advice service is accessible by telephone and on a drop-in basis. The service is delivered by 30 volunteers who are all disabled people. In this way the advice service and the way it is run has the combined objectives of providing information and advice to disabled people about their rights and at the same time providing opportunities to develop skills, confidence and for some to move on to paid work.

NTDIC gather feedback from service users through a monthly customer satisfaction survey of 10% of enquirers. The questionnaire has fifteen questions covering: service delivery; access; communication; outcomes; satisfaction; suggestions for other services; and competence of the volunteer adviser.

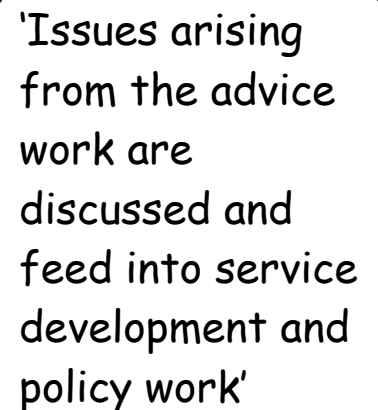
In addition to gathering feedback formally the drop-in acts as an informal gathering place for volunteer advisers, staff and members. Issues arising from the advice work are discussed and feed into service development and policy work.

The three groups for members are by definition about involvement: men's health, women's and amputee support. Two of the groups have waiting lists and all are supported by a part-time groups' coordinator working 30 hours per week. The groups provide support and self-development for members as well as social opportunities.

The groups carried out an evaluation using a questionnaire which was completed by 32 members. It covered: reasons for attending; outcomes; learning; use of other services; access; future plans (individual and group); and gaps in services.



'the service combined advice about rights and opportunities for disabled people to develop skills'



'Issues arising from the advice work are discussed and feed into service development and policy work'

There is a formal complaints procedure which covers all services.

An annual 'Disability and Carers' Festival' is held to engage with the wider community and promote the organisation to potential members and users.

Involvement in governance and staffing

The NTDIC constitution states that 51% of the elected trustees should be 'disabled people'. There is provision to co-opt up to 4 additional members and when the trustees decide to co-opt 'they shall have regard to the need to ensure that disabled people and people with intimate knowledge of disability are adequately represented'.

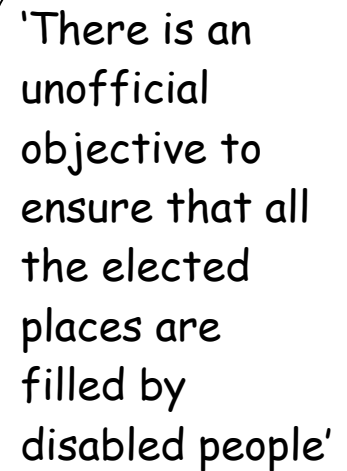
There is an unofficial objective to ensure that all the elected places are filled by disabled people. Recruitment of disabled people to the committee from the membership is done by providing good support. A flyer publicising the role goes to every member and group. There is a policy preventing current volunteers from being trustees. This was introduced because it was found that the dual role of volunteer and committee member did not work well together.

The volunteers are now formally represented on the committee. There is a volunteer representative and a shadow representative who are elected by the volunteers. The representative's role is to act as a channel of communication between the volunteers and the manager and management committee; they ensure that 'everybody gets a voice'. The representative facilitates the six weekly volunteer meeting. Staff are invited to part of a volunteer meeting if the volunteers feel it would be useful.

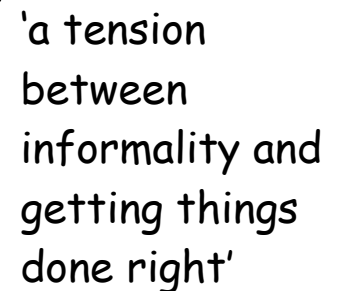
The volunteer meetings cover: housekeeping; problems; disagreements; individual issues; messages to management; and information from management. Sometimes they take a vote on an issue.

To help committee members to focus on the big picture of the whole organisation, an annual training session is held on committee roles and financial management.

The ethos of involvement and control by disabled people is translated into practice within the committee by how it is run.



'There is an unofficial objective to ensure that all the elected places are filled by disabled people'



'a tension between informality and getting things done right'

Information is accessible and strict time limits are kept to. The agenda and papers are gone through in advance of the meeting for some members to aid communication and participation. The manager identified a tension between 'informality and getting things done right'.

Involvement in external policy

NTDIC has staff, volunteers and trustees on a number of key strategic groups in the city. This ensures that the organisation is aware of developments in services and policy and has an input at an early stage.

The manager views the organisation's role as a bridge between disabled people and public sector bodies.

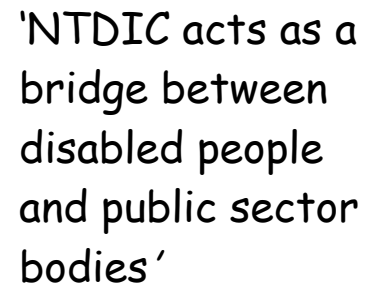
Although the role they play in facilitating consultation is not specifically funded by the city or county council it is seen as important by the membership.

The main mechanism for consultation is for the manager to gather the views of the NTDIC membership and volunteers and to represent those views on various local bodies. The presence of the volunteers in the office for delivery of the advice service provides a cross section of disabled people for the manager to consult on policy issues.

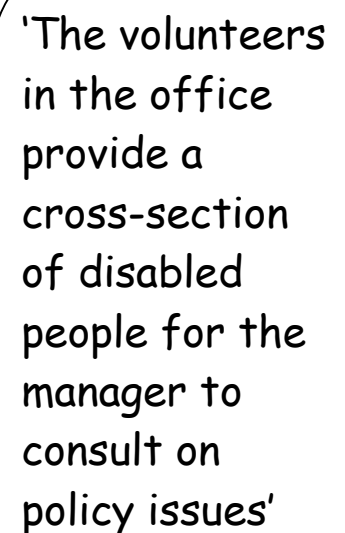
Costs and individual motivation are seen as barriers to disabled people becoming more directly involved in the policy work, for example, through attending meetings.

The NTDIC newsletter is one way that the wider membership can be informed about national and local policy issues and any campaigns.

A senior manager in the local authority has commented that it is useful to have representatives from NTDIC involved in policy work because it is not always the same people who participate and that they are confident that any representative will have asked other people what they think rather than speaking as an individual.



'NTDIC acts as a bridge between disabled people and public sector bodies'



'The volunteers in the office provide a cross-section of disabled people for the manager to consult on policy issues'

Case Study 3

South of England Association for Disabled People

The organisation

SEAD is a network of 11 local groups of disabled people, relatives and carers spread across a rural county of southern England. The county has a population of around 756,000 people.

Its current stated aim of SEAD is to 'promote the rights of disabled people'. Its key aims are:

'the **inclusion** of disabled fully into society to support **independence** so that disabled people have choice and control over their lives and a voice to help them plan and **influence** service provision.'

The current activities consist of: information and advice on disability issues; distribution of funds for equipment, small loans and grants; and social opportunities through the local groups.

Altogether over 850 disabled people are members who all receive the regular newsletter. There are also over 200 associate and 50 group members.

There is a small head office with 2 full-time and 1 part-time members of staff. There are currently 125 volunteers helping to run the local groups and working at the head office. The annual expenditure is approximately £185,000.

SEAD was started in 1943 as a network of local groups, and before 2000 it was known as the 'South of England Association for Cripples', operating on the assumption that disabled people needed charitable help.

In 2003 the chair led a review of the association's purpose and structure as a result of scrutiny of the effectiveness and funding of a number of voluntary organisations by the county council.

The SEAD aims are:

- ◇ inclusion
- ◇ independence
- ◇ influence

'disabled people are becoming more involved in all aspects of its work'

Now, in 2006, it is in a period of transition as disabled people are becoming more involved in all aspects of its work.

The review led to agreement of the new aims under the headings: inclusion, independence and influence. The trustees appointed a new senior member of staff and development worker to modernise the organisation.

Why involve disabled people?

Two members of SEAD who are volunteers and members of the management committee of trustees and directors explained from their point of view why it was important to involve disabled people in the work of the organisation.

- 'only disabled people understand what life is like as a disabled person.'
- 'non-disabled people find it difficult to perceive the ins and outs of disability.'

The director echoed these views with his own that 'first hand experience of disability is twice as powerful as second hand'. A key guiding principle for the structure and operation of the organisation now is relevance. All the efforts to involve disabled people in SEAD's work flow from 'wanting to be relevant to disabled people'.

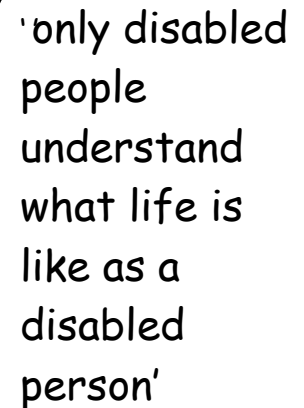
Involvement in services

Disabled people are involved as volunteers in a wide range of tasks from wrapping raffle prizes to legal advice to running local groups, resulting in a continuous process of communication about issues, needs and services.

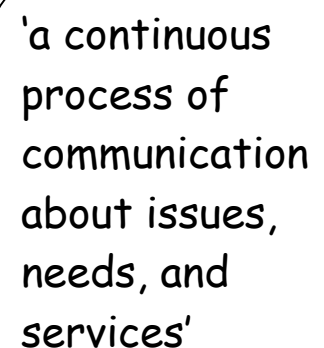
Involvement in governance and staffing

The composition of SEAD's management committee has changed significantly over recent years. Prior to 2003 the management committee was predominantly non-disabled people. In 2005, four out of ten of the trustees were disabled people. In 2006 the elections to the committee resulted in six of the ten places being held by disabled people and, for the first time, a disabled person as chair.

There are no designated places on the committee for disabled people and no formally agreed targets to achieve a



'only disabled people understand what life is like as a disabled person'



'a continuous process of communication about issues, needs, and services'

majority of disabled people. The Director described the organisation's approach to governance as based on the idea that people needed to have relevant skills to contribute whether they were disabled or not. However, he had pursued a strategy of recruiting disabled people as individual members, as volunteers and talking to them about the opportunity to be on the committee. This strategy had resulted in a growing pool of disabled people who were engaged, willing and able to stand as candidates when the time came.

SEAD's approach within the organisation was described by the Director as attempting to bridge any perceived gaps between the 'disabled world' the 'non-disabled world'. The Director views it as a positive feature of their committee that its composition is part of the bridging process.

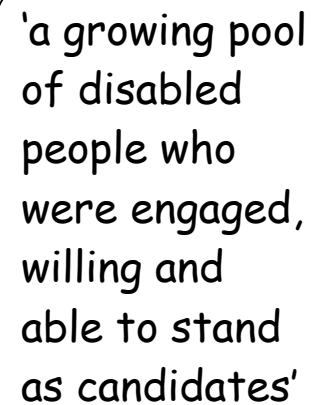
The bridging function of the committee also extends to building relationships with other organisations. One disabled committee member was involved with four other groups as a member, volunteer or trustee.

Local groups

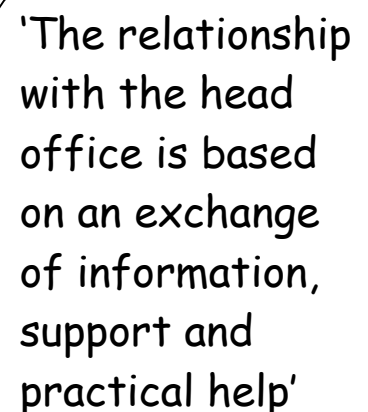
The composition and activities of the local groups vary considerably. Some continue to operate as they have done for many years. This means that they have not been part of the modernisation process initiated in 2003. Other local groups have changed and some new ones have been set up.

A local group member described how his group is run by and for disabled people. The purpose of the group is both to provide social gatherings and to try to educate local businesses and services about access needs. The group has some non-disabled volunteer supporters and runs on strong democratic principles with a small group of four members making plans and then putting these to a vote of all the members.

The relationship with the head office is based on an exchange of information, support and practical help. The Director has a clear strategy of spending time with the local groups to engage with them and to discuss practical implementation of the three new aims of inclusion, independence and influence. He describes this approach as



'a growing pool of disabled people who were engaged, willing and able to stand as candidates'



'The relationship with the head office is based on an exchange of information, support and practical help'

subtly demonstrating the relevance and meaning of the social model of disability.

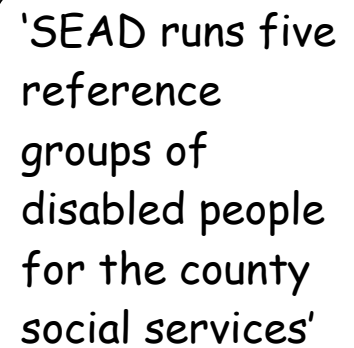
Involvement in external policy

SEAD members are active individually and in their groups in trying to influence service providers to improve access. The volunteers and committee members, through their involvement in SEAD, are more likely to be aware of a variety of access issues which they raise informally and formally with other organisations.

SEAD receives finance from the county council to operate a reference group for each of five social services areas. There are five disabled people in each reference group and they are consulted by email.

The director has regular contact with county councillors and uses this as an opportunity to put forward issues which have arisen in advice sessions.

Some members of SEAD act as representatives on local forums such as the Access Forum for the district and city councils. They have recently been consulted on parking and a new housing development.



'SEAD runs five reference groups of disabled people for the county social services'

8 Discussion

This section discusses the patterns emerging from the three case studies under the headings used to describe the different aspects of involvement in the previous section. ‘Tools for change’ which can be drawn from this analysis are highlighted in shaded boxes within the text.

Why involve disabled people

In all three cases the primary reason for involving disabled people was to ensure that what the organisation did was responsive and relevant to current and potential service users and disabled people more generally.

There was a view that disabled people are the experts on their own situations and that therefore individually and collectively they should be directly influencing decisions about services and policy.

None of the disabled people interviewed stated explicitly that they viewed involvement as a moral right, although it was clear from most responses that they did not see it as negotiable. All the organisations had clear statements about inclusion. Further, they had built reputations for high levels of involvement based on their practice. These two factors, a public statement and practical evidence seem to lead to high expectations about the extent of involvement of disabled people.

Tool for change 1 – Agree your statement of values

Produce and agree a clear, accessible statement about involvement of disabled people in your organisation. The statement should say something about values, principles and practices.

Use the statement in publicity, recruitment of members, volunteers and staff.

Overall there was a strong emphasis on involvement as a practical necessity to make sure messages about services and policies got through to decision makers.

In addition to the importance of the content of the message most of the disabled and non-disabled people in this research identified the importance of disabled people being the messengers as well as the people who decided on the content of the message. The reasons for participants wanting to speak for themselves that emerged included:

- changing attitudes towards disabled people
- control of the process and the message

- self-development
- acting as role models
- concern that non-disabled people would not be able to get the message across.

It appears that in these case studies disabled people wanted to be involved – and the organisations wanted to involve them – both for practical reasons of ensuring that managers and trustees knew about their experiences and needs, and for political reasons to play an active role in decision making processes.

Involvement in services

A significant feature of two of the cases was that disabled people were directly involved in service delivery as advisers, managers, counsellors, advocates, information workers, trainers, consultants and administrators.

This feature was believed to be an important aspect of developing involvement because it demonstrably challenged the view that disabled people need to be helped through charity.

Users, volunteers and paid staff reported that from the first contact new service users would benefit from knowing that they were being supported by someone who would be more likely to understand their experience as a disabled person than someone who was non-disabled.

Some respondents talked about their function as positive role models for other disabled people.

Tool for change 2 – Ensure that disabled people work in front-line roles

Recruit appropriately experienced and qualified disabled people as front-line service delivery volunteers and paid staff.

Recruit disabled people with potential and provide training and support to enable them to be effective front-line staff.

Gathering feedback about services was also facilitated by the fact that service users and members knew that they were talking to people who were disabled and would therefore be more likely to understand and have empathy with their own experience. Disabled volunteers and staff reported that they could quickly establish a rapport with service users.

All three organisations used a mix of formal and informal methods for getting the views of services users. Formal methods included questionnaires, complaint

procedures, forums and examination of advice case records. Informal methods encourages conversations about experience, services, local access issues, legislation, national and local policy and more.

Staff in all three cases had adopted specific strategies of meeting disabled people and engaging with them. The adoption of user feedback methods demonstrates that these organisations did not assume that the presence of disabled people in and around the organisation was sufficient as a means of gathering people's views about services.

Tool for change 3 – Make many ways to feedback

Create a wide variety of ways – formal and informal – of getting feedback from disabled people about services.

Overall a picture emerged of disabled people getting involved in these three organisations through using, delivering, developing and shaping their services.

Involvement in external policy

Two broad approaches were used to attempt to influence the policy and practice of other organisations. The first approach was to engage in formal arrangements such as an email based reference group or choosing a representative to sit on various committees or panels. The second approach was more informal and involved members and volunteers either individually or collectively finding opportunities to challenge discrimination or speak up about civil rights.

For these people, and therefore for these organisations, there was no question about whether they should concentrate on service delivery or policy and campaigning work. The two were seen as inextricably linked. Put another way the personal was political

Tool for change 4 – Link personal with political

Use the experiences of disabled people who use services to raise policy issues with other agencies.

Invite and support disabled people to choose priority issues for campaigns.

This study is likely to have a biased sample of disabled people in that those who would be asked to take part are more likely to be people with an interest in issues of involvement and disability politics. However, this does not detract from

the implications of the finding that to have to choose between service delivery and campaigning would strike at the very identity of these organisations.

All three organisations allocated time and resources to recruiting and supporting a pool of members and users who were willing to participate in external meetings. The staff used publicity, direct requests to individuals and relationship building over the long term with members and groups.

Tool for change 5 – Organise a pool of representatives

Recruit, support and use a diverse number of disabled people to participate in policy and service development work and consultations.

Build up a pool of people so that members and service users can represent themselves and avoid reliance on staff.

In all three cases there were clear expectations from the statutory services that these organisations were in a position to ‘represent’ disabled people. In two cases the organisations were prioritised for consultation and providing representatives because they were perceived as user-led.

Involvement in governance

The critical questions in the governance of any organisation are ‘Who is in control?’ and ‘How can you change who is in control?’ In any field where there are different views about what should be done and how, there will often be competition for control of an organisation and the resources it commands.

In the three cases examined in this study the governance arrangements have been designed in a deliberate way. Firstly, all three have democratic structures with individual disabled people as voting members who elect the governing body. Secondly, through a combination of written rules (the memorandum and articles of association or constitution) and mutual understanding, these organisations aimed to ensure that a high proportion of their elected trustees are disabled people.

Tool for change 6 – Act democratically

Implement decision making processes based on democratic principles. Use democratic ways of working as the primary method in the organisation.

Recruit members and develop relationships with them. Have high expectations that they will contribute, participate and vote.

All three cases had taken specific measures to make their board meetings accessible for example, by choice of venue, keeping meetings to agreed times, and providing accessible information.

Tool for change 7 – Support the board

Provide support for disabled people and others to understand and fulfil their roles as trustees.

Make all meetings and information accessible.

Check and re-check access needs of board and committee members.

In these three cases there was an emphasis on inclusion, informality and creating a supportive environment. This culture contrasts with the working methods and use of ‘the proper channels’ implied by the law and guidance on governance of charities, employment and management systems.

One organisation had adopted a policy of not allowing current service deliverers or office volunteers to be trustees. Another had decided to provide training on trustee roles and responsibilities.

Tool for change 8 – Tackle governance issues

Issues such as the balance of power between senior staff and trustees or people with multiple roles should be tackled head on.

Develop and agree policies or working procedures to ensure clear understanding of what is expected of people.

Ensure that trustees and board members work together to agree policies and procedures.

Involvement as staff and volunteers

All the organisations engaged disabled people as volunteers to support the organisation's work and offered developmental opportunities. Volunteering with these organisations was, for some, also a form of political expression or action. This finding mirrors a study about volunteering and social exclusion which found that 'some disabled people volunteered within specialist disability organisations, as these were more politically proactive about the rights of disabled people, challenging stereotypes rather than reinforcing them.' (Davis, Smith et al undated)

All the organisations had disabled staff. In WAD the concept of being an organisation run 'by and for' disabled people extended to all roles including the paid staff. In NTDIC the manager and volunteers characterised the organisation as 'user-led' which appeared to have resulted in putting more emphasis on involvement of disabled people. At SEAD the trustees had decided to recruit two staff to modernise the organisation and make it more inclusive.

Regardless of the positions within these debates about representation, qualifications for different roles and experiences of discrimination, the impact on disability organisations is real. In these case studies the organisations appeared to have all reached a kind of equilibrium. There was sufficient agreement between stakeholders for the organisations to function effectively. This did not mean that everyone agreed all the time. It seemed that the collective commitment to their objectives outweighed any individual or factional desires to change anything significant about their activities, ethos or structure.

The leadership – a combination of trustees and senior staff – appeared to play a significant role in maintaining this equilibrium. Leaders also ensured that involvement was always on their own and the organisation's agenda.

Tool for change 9 – Design leadership

Recruit and induct people to leadership roles with specific remits to develop and implement involvement of disabled people.

Key leadership roles include the senior members of staff and trustees, especially the chair.

Apply the statement about the organisation's vision of what involvement is about (see 'Tool for change 1).

Changes in ownership and control

NTDIC was set up by a mix of disabled and non-disabled people and so had involvement of disabled people from its inception in 1996. However, it was restricted to a small scale telephone service from an out of town inaccessible office. Subsequently, it relocated to an accessible city centre shop-front premises, diversified and grew.

WAD was set up by non-disabled people and was 'taken over' by a group of disabled people after some years of operation. The group that took over had a clear vision that organisations like WAD should use the social model of disability as their guiding principle and that they should be an organisation 'of' disabled people.

SEAD started as a network of groups set up by non-disabled philanthropists. The chair became aware that financial support from statutory agencies would be threatened if the organisation did not modernise and increase involvement of disabled people. As a result a new manager was appointed in 2003, and SEAD is currently in a period of transition moving towards being more user-led.

The three important themes of these organisational histories are: transformation, leadership and vision.

All three organisations have undergone changes from low levels of involvement of disabled people to high levels of involvement.

Three factors emerge as influencing this change. Firstly, there is evidence of a vision which includes a model or guiding principle such as the social model, independent living or user-led. Even if the detail is not necessarily clear as in the case of user-led, the broad message is. Secondly, there appears to have been a leader or a small group that has decided on the future direction and then influenced others to rally around and support it. Thirdly, there was a pragmatic factor that affected the organisation's situation such as the move to new premises or the requirements of a funding body.

Tool for change 10 – Use principles to guide practice

Choose a set of principles or a model to act as guidance for all the organisation's activities.

For example, the social model of disability can guide an organisation to implement practices that enable disabled people to empower themselves.

9 Lessons and conclusion

This research has attempted to explore the different dimensions of involvement of disabled people in these three disability organisations. The focus was on smaller disability organisations and the situation may be very different in medium to large organisations with dispersed structures.

The main question the research attempted to address was: what can be done to increase the involvement of disabled people in disability organisations? The term involvement is used here to mean more than a simple presence in an activity or meeting but the opportunity to contribute and have influence.

This research suggests that involvement of disabled people in a wide variety of ways has been achieved by combining:

- **Principles**
- **People in key positions**
- **Practice**

The tools for change highlighted in the above section have been derived directly from the experience of disabled people. The tools also reflect the findings of other research and guidance on user involvement and participation (e.g. Robson, Begum and Locke 2003). It is not suggested that these tools represent a universal comprehensive list of actions that will lead to guaranteed high levels of involvement of disabled people. However, this analysis of these three organisations indicates that the application of these methods in combination has enabled them to involve disabled people in line with their goals.

All three organisations had developed involvement of disabled people in a variety of ways and at different levels in their organisations. There was also a sense in which these organisations did not perceive any barriers to disabled people fulfilling the functions required to meet their goals.

The development of involvement was more than a pragmatic measure to ensure a service met needs or to satisfy a funder's monitoring requirements. From our investigation of the practices of involvement in these organisations it was clear that there were strongly held principles which lay behind them.

This welding together of principles and practice is a feature that distinguished these organisations from some others which exhibit a gap between stated principles and what happens in practice. For example, Drake (1993) found that disability organisations in Wales tended to support appointment of disabled people to influential positions but were much less likely to have done so. One strand of the debate on user involvement relates to 'rhetoric or reality' and uses terms such as 'genuine involvement' as opposed to 'tokenism'.

The principles on which these organisations based their work included:

- the social model of disability
- democracy
- inclusion
- diversity and equality
- self-determination
- self-definition
- respect for other people.

In conclusion, the evidence presented here gives a tentative answer to the question as to whether there is a ‘tipping point’ beyond which an organisation could be described as user-led or controlled by disabled people or an organisation ‘of’ as opposed to ‘for’ disabled people.

Whilst it is possible to identify higher and lower levels of involvement of disabled people, the multi-dimensional nature of organisations means that levels of involvement may vary from one activity or service or process to another. Additionally, these may vary over time.

The primary feature which emerged from these cases was that they combined principles, people in key positions and practices in most areas of their work. They were also putting continuous effort and resources into maintaining and developing involvement – so for them being user-led or an organisation ‘of’ disabled people was not a static state.

It is also significant that at different points in their histories all three organisations had undergone a transition which had resulted in a more central role for disabled people. So, rather than focusing solely on definitions of organisations based on static characteristics it may be more helpful to identify key moves or changes.

Whether these junctures are thought of as ‘tipping points’ or ‘turning points’ it is important to recognise that they will be different for different organisations and situations. Additionally, an individual organisation is likely to be developing involvement on a number of fronts at any one time and so may reach a turning point in one area and not another. On the other hand, with hindsight, critical changes can often be identified.

A lesson that all organisations could draw from this research is to view themselves as on a number of developmental paths at the same time, relating to the different aspects of their work and structure. This would place the focus on the process of change, as it clearly would have to be. After all, change is the business that drives all of these organisations forward.

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