



# **Tipping Point User Involvement Project**

## **Executive Summary**

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# Executive summary

## Introduction

Tipping Point investigated the involvement of disabled people in the decision-making of disability organisations. The project aims to promote involvement of disabled people in disability organisations through sharing experience and good practice.

This report summarises the findings of the Tipping Point research. The research was completed in two distinct phases: first, a survey of disability organisations by questionnaire and, second, three case studies of small disability organisations.

The first part of the summary presents the findings of the survey. The survey found a wide variety of practices and methods for involving disabled people. It also found that organisations were at different stages of development and took different approaches to involvement.

The second part of the summary presents the findings from the case studies. The case studies revealed that high levels of involvement could be achieved by combining **principles, people in key positions and practices**. The cases are also used to derive ten suggested 'Tools for change'.

RADAR commissioned research which was undertaken by researchers at the Centre for Institutional Studies at the University of East London. The researchers set up a Disabled People's Panel to advise on the research and the context of involvement of disabled people.

## Survey findings

48 organisations responded to the detailed survey sent to RADAR members and additional organisations identified by the Disabled People's Panel.

### Governance

Membership of governing bodies was key to successful user involvement in disability organisations with nearly six out of ten (57%) trustees who were service users. Nearly two-thirds (60%) of organisations had constitutions which ensured that there were disabled people on their governing bodies. A quarter had formal targets and a third had informal targets.

The results suggested a distinct difference between organisations with significant participation of disabled people at board level and those with none.

Seven in ten organisations had individual membership options. The largest sub-section of members for most organisations was current service users followed by past service users and disabled people who do not receive services from the organisation.

### **Staff**

One fifth of all the paid staff and volunteers in the organisations that responded to the survey were disabled (15% were disabled and 5% were service users or past service users). The proportions in individual organisations varied greatly.

Over four in ten (43%) organisations had workforces where more than half of staff were disabled including one in ten (11%) where all employees were disabled.

Organisations described a wide range of ways in which they encourage and facilitate the employment of disabled people.

### **Methods of user involvement**

Organisations used a range of methods to gather the views of disabled service users. The most widely used method was questionnaires (81%) followed by meetings and discussions (67%), groups and forums (54%). Organisations also mentioned the use of newsletters, the internet and informal communication and feedback mechanisms.

Just over half (56%) of the organisations in the study stated that they had staff with specific responsibility for user involvement as part of, or all of, their job. One in five organisations (19%) had a budget for user involvement.

Whilst some organisations identified specific staff and budgets for user involvement, many more organisations were undertaking activities to gather the views of service users. This finding suggests that in these organisations involvement work was integrated into their general workload.

### **Developing involvement**

Around one quarter of the organisations in this survey indicated that they felt it would 'help them a lot' to have contact with other organisations to share information and have access to training and advice on involving disabled people. A further half of the respondents said it would 'help them a little' to have more support of this kind.

The survey respondents completed a self-evaluation to indicate strengths and weaknesses regarding involvement. Six out of ten (60%) of organisations reported 'seeking feedback to monitor and evaluate services' as a 'strength area'.

Half of respondents felt that ‘the collection of members and/or service users’ views for use in policy and campaigning’ and ‘systematically informing service users about significant changes that occur in their organisation’ were strength areas.

Areas which attracted less positive responses were ‘opportunities for members/service users to become involved in evaluation and monitoring as researchers or evaluators’ and ‘opportunities for involvement via paid employment and volunteering’.

Barriers to involvement were identified. Two-thirds (65%) of respondents agreed that ‘many of our service users and/or members do not want to become involved’. And, nearly one-third (29%) of respondents agreed that some of their users would find it difficult to or impossible to take part in the kind of involvement activities that they can currently offer.

Very few respondents perceived a resistance to user involvement amongst staff (4%).

### **Organisational factors**

There were no strong associations between organisational factors such as size, age and whether it was a membership organisation and the levels of user involvement within the staff and board. Although the samples available for these comparisons were small, they suggest that there were other factors that affect the degree of user involvement. The case studies were used to identify the practices that have enabled organisations to involve disabled people effectively.

### **Case study findings**

Three disability organisations, each with an annual expenditure of under £1m, a variety of activities, in a town or county, and relatively high levels of involvement were chosen for the case studies. The objective was to learn about the process of involvement from the disabled people participating in these organisations.

The main question the case studies aimed to answer 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.

These cases suggest that involvement of disabled people in a wide variety of ways has been achieved by combining:

- **Principles**
- **People in key positions**
- **Practices**

The 'Tools for change' below have been derived directly from the experience of disabled people in the three cases. The analysis of these three organisations indicated that the application of these methods in combination had 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. These organisations did not perceive any barriers to disabled people fulfilling most of the functions required to meet their goals. Although it was the practices which made involvement a reality, all three organisations were guided by overarching principles or models.

### **Principles**

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.

On the basis of these principles, the research developed a proposal of 'Tools for change'. The 'Tools for change' aim to help organisations to get disabled people into key positions and implement practices which enable involvement.

### **People in key positions**

Recruiting disabled people as volunteers, especially working as the point of contact with the organisation, was seen in two of the organisations as an important method of involvement.

All organisations had disabled staff although the proportions varied considerably. In one case all staff were disabled. In the other two cases smaller proportions of the staff were disabled. In these case studies the organisations had recruited people in leadership roles who had the experience, understanding and skills to implement involvement of disabled people at all levels of the organisation.

All three organisations promoted membership for disabled people and viewed members as an important group who could benefit from and contribute to the work.

### Practices

The 'Tools for Change' summarise the practices which the case study organisations used to implement 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.

#### **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.

#### **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.

**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.

**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.

**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.

**Tool for change 7 – Support the board**

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

Make all meetings and information accessible.

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

**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 made clear.

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

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

**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').

**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.

### **Conclusion**

These three organisations put continuous effort and resources into maintaining and developing involvement – so for them being an organisation that involves disabled people is not a static state.

It was 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.

Whether these junctures are thought of as ‘tipping points’ or ‘turning points’, it is important to recognise that they were different kinds of transition for different organisations and situations, and for other organisations are likely to be different in other ways. 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.

One 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.

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### **More information**

For more information about the Tipping Point Project contact: RADAR

For more information about the research or to get advice and training about user involvement contact: Paul Robson, Centre for Institutional Studies, School of Social Sciences, Media and Cultural Studies, University of East London, email: [p.robson@uel.ac.uk](mailto:p.robson@uel.ac.uk), tel: 020 8223 4263.