



Involvement for Real Equality

The benefits for public services of involving disabled people

Report for the Disability Rights Commission

September 2007

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to improve social results

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1. Introduction

This report describes the benefits gained and lessons learned through involving disabled people in the development and implementation of disability equality schemes (DESS) in a range of public organisations. It suggests that while involving disabled people may present challenges for some authorities, if it is properly resourced and meaningfully conducted, it can result in significant benefits for all those concerned.

The public organisations surveyed comprised local government, higher and further education institutions, health and housing authorities. In each case we interviewed a senior manager, an equalities lead and someone from a disabled people's organisation to find out what they had learned from the process of preparing and implementing a DES. The report does not suggest that the participating public organisations represent best practice in all aspects of disability equality but our 'appreciative inquiry' approach highlights the benefits of effective involvement. Through this, we aim to share examples of effective practice so that all public bodies can learn from and use the techniques and approaches to deliver results that make a real difference to communities.

This report builds on research OPM conducted in phase one of the 'Capturing the Value' study that showed that as a result of the DED, involvement of disabled people in some government departments' work had taken place earlier in the policy process. A key aim of the second phase of this research has been to establish if or how this has happened in other public organisations and, if it has, what benefits it has brought. OPM's other work for the Disability Rights Commission (DRC) has been evaluating its impact and creating a toolkit for local authorities about developing their DESSs.

2. Summary

OPM (Office for Public Management) interviewed a range of senior managers, equalities officers and disabled people's organisations (DPOs) across a number of public organisations to gauge the benefits, both for organisations and individuals, of involving disabled people in developing and implementing their disability equality schemes (DESs). Analysis of the interviews shows that through involving disabled people, organisations were able to:

- improve their performance
- design and deliver better public services
- change organisational culture to promote disability equality
- become better employers
- strengthen involvement processes and outcomes and improve trust in public services.

The following section of the report provides a summary of these findings.

Improving organisations' performance

Organisations reported that involving disabled people in the development and implementation of the DES helped them to improve their performance in relation not only to disability issues but also to broader objectives.

Efficiency gains were made through more appropriate service design during the planning stages. This was achieved through listening to the expertise and experience of disabled people thus avoiding, for instance, costly changes to services or buildings at a later stage.

Organisations reported that they had moved, or were about to move, towards reaching broader targets, such as increasing learner diversity or decreasing deprivation and improving health outcomes, as a result of involvement. One higher education institution reported making changes to the text of the entry system on the basis of

recommendations made by disabled students who were involved in developing the DES, which had the added benefit of helping other minority groups:

‘Another example [of changes that helped reach wider targets] are entry systems – older people and international students were having difficulty read[ing] the writing.’

(Senior Disability Officer, Higher Education Institute)

Many respondents felt that the process of involvement was more meaningful than regular consultation, and helped to restore trust in public services. By engaging in discussions that were often led by the grassroots, or organisations that are user-led, disabled people influenced the agenda for change, rather than only being consulted at the end.

‘Involvement is not a one-off thing. You need to give it time, to go back 2 or 3 times...’

(Surya Shaffi, Disability Advisor, Liverpool PCT)

Listening to disabled people also helped to build sustainable services; services that better meet the needs of users and are therefore likely to be more effective in the longer-term.

Making public services better

Public services have improved in a number of ways through involvement: the information used by organisations who have involved disabled people in developing their DES is more sophisticated as it is grounded in real-life experiences, thus helping organisations to make the best decisions about the services they provide.

Involvement has also aided transparency; the continuous organisational commitment required has encouraged organisations to track suggestions made and the resultant changes in action plans, proving to users that their opinions are used constructively.

Involvement has helped services become more customer focused, recognising the diversity of communities, including training of service providers to take disability issues into account.

‘Through the Disability Equality Scheme we’ve got the accessible approved provider list ... in all our courses and all our providers signed up to that. It wasn’t something we were doing before.’

(Paul Rouhan, Learning and Development Manager, London Borough of Tower Hamlets)

Changing organisational culture

Organisations described how involvement has improved understanding and commitment to disability equality in their workplace. Comments made in focus groups on disability issues were sometimes shared throughout organisations, helping to deepen understanding and win the ‘hearts and minds’ of staff. Using ‘real’ comments helped foster an atmosphere of openness and greater commitment to the social model of disability amongst staff.

The commitment of senior management was acknowledged as vital for involvement. Senior leadership helped to embed the importance of diversity and disability issues within an organisation, and also provided opportunities for having disability issues considered at higher levels, for example, by the governing bodies of public organisations.

‘The fact that [the Chief Executive] was there showed commitment, that it was not just lip service.’

(Surya Shaffi, Disability Advisor, Liverpool PCT)

Becoming better employers

Organisations have found that changes made as a result of involvement have helped them to harness the full potential of their employees by recruiting and retaining disabled staff more easily.

Through tangibly involving disabled people from the community and voluntary organisations in the process, staff with undeclared

disabilities have begun to feel more confident about disclosing these and contributed more fully to the process of designing and delivering an effective DES.

Changes made as a result of the DES, such as introducing personal development plans and specific training courses, have helped disabled staff to widen their career opportunities, and simultaneously improve the skills of the workforce. One local authority senior manager reported that by providing opportunities for disabled staff to improve their career prospects, his workforce 'would be more effective as a team'.

(Paul Rouhan, Learning and Development Manager, Tower Hamlets Local Authority)

Stronger involvement and building public trust

Involvement is becoming more central to decision-making across authorities. Some organisations are adopting new structures and processes for permanently involving disabled people, such as task working groups.

Interviewees identified working with disabled people's organisations as an important method of strengthening involvement, as these are networked with a far larger number of disabled people.

'[The DPO] ensure[d] that the involvement of disabled residents reflected the ethnicity of the borough and the particular issues that were relevant ... to disabled people with different ethnicity, particularly the large Bangladeshi and Somali population who's experience of disability is very different compared to the white population.'

(Equality Officer, Local Authority)

Through the process of public organisations demonstrating that they want to listen to, learn from and feed back to disabled service users, some organisations have witnessed the beginning of a powerful

process where users willingly contribute to co-creating solutions to service challenges. By passing on the 'good word' within communities, these individuals have contributed to a greater understanding and trust in the authority.

3. The context for involvement

‘Persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.’

– UN Convention on the Rights of Persons with Disabilities, December 2006

The involvement of disabled people in promoting disability issues is an increasing priority, both in the UK and internationally. The UN Convention on the Rights of Persons with Disabilities, which makes specific reference to involvement, has been being ratified worldwide since December 2006. In the same month, the UK Minister for Disabled People, Anne McGuire, launched Equality 2025, the network of disabled people that communicates directly with government on disability issues.

The move towards greater involvement also comes as part of a cultural shift in public service provision. It is increasingly the case that the involvement of key stakeholders and users is a prerequisite to decision-making. Increased involvement of disabled people in decision-making and discussions will help public organisations to develop a deeper understanding of the diversity of their users and of the issues affecting disabled people, and ensure that they develop appropriate long-term solutions.

Involvement continues to be a crucial issue in 2007, with Education Minister Lord Adonis and Economic Secretary Ed Balls publishing the report *Aiming High for Disabled Children*, which allocated £5 million for involving the parents of disabled children in shaping services at a local level, including parent forums to ensure that disabled children and their families are supported and empowered. The Office for Disability Issues study, *Equality for Disabled People: how will we know we are making progress?*, also looks at involving disabled people in deciding what equality should look like and how progress should be measured.

The Disability Equality Duty (DED) came into force on 4 December 2006. It is a legal requirement on public organisations that aims to promote disability equality across the public sector. It helps public organisations change their services and policies to make sure that they take full account of the people covered by the Disability Discrimination Act – currently one in five of the UK population. The DED sets out what public organisations must have due regard to in order to promote equality of opportunity. All public organisations covered by the specific duties must:

- publish a Disability Equality Scheme (including within it an action plan)
- involve disabled people in producing the scheme and action plan
- demonstrate they have taken the actions in the scheme and achieved appropriate outcomes
- report on progress
- review and revise the scheme.

As with Aiming High for Disabled Children and Equality for Disabled People: how will we know we are making progress?, the emphasis on involvement in the DED requires a more active engagement with disabled people than mere consultation.

4. What we found out

This part of the report details the main findings from the research that we conducted across a range of public organisations, including local authorities, primary care trusts and higher education institutions, when interviewing senior managers, equalities officers and DPOs that were involved in the development of a DES. Analysis of the interviews shows that through involving disabled people, organisations were able to:

- improve their performance
- design and deliver better public services
- change organisational culture to promote disability equality
- become better employers
- strengthen involvement processes and outcomes.

Making public services better

The majority of interviewees reported that as a consequence of involving disabled people in their authorities' schemes they were able to design and deliver better public services. A number of interviewees expected to see the effect of this in the coming months and years with higher levels of satisfaction and fewer complaints.

'It's [involvement] going to add all sorts of value, in terms of levels of satisfaction ... in the end we will have better policies and better services.'

(Teresa Evans, Equality Officer, Barking and Dagenham Local Authority)

Interviewees thought that services would improve because of the detailed and sophisticated information they received from disabled people on existing barriers to services and thoughts for future improvements. These could then be incorporated into the

organisation's action plan to ensure that future strategy and direction was grounded in real-life issues and experiences.

'People who came forward to shape the action plan talked from their experience about really practical things.'

(Doreen De Bellotte, Director of Human Resources, Ravensbourne College of Design and Communication)

Many interviewees talked about the quality of information being superior as they were not second-guessing what the issues might be.

'The information we get is robust and focused so we know what has gone into our DES because the experts have told us.'

(Heather Wills, Head of Community Services, Libraries and Heritage, Barking and Dagenham Local Authority)

This meant that sometimes authorities were surprised by the priority areas highlighted by disabled people. For example, in one local government authority community safety was raised as a major concern, not only at night time but in the daytime, which was a completely new finding. Disabled people were involved in deciding where the authority should focus its attention and what the most pressing areas for change were.

'At the beginning, before we had an agenda, disabled people were involved in setting the priorities. We thought we knew what the gaps and barriers were but they said other things.'

(Surya Shaffi, Disability Advisor, Liverpool PCT)

Authorities used a variety of ways to identify priorities for disabled people. One health authority set up a reference network of people with specialist interests to try and build a joint approach. The network met three times during the development of the DES and sifted through the data the authority had collected from their surveys and workshops to

determine the priorities to take forward. Reference network members could also receive training on facilitation skills and were paid for their work.

The action plan

As part of a DES, public organisations are required to publish an action plan which details the activities different parts of the organisation are committed to undertake to achieve certain objectives. The actions in the plan should be distilled from the views and opinions expressed by disabled people involved in creating the DES. One DPO and local authority reported that cross-referencing what disabled people had told them with the actions that were included in the plan helped build trust in involvement. Trust was built by showing disabled people how their involvement had led to actions being included and prioritised in the authority's plans. For example, lack of staff understanding and training on disability came up as a major priority from disabled people and this is now prioritised in the action plan. This prioritisation demonstrates how user involvement has influenced the authority's future direction and it is clear to both the disabled people involved and external stakeholders why certain areas of work have been planned. Across authorities the action plan was recognised as providing transparency to the process of involvement. Through it, organisations were able to demonstrate how involving disabled people had influenced the organisation's policies and future strategy.

'The action plan was based on the outcomes of the research with disabled students. It focused mainly on the accessibility of teaching and teaching and learning resources.'

(Sharon Hocking, Student Welfare Officer, Ravensbourne College of Design and Communication)

‘I think so many times with user-involvement people go away and they never come back and say, “actually what you told us meant that and that is why we did this”.’

(Karen West-Whyllie, Chief Officer, Barking and Dagenham Centre for Independent Living)

Improvements in services

Evidence of improvements in services was clear across the full range of public organisations we consulted. The principal areas of improvement are outlined below.

Personalisation of services

Public organisations were able to hear first hand from disabled service users what their ideas and recommendations for future improvements were. As a result, a number of interviewees suggested that this process had helped their organisation to become more customer focused. This often involved going beyond compliance with the law and looking at responsive personalised services which meet the needs of all customers.

‘If you have customers, your whole objective as a housing provider is to ensure that everyone has an equal access to the service and that you deliver services appropriate to need.’

(David Carrigan, Diversity Manager, Housing Corporation)

Designing more responsive services to meet the needs of all service users often involved staff training or the training of other service providers. For example, there was an ongoing issue in one local authority with taxis not accepting dogs, including guide dogs. As a result of involving disabled people and understanding that this was a widespread issue, the council is organising disability equality training for local taxi drivers. Some authorities also reported a better understanding and focus on hidden impairments. This was prompted by findings from research with students at a higher education

institution (HEI) and achieved through more staff training on mental health issues and stress.

Some authorities had worked in partnership between local government and health to develop a joint scheme. This had helped them equally to benefit from involving disabled people, capitalising on the information and advice they could provide. Further, some people we spoke to felt there was better communication between the organisations as a result and they thrived from the outside scrutiny and pressure that the partnership brought.

Changes to service design

There are examples from a number of authorities that services had been redesigned to make them more accessible and effective as a result of the views of disabled people. For example, one HEI reviewed its educational programmes to ensure they met the needs of their students so they could engage to their highest potential. In one creative educational institution much emphasis is given to group work and presentations and for some disabled students, for example with those with Aspergers, this can be particularly challenging. Once this issue was highlighted in discussions with disabled students as part of their involvement work, students were given more support and preparation for these types of situations. This finding was made as a direct result of one-to-one involvement discussions, where people with Aspergers felt comfortable discussing this issue. This finding has also affected the admission procedure with group interviews no longer mandatory but offered as a choice.

Impact assessments

Through the direct involvement of disabled service users there have been improvements to impact assessments across a number of the public organisations we spoke to. Moreover, some interviewees felt there was now more 'buy in' across organisations regarding the purpose behind the assessments and the need to do them.

‘Having the input from disabled people gets people [staff] thinking more about what impact their policy may have and really mainstream them into our work. The process of going through the DES has increased staff understanding so they can conduct an impact assessment from a better place of understanding.’

(Heather Wills, Head of Community Services, Libraries and Heritage, Barking and Dagenham Local Authority)

In one HEI, respondents to a survey sent out by the university raised concerns about the quality of their interview experience and questioned whether they had been discriminated against as a result of their disability. As a result, the admissions policy was immediately assessed and significant changes have been made. The interview process has been changed with the aim of separating academic decision-making from the need for support requirements and the interview focuses solely on academic ability.

More outcome focused

Involving disabled people in the development of the DES has also helped organisations become more focused on outcomes. This was often because disabled people wanted to see concrete examples of how their participation was aiding change.

‘We communicated what the scheme was and where it had come from, how it related to the corporation’s business and saying that we ought to focus more on outcomes than producing a huge massive scheme that looked wonderful but actually didn’t have a great impact.’

(David Carrigan, Diversity Manager, Housing Corporation)

One authority said that it was clear that outcomes also needed to be ‘long term’

(Surya Shaffi, Disability Advisor, Liverpool PCT).

Improved access to services

Through the involvement of disabled people, the public organisations we interviewed had been able to improve access to their services in a number of ways, including:

- more accessible information
- more available information
- improved physical access
- improved staff and partner training.

While much of this work had already been started following the Disability Discrimination Act 1995, work on the DES often enhanced improvements to access. For example, disabled people highlighted access to information across all sectors as a barrier. As a result of their involvement in authorities' DESs, a number of changes were made including making their information available in audio format, Braille and large print. Some service users pointed to a lack of available information in some authorities. As a result, one HEI improved its information about support provided to disabled students before coming to university. In addition, there is a specific talk about disability at open days and the open-day invitation now includes questions about visitors' additional needs.

Public organisations drew on disabled people's expertise and experience to improve physical access to buildings and services. For example, a group of disabled students at one university was asked to investigate what parts of the campus were accessible and what did not. This data is now going to be incorporated into the design of one of the new university buildings.

Improvements cannot only be seen in the actual services that public organisations provide, but also through their work with other sectors and agencies. For example, one local authority found out that local disabled people were keen to be involved in, and benefit from, investment in the local area through local employers and businesses. As a result, the council has engaged with the local business forum and organised opportunities for disabled people to speak to employers and

demonstrate their positive experiences of being employed. This has helped to raise awareness of disability equality with local employers and challenge negative perceptions.

Improving organisations' performance

A number of interviewees reported that through the involvement of disabled people there had been improvements in organisational performance. This was reflected in: an enhanced ability to meet organisational objectives such as inclusive services; an ability to build trust in public services; efficiency gains; and building sustainable services and communities.

Meeting strategic objectives

A number of the senior managers we spoke to felt that their disability equality work and involving disabled people had helped their organisation to meet its wider organisational objectives. Examples of this included a university that had a key objective of widening participation and learner diversity. The university served a relatively locally deprived community with higher than average numbers of disabled people. Its work on involving disabled people and promoting disability equality was expected to help it achieve this strategic objective by making it easier for disabled people to study there. Furthermore, an interviewee within a health authority stated that achieving disability equality would reduce deprivation and therefore in the long run improve health outcomes for the local area – thus meeting one of the authority's key objectives.

‘With the emphasis now on a patient-led NHS, providers are now making services more inclusive – there is a business case for equality.’

(Martin Wilson, Senior Manager, North East Strategic Health Authority)

It seems clear there is a stronger business case for equality in the climate of service-user led public services.

Efficiency gains

We found clear examples of how public organisations have been able to make efficiency gains through drawing on the knowledge and expertise of disabled people. One local authority thought it was improving accessibility by making more pavements with a dropped curb. However, the council had not involved disabled people in deciding where the adjustments should be made, which was mainly on busy road junctions with no middle island to cross to. As a result the road and pavement was no more accessible for wheelchair users than before and did not meet their needs. Since this incident, the council has become more aware that it is inefficiently spending public money if it does not involve service users at an early stage. Another local authority uses an ‘expert by experience’ panel to looking at future designs of public buildings. This follows a situation where a hospital unit was built in an inaccessible style and cost over £70,000 to put right. As one equalities officer stated, ‘the builders are realising that if you make buildings more accessible it will make it better for everyone and it will cost you money if you get the design wrong.’

(Senior Disability Officer, Higher Education Institute)

The case for equality can effectively be made a performance issue and this can lead to more commitment from staff and senior managers. It can also help ‘second-tier’ authorities such as strategic health authorities (SHAs) to apply pressure to ‘first-tier’ organisations such as primary care trusts (PCTs).

‘We are doing better than other authorities where equality isn’t seen as a performance issue.’

(Martin Wilson, Senior Manager, North East Strategic Health Authority)

Second-tier organisations can influence service providers to manage their resources more efficiently and promote equality of access for disabled people. For example, the Housing Corporation reported ensuring service providers' allocation policies are making the best use of resources when it comes to disabled service users.

'It's about how well you manage your assets, and that comes into the efficiency agenda as well.'

(David Carrigan, Diversity Manager, Housing Corporation)

Building trust in public services

Involvement as opposed to consultation was seen as building trust in local services. The process and outcomes of involvement were seen by many as more significant and meaningful than consultation which tends to restrict input from service users towards the end of the decision-making process. Further, involvement was seen as being a more grass-roots movement, being led and developed by disabled people themselves rather than the public organisations. This process happened both with service users and, as was the case with Liverpool PCT, the organisation's own staff through the Disabled Staff Network:

'If it had been token consultation it would not have been credible. It would have been top-down but this was more bottom up.'

(Joyce Carter, Consultant in Public Health Medicine, Liverpool PCT)

Authorities often built fruitful partnerships with local DPOs. These organisations often acted as conduits between disabled people and public organisations and facilitated the involvement of a wider number and range of disabled people.

'The project has shown that joint working between statutory organisations and user-led organisations can be valuable in building bridges.'

(Susie Balterton, Policy and Training Director, Vision Sense)

As well as the partnerships that public organisations developed with DPOs, the different opportunities to directly influence the future strategies of public organisations were seen as having a positive effect. As a result of forums such as public meetings and focus groups many interviewees felt there were improved relationships between disabled people and their organisation.

Sustainability

A number of the people we interviewed felt that by listening to and acting on the priorities and advice of disabled people they were able to create better and more sustainable services. As a result of being advised on what policy areas should be prioritised or how services could be redesigned, interviewees felt that services meet the needs of all service users better and as a consequence, services are more sustainable.

‘This is probably the first time where we have involved disabled people saying “Right, these are the priorities for this Scheme, this is what you need to do.” This is very different to what the council usually does and it’s something that has benefited the organisation because we can hold our head up and say, yes we involved disabled residents and staff and as a result these are the main objectives that they told us are the most important areas of their lives that need to be addressed.’

(Equality Officer, Local Authority)

Changing organisational culture

A number of people we spoke to as part of this research reported that the involvement of disabled people in their DES had acted as a catalyst and led to an improved understanding and commitment to disability equality across their organisation.

Credibility

The extensive involvement of disabled people gave many authorities' schemes a credibility they would not have had otherwise. This meant they stood up to scrutiny from staff and service users and promoted commitment to the plans within them.

'The methodology used has made our DES very credible. It genuinely involved disabled people and was led by them. This means that it will stand up to senior managers who might otherwise dismiss it.'

(Martin Wilson, Senior Manager, North East Strategic Health Authority)

The fact that disabled people were actively involved in shaping the content and priorities of authorities' DESs was seen by many as central to 'winning the hearts and minds' of all staff to further disability equality within their organisations. For example, following one focus group with disabled people on the council's one-stop shop, a quote from a disabled service user on the attitude of council staff was used in a presentation to the Corporate Equalities Team. The head of service responded by asking if they could share the quote with their staff team to make them more aware of how their attitudes could either be a support or barrier to disabled people accessing services. Hearing the voices of disabled service users has given staff in some of the authorities we spoke to the opportunity to develop a better understanding of the issues relating to disability equality. Further, involvement of disabled people helped equalities officers and leaders to make the case more effectively within their own institutions.

'If you are a disability practitioner, you are pretty much a lone one. If you have got the voice of students and staff behind you, you have a much more powerful message. It is not just me; it is me and 100 others. It is numbers and proof.'

(Sharon Hocking, Student Welfare Officer, Ravensbourne College of Design and Communication)

Equalities officers and senior managers reported that being able to present key findings from research and use real comments made by service users helped to get the message across very powerfully. An enhanced staff understanding is reflected in a greater commitment to the social model of disability, which some interviewees reported. A number of the equalities officers we interviewed felt there was more of an openness and commitment to solving issues within their organisations to create an environment which works better towards disability equality.

‘There is a real understanding of the need to adopt the social model [of disability] and how disabled people have been excluded so there is a real commitment ... it’s about ongoing involvement with groups and communities.’

(Teresa Evans, Equality Officer, Barking and Dagenham Local Authority)

There is also evidence of commitment in other changes such as the higher take up of e-learning training courses on disability equality amongst staff in one of the local government authorities.

The role of senior leadership

The change in organisational culture which some authorities reported is reflected in the senior leadership demonstrated on disability equality. This is an iterative process with senior leadership also helping to build organisational commitment to disability equality.

‘Our Chief Executive attended the open-day event. The fact he was there showed commitment, that it wasn’t just lip service.’

(Surya Shaffi, Disability Advisor, Liverpool PCT)

‘The senior leaders were the main reason it worked otherwise I don’t think we would have had the same impact. If you don’t have

senior people on board then there are always other priorities that will get more attention.'

(Senior Disability Officer, Higher Education Institute)

Senior leadership and commitment to involving disabled people is also reflected through strengthened structures to enable this. For instance, there were multiple examples of disability equality forums and working groups feeding into the governing board of authorities. Interviewees were also keen to emphasise the importance of embedding action plans into other organisational progress and monitoring mechanisms so that senior managers and heads of service are prompted to consider disability equality in planning and monitoring of public services. This was supported by improvements in monitoring disability which is now automatically incorporated into many of the authorities' reporting processes. This data is then considered at key meetings, supporting the mainstreaming of disability equality into the college's planning processes.

Becoming better employers

All of the authorities consulted had made clear arrangements for involving their disabled staff members in the development of the DES. Disabled staff were able to offer a unique insight into how their organisation could become a better employer for disabled people as well as providing better services. Changes and improvements that have been put in place since discussions with disabled staff began have meant that organisations are increasingly harnessing the full potential that their staff group can offer. One local authority worked with disabled staff to produce personal development plans and a specifically designed development course for disabled staff. This had the simultaneous effect of increasing the skills of the organisation's workforce whilst improving career opportunities for disabled staff. This was considered to be much more effective as it really focused on the

areas that were important to disabled staff and met their specific development needs.

‘It meant it was a better course because [disabled] people were involved in it. ... I can set up a course but is it meeting the need of the constituents? If you’re setting up a course to support people, then they should have a say in that.’

(Paul Rouhan, Learning and Development Manager, Tower Hamlets Local Authority)

Feedback from participants that attended the personal development course showed that assertiveness skills of disabled staff within that authority have gone up and some have started looking at managerial roles.

Other changes that authorities had made included funding a recruitment advice line where potential and current employees can speak to trained professionals to find out what specific policies or support they have in place to support disabled staff members, or to get advice about disability related issues at work. With the service, the university is hoping to attract more applications for vacancies.

‘If [disabled people] want to ring to find out if we are disability friendly, they may not want to come through to HR. They may prefer to go through to a third party.’

(Doreen De Bellotte, Director of Human Resources, Ravensbourne College of Design and Communication)

Work within this organisation also included working with disabled staff to develop a disability policy. In addition, a policy and procedure specifically for staff with dyslexia has been developed in conjunction with disabled staff.

It is anticipated that these changes within authorities, based on what disabled staff have prioritised, will help the organisations to become better employers. As a consequence they will be able to recruit,

employ and retain more disabled staff. In addition, when employed, it is expected that disabled staff will now be able to work to their full potential through the removal of barriers and ensuring conditions are in place to support them.

Stronger involvement

There was clear evidence across a range of public organisations we spoke to that work on their DES has led to improved involvement processes and outcomes. This is significant within a policy which emphasises the value of service user involvement and how this can improve public services and sustain local communities. Improved involvement within organisations was demonstrated in a number of areas.

More strategic engagement

There is some evidence that involvement now happens at an earlier stage with the result that it is more meaningful and has a greater impact. For instance, a parks and open spaces project in one local authority has involved disabled people making recommendations for change from the beginning of the project rather than at a specific stage. Involvement is also happening at higher levels of the organisation such as within strategic groups and at the business planning stage.

‘They’re closing the gap between policy and practice. I see a lot more involvement happening at the business planning stage; it’s much more integrated.’

(Susie Balterton, Policy and Training Director, Vision Sense)

As part of more strategic involvement, work on the DES has led to some authorities setting up new structures and processes for involving disabled people that will continue as a permanent fixture in the organisation’s work.

‘The major change [since the DED] is that we now have a standing group of people available for consultation to give their opinions, to assist with monitoring.’

(Senior Manager, Higher Education Institute)

Permanent new structures such as disabled working groups and forums support the mainstreaming of disability equality into the everyday work of organisations. Most people we spoke to stress the need for involvement to be ongoing and that progress was an ever evolving journey that organisations and disabled people needed to make together: ‘Rome wasn’t built in a day.’

(Sue William, President, South Downs Association of Disabled People)

Developing organisations’ skills

Some interviewees stated that the experience of involving disabled people in developing their DES had built up the staff’s confidence and ability to involve disabled people effectively. A number of interviewees reported that their organisations’ skills in involving disabled people in service design and delivery had improved and could now be applied to other situations which required input from service users. Some interviewees regarded as useful the fact that involvement of disabled people is enshrined as a statutory requirement within the Disability Equality Duty as it empowered their work on disability equality.

‘It makes it slightly easier to implement ... the fact that it is a statutory obligation as well gives us some leverage.’

(David Carrigan, Diversity Manager, Housing Corporation)

Authorities recognised the need to offer a range of involvement methods to engage with and help different groups of disabled people to get involved. One health authority offered ‘safe space workshops’ to groups whose voices are traditionally harder to hear. This includes: disabled children and young people, disabled travellers, mental health

users, learning disabled people, deaf people and staff, and HIV positive men and women.

‘The safe space workshops were probably the most important part of the project as they helped us to find out about the experiences of people in these groups that we probably wouldn’t have heard otherwise.’

(Matthew James, Former Equality Officer, North East Strategic Health Authority)

These workshops included identifying discrimination and barriers to services currently facing disabled people. For example, some HIV positive patients reported being told that they would need to wait until the end of the day to be operated on so as not to contaminate other patients.

Informal processes such as small group discussions or one-to-one interviews supported the involvement of traditionally ‘hard-to-hear’ groups.

‘It was nice to have the opportunity to sit down with individuals. I was particularly interested in what they thought needed to be done.’

(Doreen De Bellotte, Director of Human Resources, Ravensbourne College of Design and Communication)

Many people we spoke with were keen to emphasise the value of face-to-face engagement with disabled people and felt that first-hand accounts were much more useful and powerful than third-hand reports.

In addition to the methods of involvement discussed above, more conventional methods such as focus groups and open-day events were used to hear a wide range of views. By offering local disabled people a choice of how to get involved, authorities ensured there were options open which would meet the individual preferences and needs of the widest range of disabled people possible. Authorities developed a range of written materials to publicise and support the different ways

for disabled people to get involved. For example, written materials were often produced in a variety of languages and formats including large font and Braille.

‘If additional support was needed, we did it.’

(Surya Shaffi, Disability Advisor, Liverpool PCT)

Disabled people themselves suggested what kinds of supporting materials were needed. Without these recommendations such a variety of formats would not have been used and consequently involvement would have been limited.

As well as developing organisations’ skills, involvement can also build the capacity of disabled people who take part. For example, in one health authority two of the DES Reference Network members are now in full-time employment as a result of the new skills and experiences they developed while being involved with the authority’s network.

Ensuring inclusiveness

Public organisations and DPOs frequently took an active approach to involving disabled people, highlighting the importance of getting out to where people lived, worked and socialised to hear their views.

‘Making sure that we went out to people’s places [was important]. It’s important to be open and flexible, to go out to projects where people are at.’

(Stephen Hodgkins, Disability Information Training Opportunities, Tower Hamlets)

There was a sense that it was not solely sufficient to expect disabled people to come along to events but that engagement really needed to be taken out to where people lived and worked.

Further, particular emphasis was placed by many of the authorities on involving people who do not consider themselves to be disabled but

nonetheless now fall within the new Disability Discrimination Act (DDA) definition, such as those who are HIV positive and people with cancer. Organisations found that using publicity to increase awareness of who comes under the definition of disabled encouraged wider participation. In this respect, publicity needed to include images of disabled people that extended beyond the traditional images of wheelchair users. In one authority, disabled people suggested using images of a variety of disabled people involved in community activities in publications and other publicity material.

A number of the public organisations across health, education, housing and local government had partnerships with local DPOs to involve local disabled people.

‘We have got lots of contacts with lots of different groups and we’re not just about mental health issues or physical disability or learning disabilities, we have got a range of people and we were able to make contact with a bigger range of groups ... so I think allowing the disability group to lead on that is quite an important thing.’

(Stephen Hodgkins, Disability Information Training Opportunities,
Tower Hamlets)

‘As a user-led organisation, involving users and consulting disabled people is what we do all the time, so it becomes second nature to us.’

(Karen West-Whyllie, Chief Officer, Barking and Dagenham Centre
for Independent Living)

These DPOs were often seen as sources of expertise as well as having extensive networks and contacts with local groups and individuals. As a consequence of partnership with these organisations, organisations were able to engage with a much wider and larger number of disabled people.

How organisations overcame challenges to involvement

The overwhelming majority of authorities and DPOs involved in this research were incredibly positive about their involvement in both the process and early outcomes of their work to develop their DES. However, developing an ambitious DES to bring about real change can be challenging. There are a number of common challenges that interviewees reported and some suggestions of how to overcome these are detailed in the following section.

Poor data on disabled staff

When it came to talking with and ascertaining the views of disabled staff, many authorities found that they held poor data on who considered themselves disabled in their own organisations. There was a concern amongst some disabled staff members that their job may be at risk if they disclosed an impairment or they would be treated differently by colleagues. Other staff did not consider themselves to be disabled. As a response, some organisations communicated with the whole staff group to 'capture' people who may not consider themselves disabled or feel comfortable disclosing information relating to a disability. Authorities also tried to build trust and encourage disclosure, for example, through the staff survey. When asking the question, 'Do you consider yourself to be disabled?' this may include a note that the definition of disability has been extended under legislation to include conditions such as MS, cancer, and HIV/AIDS.

Gaps in communities

Despite being pro-active and trying to engage with a wide range of disabled people, some organisations found it difficult to involve certain groups. A number of interviewees reported that hard-to-reach groups included:

- BME groups
- children and young disabled people

- those with a ‘hidden’ disability such as mental health condition
- newly classified disabled people such as those with cancer or HIV positive.

To ensure the involvement of the widest possible range of disabled people, organisations stressed the need to offer different methods such as surveys, focus groups, individual interviews and public events. It was also thought essential to leave a realistic amount of time and resources to make involvement meaningful.

‘[The DPO] offers different ways of disabled residents getting involved and not just through ... workshops but also one-to-one sessions, when a disabled resident felt very uncomfortable being part of a workshop.’

(Equality Officer, Local Authority)

Consultation fatigue

Disabled people were more willing to get involved in the development of the DES because it is seen as distinct from other types of consultation. Involvement meant an active and often continuous process in which the purpose of the process and its outcomes are clear. It was important to make the distinction to participants between involvement and consultation.

‘We wanted to make sure people knew what involvement was, that it wasn’t consultation . . . people could have a say in what was being prioritised.’

(Surya Shaffi, Disability Advisor, Liverpool PCT)

One authority found it vital to be clear about the outcomes of involvement so people knew what they could expect from their invested time and energy.

‘People only get consultation fatigue when they're not told why their views are important or the extent to which improvements will be delivered as a result. Disabled People who are respected

and truly valued by authorities - which include adequate resources - are usually happy to participate when they can contribute, influence decisions and have their experiences fed into real outcomes for all.'

(Susie Balterton, Policy and Training Director, Vision Sense)

Some of the organisations we spoke with had involved disabled people in partnership with other local public organisations. This reduced the involvement overload many DPOs were experiencing when the DESs were being drawn up. Stressing that involvement was not a one-off but an ongoing process of improvement was also felt to be helpful.

The need to build trust

An overriding view from research participants was the pre-requisite to build trust with disabled people and DPOs.

'It's not like there is this magic group of disabled people who will just be there and give you all the answers ... it has got a lot to do with relationships between groups and relationships between people in the council and the community sector and people.'

(Stephen Hodgkins, Disability Information Training Opportunities,
Tower Hamlets)

Trust needed to be built up before and during the work on the DES and will need to be maintained during the schemes' implementation and monitoring. Trust can be built by making expectations for participation clear and explicit with stakeholders. It can also be developed during involvement processes, for example, one health authority brought in advocacy support and counsellors to workshops as many participants would be talking about painful past experiences for the first time.

'We felt it was part of our responsibility to take real care of people. So that's telling people why we're asking these questions, what's

going to happen to the information and reminding them that it's confidential.'

(Martin Wilson, Senior Manager, North East Strategic Health Authority)

Trust between public organisations and disabled people can be built on by making it clear how the person's involvement is valued, respected and has an impact.

5. Conclusions

The organisations we interviewed reported a number of areas in which the involvement of disabled people in developing and implementing the DES has had very positive consequences. Importantly, involvement helped to create better public services, helping organisations to become more customer focused, particularly in terms of recognising the diversity of the communities they engage with.

Significantly, organisations commented that their overall performance had improved as a consequence of involving disabled people. They were making efficiency gains by harnessing the expertise of disabled people to help with more appropriate service design and they were reaching wider objectives in areas such as improving health outcomes and increasing learner diversity. The distinction between the value of involvement as opposed to consultation is clear. The active commitment involvement requires means that disabled people are involved throughout a process rather than just at the end, thus going some way to restoring trust in public services.

In addition to external effects, the involvement of both disabled staff and service users often corresponded with a change in organisational culture. Organisations described involving disabled people as improving the understanding of and commitment to disability issues in the workplace. Sharing 'real life' experiences of disabled people in some cases helped to win the 'hearts and minds' of staff to commit to disability equality. Involvement of disabled staff also encouraged employers to utilise the full potential of all their employees.

Through the process of demonstrating that they want to hear, learn from and engage with disabled service users, some public organisations have witnessed the beginning of a powerful process where users willingly contribute to co-creating solutions to service challenges. This has resulted in an increased level of trust between those engaged in these processes and the organisations involved.

Lastly, the findings from this research suggest that involving service users and communities, as opposed to consulting them, is a powerful

way to co-create more effective public services and to build strong relationships between public organisations and the communities they serve.

6. Appendix 1 – How we did the research

The research process

The research, undertaken over a period of two months, took the form of a small-scale qualitative study based on the experiences of 10 selected public organisations. We held 28 in-depth semi-structured interviews with the following three informants from each body: the Equalities Officer who led the development of the Disability Equality Scheme, a senior manager with a responsibility under the DES action plan and a representative of a DPO involved in developing and monitoring the organisation's DES. This approach was taken in order to give a 360-degree view of the different perspectives on how the involvement of disabled people has influenced the authorities' policies and services.

Eleven out of 28 interviews took place face to face with the remaining 17 conducted over the telephone. The face-to-face interviews, excepting one where notes were made during the interview, were tape recorded and transcribed and telephone interviews were simultaneously transcribed. All interview notes were then coded and sorted into an analytical framework allowing the research team to determine key themes and report on the findings.

Public organisations included in study

Interviews with equalities officers, senior managers and DPOs were conducted with the following public organisations:

- Tower Hamlets Borough Council
- Barking and Dagenham Borough Council
- Rotherham Metropolitan Borough Council (Joint DES with Rotherham PCT and Rotherham NHS Foundation Trust)
- University of Wales, Newport

- Ravensbourne College of Design and Communication
- The University of Oxford
- North East Strategic Health Authority
- Liverpool PCT
- Hampshire PCT

In addition, we interviewed the Equality Officer from the Housing Corporation.

The 10 public organisations were selected to cover a range of public sector types (local authorities, higher and further education Institutions, housing and health authorities) and an inclusive geographical spread across England and Wales. The primary consideration for inclusion was the ability to offer examples of good practice in terms of involving disabled people, the positive impact and methods of involvement. In some cases authorities were included to give insight into the difficulties faced by a particular type of authority, and therefore furthering understanding of the progress made due to the introduction of the Disability Equality Duty.

Where permission has been expressly given, quotes have been attributed to interviewees.