

Making connections

Making connections

Developing inclusive leisure in policy and practice

Pippa Murray



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Joseph Rowntree Foundation
The Homestead
40 Water End
York YO30 6WP
Website: www.jrf.org.uk

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1 About this report

Background

The Leisure Project funded by the Joseph Rowntree Foundation (JRF), *Hello! Are You Listening?* (Murray, 2002), showed a wide gap between the inclusive language of government and other official bodies, as found in various policy documents and in recent legislation; and young disabled people's daily experience of exclusion in every area of leisure activity. The project on which this report is based took that gap as a starting point and aimed to engage with young disabled people, bringing them (with families, friends and allies in the voluntary and statutory sectors) into dialogue with those responsible for leisure provision. Building lines of communication between the users and providers of leisure is more than just a basic prerequisite to the planning and delivery of services that young disabled people can actually access. It is also an important act of inclusion in its own right.

Project methods varied with the wishes and priorities of participants, and with the local situation as regards leisure provision. The report does not, therefore, present any one method for getting young disabled people and service providers talking to one another, but shows the desire to enter into dialogue, when sincere, as opening up a range of possibility. Instant and sweeping change at the point of provision is not likely to ensue: rather, the creation of a fertile space wherein professionals can listen to and reflect alongside young disabled people. In this way, the views of the latter – that their being valued is essential to development of services that truly reflect their entitlements and aspirations – can be met with inclusive action here and now.

The four main groups

In order to include the widest possible demographic mix, the project worked with individuals as well as groups of young disabled people across a variety of settings in both the statutory and voluntary sectors. The backbone of the project, however, consisted of four main groups: Ipswich, Sheffield, Swansea and Dudley.

Ipswich (Out and About)

A well-established voluntary organisation, Out and About, provides a wide range of leisure opportunities for disabled children and young people. Though based in Ipswich, its contacts go deep into the surrounding Suffolk countryside, to give a representative mix of both urban and rural communities. In recent years, Out and About staff have based their work on the social model of disability (discussed in Chapter 3) and, in addition to providing leisure activities at weekends and during school holidays, are keen to take up opportunities that enable young disabled people to express their opinions and tell of their experiences.

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Although the young people in the Ipswich strand had a common point of reference in Out and About, they did not all know one another.

Sheffield

Here, a small group of young people, brought together through use of a respite care service, combined with individuals from various voluntary support groups to engage in a consultation on the facilities offered at a leisure centre, which seeks to become more welcoming of disabled people. The group includes some whose impairments are complex enough for them to be seen as the most difficult to include in consultation.

Swansea (Interplay)

Interplay is another well-established voluntary group, providing a range of leisure activities and holiday schemes for young people with a wide range of impairments. Though an organisation for disabled young people only, its connections with voluntary agencies catering for disabled and non-disabled make it well placed to develop and explore themes of inclusion.

Young people attending Interplay have recently had opportunities to be involved in a range of consultation initiatives with, for example, the Welsh Assembly.

Dudley

The group here had no existence prior to the current project. Because of this, and because the events leading to its formation illuminate many issues at the heart of inclusion, the next chapter is entirely given over to the experience at Dudley.

Basic procedures

For the most part, this section comprises a factual description of the way I worked. Where Chapter 2 gives a detailed account of how the strand at Dudley developed, this is an outline sketch of the methods common to all strands.

Making contact

For each of the project's four major strands, the initial contact with young disabled people was through local organisations. In Swansea and Ipswich, these were voluntary organisations already known to me from previous work; in Dudley, the

connection was through a worker in the voluntary sector; while statutory sector contacts, also from previous work, were my first port of call in Sheffield.

Once I had identified a main contact within the local organisation and made an initial overture, I would set up a meeting to explore common ground and discuss ways in which the research project might support that organisation's needs and interests. In this way, all parties gained: the project through establishing, far more rapidly than could otherwise have happened, real contact with young disabled people in four distinct geographic locations; the local organisations through being able to fine-tune things to suit their own concerns. But most important were the benefits to the participants. The involvement of a host already known to them gave these vulnerable young people a safe 'anchor point', able to mitigate any damage caused by a short-term consultation raising sensitive issues only to disappear 'into the sunset'.

Though these means provided the greater part of the project base, additional contacts were made by networking widely, especially at the beginning: attending conferences to publicise what I was doing, inviting people to make contact, putting out calls for stories from young disabled people, accepting invitations to meet them, welcoming the involvement of friends of participants. Opportunism also played a part, as did outcomes, which, though beneficial, could not have been predicted. For example, following my delivery of a training session on consulting young disabled people, a group of youth workers put on a consultative workshop for young disabled people they worked with. Some of the messages to come out of this workshop were fed into the research project – see the contributions from Kim and Liam in Chapter 4.

Consent

Letters were sent out to young disabled people and their parents, letting them know about the project and inviting them to a specific event – a talk, an interview, workshop or day of action planning. Where a local organisation was involved, these invitations went out under its letterhead.

The invitations also contained a consent form whose return was an essential precondition of participation. But, because of the consequences of some impairments, I could not rely on written consent as conclusive proof that a participant understood every implication of involvement. At the event, I would watch for signs of discomfort or withdrawal and, where these were in evidence, try to involve them in the process – see the story of Rebecca in Chapter 5. Had her disengagement and seeming discomfort continued, I would have had to conclude she did not want to be involved in the project.

Levels of participation

Participation was 'à la carte' – many young people chose to be involved with one or other, but not all, aspects of the project. Some came to exploratory workshops, others to consultation events. Still others did their own thing in an area that interested them: Nathan was a case in point. On hearing of the interest many participants had in shopping – an interest he shared – this young man devised a questionnaire for shop owners and managers in his local shopping centre. Similarly, a group of young disabled people, having collectively established transport as a major source of frustration, took it on themselves to conduct an audit of its provision in their home town of Swansea.

Support

Prior to any event, young disabled people and/or their parents were asked to tell us of any support needs. These were provided on the day either by paying for the participant's support worker to be present, or by supplying an experienced alternative.

At other times, what was needed was not a support worker but a communication system that would allow the individual to engage. The parents of one young woman we wished to interview alerted us to the need to prepare cards if we were to have a chance of finding out what she liked. This we did with great success, the young woman choosing between smiling and sad faces when shown a photograph of a place or activity. Establishing a means of communication allowed her to relax totally and we had a delightful morning together. There is little doubt that the painstakingly careful preparation of the cards allowed for a richly rewarding interview and paved the way for the further involvement of this young woman.

On those occasions where we failed to produce a communication system that would allow an individual's participation, our fallback position was simply to give him or her a good time. We did this by finding out favourite leisure activities – swimming, shopping, eating out, or whatever – and then providing opportunities for these, while observing and noting what their experience appeared to be. Having such a fallback meant nobody, however severe their impairment, was excluded.

Running the events

One-to-one interviews had no preordained structure but the aim was always the same: to find out as much as I could about the individual's experience of leisure – their likes, dislikes, hopes and frustrations. Whatever worked.

Workshops typically had around 20 participants, action-planning days far more, so these events could not be approached in such an ad hoc manner. Although flexibility was called for even here (more on this in Chapter 6), there was a basic formula, as follows.

- *Welcome* : arrivals, drinks, introductions – in most cases, the participants did not come as ready-made groups. Rather, they were collections of individuals known to the local organisation but not, prior to the event, to one another. Support workers, where we had been asked to supply them, would at this point be introduced to the person they were to look after. (To my surprise, several young people were willing to be supported by strangers, even where the care needed was intimate.)
- *Warm-ups* : typically ‘ice-breaker’ activities. One that ran particularly well involved asking participants, prior to the event and regardless of age or role, to bring an item that said something about themselves. These were collected from each person on arrival and put into a cloth bag from which, when the time came, they would be fished out one by one. The owners (or persons speaking on their behalf) would identify themselves and, if they chose, say what the item meant to them. As well as taking care of introductions in a simple and effective manner, the very ordinariness of most items (photographs, teenage magazines, CDs) served to unite the group and underline the fact, explored in Chapter 4, that the participants are first and foremost young people.
- *Exploration* : through interactive games, artwork, drama, puppets, photographs, computer and other means – working sometimes as a whole group, at other times dividing into subgroups – the participants explored the key questions of this project. What do you like to do? How often, and with whom? What gets in the way?
- *Lunch* : an opportunity for everyone to chat and build relationships, since most of the young people had not known one another prior to the consultation.
- *Exploration* : games, artwork, drama, etc. would again be used, this time to explore the question – who do you want to tell about your experience?
- *Closing session* : presentation of artifacts created, enabling clarification and summary of underlying issues; ‘what we enjoyed about today’; thanks and goodbyes.

Feedback

At the close of any event, I would feed back to the young people in the form of a summary of what had taken place. Most often this took the form of a closing session in which the group as a whole pulled together the most salient points. Typically, these summaries would be displayed as they were being written, using a flip chart or whiteboard.

Besides this instant feedback, I wanted something in the more permanent form of written summaries. These I had intended to produce as wordprocessed mixes of text and photos to be distributed to participants. But, when a photographer and graphic designer volunteered to take pictures of the events, and produce professional-looking newsletters, I took up his offer right away. The results were highly beneficial in a number of important ways.

- They admirably fulfilled their original purpose as documentation, a form of illustrated minutes: ‘this is what you said on the day’; ‘these are the issues you raised’; ‘this is what I have tried to do in the report’.
- They were well received by the participants, who clearly took great pleasure in seeing themselves and their messages in print.
- They were of a high visual standard, using combinations of image, text and colour in ways calculated to appeal to young people as well as communicating with users who do not read. As such, they gave positive affirmation of the high value I attached to those people and to the process of consultation.
- For the same reason, the leaflets played a part in mitigating the potential danger of those consulted feeling abandoned after the consultations had ended. This benefit should not be overstated – far more important in this respect was the involvement of local organisations that had been working with the participants before this project, and will continue to do so now it is over. But I felt it important to leave participants with a marker and was glad to have been able to give them such a polished record of their involvement.
- Last but not least, the leaflets provided a statement, of how young disabled people felt and what they wanted to happen, which could be sent to service providers and other stakeholders.

An example of these leaflets is given in the Appendix to this report.

2 Dudley

In the spring of 2002, with this project no more than a proposal, I first heard of a Mencap coordinated project focusing on disabled young people's access to mainstream leisure. Based in Dudley, the Me Too! project appeared to have a very positive thrust, as well as coinciding with my own research interests. The potential for partnership seemed worth pursuing and a call to Mencap's head office led me to Me Too! coordinator, Michelle Cox. Over a series of telephone conversations, Michelle's responses were consistently encouraging as we began to speak in earnest of a possible merging of effort and resource. Though funding for this project had yet to be approved, I thought it worthwhile to pay a personal visit. It was to be the first of many in a working relationship of great benefit to both projects.

In autumn, the Joseph Rowntree Foundation gave the go-ahead for the Leisure Project. By this time, Michelle and I had agreed on the Youth Service as an obvious starting point for building a relationship between young disabled people and service providers. We already knew from the Me Too! project that this agency was keen to offer an 'inclusive service', with one club in particular said to be well attended by disabled young people. Based on this, our initial strategy seemed reasonable: we would go to the club, identify its 'critical success factors' – that is, isolate whatever feature, policy and staffing variables appeared to promote inclusion – and take these into not only other youth clubs but also related areas of provision, such as leisure centres and social services. Our preliminary model, then, envisaged first establishing and then spreading 'best practice'.

Michelle's contacts and local knowledge were invaluable from the start and she soon arranged for us to visit the youth club we had heard such good things about. All seemed well as we arrived on a busy evening but, when we spoke to the coordinator, it emerged that disabled young people had used the club only in the summer holidays, through a scheme arranged by social services to bring them in from a school outside the local catchment area. It had been a difficult experience, with co-coordinator and staff welcoming their presence but lacking the skills to facilitate their inclusion. Inevitably, the result had been two distinct groups having little to do with one another and, once the summer scheme had ended, the disabled young people never returned.

This was a setback but there was one encouraging aspect. The coordinator, disappointed by what had happened and genuinely interested in finding a way forward, still wanted to make the club 'inclusive'. He was at a loss as to how this might happen but, clear that our 'best-practice' model would now have to be revised, we were able to go away in the knowledge that someone in the youth club was committed to change. We agreed on a new approach: to make contact with the young disabled people who had used the club the previous summer and ask if we

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might talk with them in their homes, at school, or wherever else they chose to meet with us. Our aim was to gather information on what would be needed for them to enjoy visiting the club.

Again, though, our plans were not to be. With letters to these young people drafted and ready to go out, we heard the sad news that the youth club coordinator, taken ill suddenly, had died. He had been the leading light at the youth club, the one person with the drive to move things forward and, even if there had been strong interest from other staff, now would not be the time to proceed. The club was in shock and we could hardly burst in at such a time with new ideas. But neither could we afford to wait. We appeared to be back at square one, looking for a new direction.

Our next move was a 'two-pronged' approach. Using the Disability Register, we wrote to young people and their families in the area, telling them we were looking at access to mainstream leisure and would be interested to hear their experiences. We also approached the Dudley-based Orchard Parent Partnership who, knowing Michelle and having read my previous publications, invited us to give a presentation at their forthcoming meeting. This we did, to a reception sufficiently encouraging for us to put out a call for any young disabled people and/or families willing to get involved.

The responses to these initiatives gave us some 20 families, all indicating they would be happy to be interviewed. At last we felt we had begun. On dark November evenings, memorable for the frequency with which we managed to get utterly lost, we made our way round the streets and lanes of Dudley – talking with young disabled people and their families, finding out what they liked doing, what they wanted to do but could not, and what help they would need to overcome the obstacles. Predictably, leisure being a huge subject, we received such an overwhelming array of answers we really didn't know how to make sense of them. People seemed to be coming from so many directions, and with so many different requests, we were hard put to find any common ground. This person wanted swimming lessons, but was excluded; that person wanted to go to a *Star Trek* convention. Girls wanted to go shopping, boys to play football; some wanted time out from families, others were completely happy doing things they had set up with parents – it all seemed very confusing!

Two things helped us break through the apparent impasse. One was a 15 year old with a social life so full she had no time for anything else. Her life was unusually organised because her parents had good support systems and, since she was their youngest child, they were able to drive wherever she wanted to go. Having found

one disabled young person apparently happy with her lot, it occurred to us that a significant variable might be at work; one whose absence from the lives of the other interviewees would give us that elusive unifying factor. Could we have discovered in this individual the exception which proves the rule?

As we looked at this girl's situation, we were struck by how rare it is for parents to be in a position to take their children wherever they want to go. For most young people, getting from A to B is an issue and, when impairment is part of the picture, that issue can become a major obstacle. This led us to a consideration of transport, from which something else then emerged. Beneath the surface disparity of needs, interests and desires that had at first seemed so confusing, we were able to tease out the common thread of *isolation*. The closer we looked at the findings from our interviews, the more we were confronted by a near universal paucity of peer friendships and of opportunities to get into the spaces where friendships are made.

This is not to say that lack of transport is the only, or even the most important, cause of the loneliness we uncovered. As the next chapter will show, a wide range of mutually reinforcing factors make it very hard for young disabled people to forge and maintain peer relationships. But the discovery of an *exception* (a relatively privileged young person with an impairment) pointed us to a *rule* (disablement = transport problems), which in turn led us to social isolation, arguably the most serious consequence of disablement.

The second breakthrough had less to do with logical analysis, more with inspiration. At the home of one young man, we were treated to an in-depth discourse on *Star Trek*, the cosmos and the awesome hardware with which contenders in the next inter-galactic spat will seek to persuade one another that resistance is futile! Most of it went straight over our heads – but his passion was infectious. Sitting in the car afterwards, Michelle and I experienced simultaneously one of those 'aha!' moments. It had nothing to do with Mr Spock, the empire striking back, or the prospect of dark forces unleashed across our solar system. Quite simply, and without intending to, this young man had taught us to THINK BIG ...

From these two breakthroughs in focus and in spirit, our attention was directed to the isolation of young disabled people and on being bold in our approach. We were happy with the progress we had made, with the contacts forged and with the information these had yielded. But the fact we had seen everyone at home – with their parents but separate from their peers – had now acquired a new significance in our eyes. The next move, surely, must be to bring together the people we had so far seen only in isolation from one another.

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With our newly acquired taste for 'Thinking Big', it would have been easy to jump ahead of ourselves at this point. Given our aim of setting up consultation events, the idea of killing two birds with one stone by bringing together these young people *and* service providers was tempting. Why not set up an action-planning day of some kind, where the young people could come together as a body and speak directly to the professionals?

We realised, however, that we weren't ready for such a day. The young people visited in their homes had never taken part in a consultation process – none had had the chance to develop the levels of confidence required. Nor, for that matter, were we ready. Michelle had the contacts but we had done little work as yet with service providers in the area. The idea of an action-planning day was exciting but would have to wait. First, we needed to prepare the ground.

One thing we had done when visiting the young people in their homes had been to leave them with a disposable camera. We had asked them to take photographs of things they enjoyed doing: places they went to; people they liked to be with; anything that gave them pleasure or struck them as significant. (For those unable to use the cameras, we had asked parents to photograph the things their sons or daughters enjoyed.) When all the film had been used, they were to send the cameras back so we could have two sets printed: one for the young people, one for the project.

In the meantime, my attention switched to the other strands of this project: to Ipswich, Sheffield and Swansea, where similar groups were at various stages of development.

By the spring of 2003, we were ready for a group meeting at Dudley. The cameras had been returned, the photographs printed. We had written to the young people, inviting them to a Sunday workshop at a local community centre and this was to be the first time they would meet one another. In that workshop, we explored their experiences again, this time using the photographs – some of which we'd had blown up – as a way in. These, together with various art and craft materials, enabled them to let us know about their experience of mainstream leisure: what they would like to do and what factors held them back.

Largely as a result of Michelle's contacts, we had a great deal of help on the day – a fact that proved a mixed blessing. On the plus side, we had specialist expertise (an experienced facilitator with a large repertoire of interactive 'ice-breaker' games and two digital photographers with the means of producing on-the-spot prints). We also had the advantage of a very high ratio of support workers to young people. On the

minus side, we had a very high ratio of support workers to young people! While this gave an advantage in support and attention, it also brought two problems. One arose from the fact some of the support workers were also meeting for the first time, leading to occasional role confusion. The other problem, more serious, was that our ability to provide almost one-to-one attention tended to undermine our aim of uniting these young individuals as a *group* with a sense of shared identity.

(It cannot be emphasised too strongly that this was not the fault of any individual or agency. Indeed, to even label it as a 'fault' is misleading. It seems much more useful, as well as more positive, to regard what happened as an interesting learning experience, a valuable lesson to have emerged. That lesson, it seems, is that we should think carefully about the aims of an event, and put more time and care into thinking through the details of how those aims are to be achieved, and into considering what factors might put them in jeopardy.)

In any case, the day was a real success. These young people, some with significant learning difficulties and communication impairments, had given us our clearest and most complete picture to date of how they saw their experience. And the most striking thing about this picture – which told of sports and pop stars, teenage romance and job aspirations, family gripes and money blues – was its sheer *ordinariness* :

... playing with my brother ... playing the guitar ... like to own my own horse ... I want to be a lifeguard ... I want to be a teacher ... I love my dog ... would like to go trampolining ... weight training ... swimming ... playing with PlayStation ... go out with mates ... bowling ... love football... going to park ... like to be outside ... go to pictures ... travel ... go to McDonald's ... like ball games ... meet Michael Jackson ... Gareth Gates ... get good GCSEs ... like my own home ... my nails polished ... watch TV.

These people showed the same interests and aspirations as any other young teenagers. But theirs is also a tale of exclusion, of no way in. Now, however, that wasn't something we had to figure out – we were being *told* this was the case, and in no uncertain terms.

Scores of photographs had been taken of the day. These, together with pictures and posters produced by the participants, gave us a rich set of documentary materials. The task now was to find ways of presenting the messages. It was time to prepare for the action-planning day.



Exploring experiences of access to leisure

Yet again, Michelle's contacts were invaluable. They gave access to a range of contacts far wider than I would have been able to reach, spanning as they did most of the key figures in the statutory and voluntary sectors. A date was set (28 June) and a popular venue (the Dormston Centre at Sedgley) was booked. A flyer, incorporating some of the photos taken at the workshop, was designed, printed and sent to the original participants and the professionals we had targeted.

Within a fortnight, the responses from the professional agencies – some indicating not only the intention to come but also delight that such an event had been planned – were sufficient to guarantee a very full attendance. Meanwhile, we had begun planning the day, determined to offer something for everyone. We had a serious message to put across but wanted to do it in a fun way. It was just as important, perhaps more so, that the young disabled people whose day it was actually enjoyed themselves. (We decided the professionals ought to have some fun too!)

Neither Michelle nor I are trained event organisers but we knew that many threads needed drawing together for the action-planning day to be a complete success. What we were aiming for was not simply a platform or showcase for the young disabled people now involved. Neither was it to be simply a fun day out. We intended it to be both of these things plus an unprecedented opportunity to build relations between young disabled people and service providers.



Flyer for the Dudley Day of Action Planning

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Michelle persuaded the Youth Service to provide 'Cyberbus' – a completely refitted double decker, packed with technological wonders, which was to prove a magnet for young and old, disabled and non-disabled alike: a source of great fun throughout the day as well as being an ideal venue for hanging out and a wonderful bridge builder. (Not least because the workers provided with the bus were themselves from the Youth Service, an agency eager to gain more experience of working with disabled young people. They responded magnificently.)

The big day began with everyone coming together. As Daniel, a participant at the earlier workshop, stood to welcome the attendees and declare the event open, our nerves began to settle. Daniel's welcome apart, none of the young people from Dudley had felt ready to talk but we had invited Nathan, a young man from the Sheffield strand of this project, who was confident and completely unfazed at the prospect of delivering a keynote speech to a gathering of 70 people.

Nathan proved an inspired choice. Able to use language but not speech, he relied on facilitated communication to deliver a strong and clear message about the need for radical changes in thinking and in practice. Speaking directly from his experience of the things he likes to do – swimming, shopping, eating out – and the barriers he routinely encounters, Nathan explained how lack of physical access and personal support frequently get in his way. By his manner as well as his message, Nathan's presence had an electrifying effect. If anyone had come expecting 'just another conference', they now knew different!

Nathan was a hard act to follow but Dr C., a disabled adult, proved up to the challenge. Very different in style, but equally effective, she set access to leisure firmly within the context of legal as well as human rights, showing how the Disability Discrimination Act of 1995 can support initiatives that broaden access. Her experience of bringing disabled and non-disabled people together to improve access to the countryside enabled her to pick up where Nathan had left off, showing *how* to make things happen, and setting a positive, 'can-do' tone for the day.

Last of the keynote speakers was J., a professional from a local authority, who outlined an exciting developing framework for making services inclusive. This presentation, also placed in the context of legal rights, added a crucial strand in putting change within the bounds of possibility.

By the time J. had finished, the Dudley service providers were hooked. Everyone wanted something to happen but were unsure what, or how. After a short break, three workshops ran in parallel. One was for and led by parents while a second looked at support issues, shifting the focus from impairment to access. This

workshop was about people taking responsibility and the participants decided on a two-prong approach, which combined doing whatever they could within the role they happened to have, while also using the Disability Discrimination Act (DDA) to support their initiatives. The third workshop explored ways of developing strategic frameworks to support service provision.

Young people were welcome to attend these workshops but, while the majority had chosen to listen to the keynote speakers, most now opted for 'Cyberbus', staffed the welcome stand (one or two stragglers were still arriving), or simply hung out together.

Lunch, a generous and beautifully presented buffet, with soft drinks free from the bar, was provided by a local company employing young people with learning difficulties. We all ate together, numerous animated groups spreading across a large sunlit balcony, with everyone seeming at ease. Evidence of how well things were going was given by the heart-warming sight of service providers engaging disabled young people, themselves visibly more confident, in conversation.



Hanging out

After lunch, we held the action-planning workshop, involving most of the adults, with each participant charged with producing answers to a series of pre-planned questions.

- What's my vision?
- What's my focus for change?

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- Who do I need to work with and what do we need to do together?
- What am I going to do over the next week, month, year?

The outcomes were sets of commitments – many of personal significance to those making them, but three having wider and more public implications. The Early Years Development and Childcare Provision committed to a continuation of funding for the Me Too! project worker (Michelle's post), while Mencap promised to develop a Children's Panel to advise and support service providers. For its part, the Youth Service pledged funding for a follow-up event that will monitor progress on these commitments and identify future directions.



Focussing on action

Parallel to the action-planning session was a drama workshop led by Open Stage, a local theatre company for disabled and non-disabled performers, and attended by most of the young people along with a few of the service providers. This workshop gave the opportunity for spending fun time together, free from the pressures of a disabling world.



The day ended on a high note

After a long coffee break, which brought everyone back together, the day ended on a high note with a creative performance in mime from Open Stage, who used the Dormston's impressive stage and lighting to deliver a spellbinding act.

The Dudley day of action planning was an unprecedented success, marked by a genuine buzz of interest and enjoyment that heightened rather than distracted from recognition of the seriousness of the issues. The atmosphere was energetic yet relaxed, with young disabled people having a good time and visibly growing in confidence as the day progressed, while service providers felt safe to ask 'real' questions. The commitments made gave the day a forward thrust: the promise, informed by the aspirations of these young people, of change.

Observing the leap of understanding taken by some of the service providers during the day – 'we need to stop thinking about impairment and start thinking about barriers' – had given us, the coordinators, further insights into the root causes of the gap between the rhetoric of policy and daily experience. It is these insights, applied to the stories told us by participants not just at Dudley but all strands of this project, that give the structure of the next chapter.

3 Understanding the gap

Introduction

This chapter argues five distinct but interrelated themes.

- 1 There is a wide gap between the *rhetoric* of stated policy – embedded in legislation such as Valuing People, and in policy initiatives like Quality Protects and the National Service Framework – and actual *practice*.
- 2 This gap is made comprehensible, at least partially, when we see that current rhetoric tends to be informed by a *social* model of disability; practice by a *medical* model.
- 3 The medical model of disability underpins and reinforces, in ways direct and indirect, the many physical, social and attitudinal barriers that prevent disabled young people from fully participating in mainstream, ordinary activities.
- 4 A far wider understanding and acceptance of the social model of disability – first and foremost by service providers but also by the public at large – is absolutely central to the dissolution of those barriers.
- 5 Disabled young people, whether or not they have heard of the social model of disability, display a keenly intuitive understanding of the fundamental distinction that model makes between impairment and disability.

Sometimes it's my medical condition that stops me being able to go out, like when I don't feel well or my body stiffens up too much to sit still; other times it's because there are steps into places or I have no one to take me or no one to go with.

(Lloyd, 17)

The first of these themes is the subject of the next section, a brief outline and categorisation of the barriers to leisure, which, in sharp contrast to the rhetoric of policy supporting inclusion, show exclusion to be a daily reality for young disabled people. The other four themes, less easily separable, are addressed in the subsequent section, 'Models of disability'.

Barriers to leisure: the gap between rhetoric and practice

Young people in transition to adulthood should have the same opportunities as non-disabled young people. All services should be able to demonstrate that provision is delivered within an anti-discriminatory framework.

(Transition Task Group: External Working Group on Disabled Children, 2003)

Sadly, in spite of such policy statements, the majority of disabled young people face a range of obstacles that make it difficult or impossible to enjoy ordinary leisure activities. These barriers – environmental, attitudinal and social – impact on one another in a variety of ways to exclude young disabled people from the mainstream. Based on what the project participants told us, this section outlines and categorises those barriers.

Attitudinal barriers

Being thought of as ‘different’ leads to many young disabled people having few friends with whom to enjoy their leisure time:

The main thing that stops me going out to places is distance and not having anyone to go with. I want to go down to the park on my own but my mum won't let me because I always get teased down there and come back upset. They see me as different but I'm just the same as them. I so want to have friends to bring back for tea.

(Andrew, 14)

It takes little empathy to glimpse the loneliness inherent in being excluded from relationships with peers. One young man with a very full life but few friends his own age described how he loves shopping because it puts him in close contact with other young people. Being in a busy shopping centre allows him to be part of a buzz of activity and means other people have to acknowledge his existence – if only because they are forced into contact with him as his wheelchair bumps into the back of their legs. Such accounts evidence the painful gap between a culture promoting ‘equal opportunities’ and the daily experience of exclusion.

Social barriers – time and money

The consequences of impairment can mean it takes longer to perform essential tasks such as communicating, getting dressed and moving from A to B. Energy must be prioritised, time used effectively. As we will see, this different experience of time can give young disabled people invaluable insights into not only their own situation but also society in general.

At various points during this project, it was necessary to slow down in order to fully engage with and seriously listen to participants. For example, to include young people with a range of impairments in project workshops meant allowing sufficient time to enable everyone to participate comfortably. Groups took the time to listen to young people who need longer to speak, or to communicate in some other way. And

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the time given for comfort breaks, meals and snacks was extended so everyone could eat at their own pace and still have time to relax before going back to work.

When speaking of time as a barrier to inclusion in the wider world, young disabled people identified various ways in which the fast pace of life hinders or prevents their full participation in mainstream activities. Ashleigh told how her need for extra time to complete homework assignments gave her less time than non-disabled peers to hang out with friends in the evening or at weekends. This means she misses out on teenage adventures, so cannot take part in conversations about 'what we got up to last night'. Meanwhile Lloyd reported being refused service in pubs or cafes because it takes him longer to spell out his order. When this happens, both he and his friends are given the message that he is not a valued customer, that his impairment is a reason to ignore his presence.

The identification of time as a barrier presents great challenges to our organisations and structures, as society so often assumes it is good to get things done quickly and 'move on'. The experience of young disabled people in a fast-moving world can give them a wisdom we could do well to reflect on:

Most people in their lives miss what is growing around them. We who can't be speedy have the opportunity to be aware of the insignificant and make it important.

(Katherine, 18)

The only way this wisdom can be fully appreciated is to spend time with young disabled people, to understand their different perspectives. This understanding in turn gives us a greater willingness and ability to listen and learn, moving us from a vicious circle of not listening, not understanding, listening less to a virtuous circle of listening, understanding, listening more.

Time was one of two commonly cited social barriers to inclusion. The other was money and participants told how their inability to earn it through the usual route of Saturday jobs makes them less able to do those things that create togetherness – going out with friends, watching the right films, buying the right clothes and listening to the right music:

If we haven't got any money then we can't go anywhere. We need more money to do things. We need cheaper houses, more discounts on buses and trains so that we can go more places, more discounts getting into places.

(Damian, 19)

Not having that extra money leaves Damian and other young disabled people unable to engage in popular activities and the significance of this goes beyond the immediate effects of missing out on good times. More serious is the loss of opportunities to build relationships with other young people. As with time barriers, the disabling effects of poverty – precisely because it is *relative* – are not fully apparent at first glance.

Nor are the effects of limited finances confined to young disabled individuals. They also affect service provision, leaving even the most enlightened of statutory and voluntary organisations unable to improve the ways they operate, through sheer lack of resources:

We believe in inclusion. We think of ourselves as an inclusive organisation ... and yet we have to turn some young people away because we do not have the funding to meet their support needs.
(Manager of voluntary organisation)

Environmental barriers

This category includes some of the most obvious barriers encountered by young disabled people. Here, as when speaking of time as a barrier, the participants in the project mixed eloquent protest with both insight and concern for other social groupings:

Shop layouts need to change – I just want space. Able-bodied people have to squeeze past too. They also need space! I can't look for clothes easily, as the racks are so close together. I can't get my wheelchair through, never mind see the clothes. I need help in reaching things from the shelves.
(Eleanor, 18)

Many other participants were equally keen to point out that the changes necessary to allow wheelchair users to go shopping would also benefit others: elderly people, for example, and parents of young children in buggies.

As with other barriers, the problems caused go beyond mere inconvenience. The difficulties Eleanor faces in getting around shops cause her to opt for mail-order shopping – so missing out on typical teenage time with friends. Yet again we see how these barriers do not simply reduce access to particular things, particular experiences. Infinitely worse is the denial of opportunities to mix, to make and maintain friendships, to be one of the gang.¹

Making connections

As with the other barriers, environmental obstacles range from outright prevention to the kind of 'second-class' access that ensures not only lower levels of enjoyment but also, yet again, reduced opportunity to relate to other young people:

When I go to the cinema with friends, the seating isn't well planned so you have to go to the front and crane your neck up and my friends go to the back and it's not very good or inclusive really. As well as this, it's louder at the front which makes me jump. It's bad planning. I want the chance to sit at the back but I never can and it sets me apart again.

(Tanya, 17)

Crucial to understanding the full effect of not being able to sit with her friends is Tanya's daily experience of exclusion in *all* aspects of her life: struggling onto a bus; getting her wheelchair round a cluttered store; trying on clothes in a tiny changing room; cafes and restaurants with tables so close together she either cannot use them at all or must endure a flurry of activity while they are moved – how many teenage girls want *that* kind of attention? And these are just the 'one-off' access problems: over the years Tanya has also had to fight for access to a mainstream education, to support enabling her to go out without her mother and even for her method of communication to be recognised. Ordinary activities that her non-disabled peers take for granted either remain out of reach or are a constant battleground.

It is within this context of exclusion at every turn that Tanya's inability to sit with her friends at the cinema has to be seen. Only by viewing the picture in its bleak entirety can we begin to see how vast is the gap between fine statements of policy ...

Disabled children have the human right to take part in play and cultural activities and to freely express themselves in cultural and artistic ways. They have the right to equal access to cultural, artistic, recreational and leisure activities.

(Department of Health, 1989, Schedule 2, Paragraph 8; United Nations, 1989, Article 31)

... and the actual experience of young disabled people.

That gap is equally familiar to their families. Lisa contacted her local social services prior to the summer holidays to see what support they might offer her 16-year-old daughter, who has complex impairments and high support needs. In addition to the one night a week Amanda has at a 'respite care' centre, Lisa was told her daughter could go to a play scheme for three days over the entire holiday. With Lisa working part-time (nights, in order to support Amanda in the daytime) and Amanda needing 24-hour supervision, this support gives neither Amanda nor her mother an 'ordinary

experience'. For Amanda, three days spread over the entire holiday gives no value to the relationship she needs to develop with her support worker, not least because it allows no time for her to teach her communication system to a stranger (who, in any case, may well be sceptical of her ability to communicate, this being a common response from professionals at all levels). The low input of care in such provision combines with scarcity of service to leave Lisa alone, frustrated and cynical about 'inclusive' services.

The frustration and cynicism generated by the gap also affects professionals working with disabled young people. A frequent theme to emerge from both the voluntary and statutory sectors was the lack of time, resources, support or training to work in the ways they would like, and which they felt would best suit the young people they came into contact with.² As noted earlier, the constant uphill struggle for funding often leaves them unable to include disabled young people with high support needs in their projects.

For all parties, then – disabled young people, parents and professionals – there is frustration at the articulation of such fashionable ideas as inclusion, empowerment, participation, choice and independence on the one hand; continuing barriers to inclusion on the other. The next section looks at the reasons for such disparity.



The gap between policy and practice is all too evident to young disabled people

Models of disability

Differences between what people say and what they do are common enough, and in public life they are commoner still. Typically, these have to do with the challenge of ‘putting money where one’s mouth is’. But the gap uncovered here points to an additional factor, unique to disability. Quite simply, rhetoric and practice in this area are informed by two fundamentally incompatible models. This section examines each in turn.

The medical model of disability

The medical model of disability views impairment as extraordinary, disabled people as ‘the problem’. Its emphasis is on getting the individual to fit in, rather than on getting society to change. Dominating societal perceptions for centuries, the medical model has been stubborn and unflagging in justifying the segregation of disabled people from family and community. (See, for example, Finkelstein, 1980; Oliver, 1990, 1996.)

It is not, however, a model we will find clearly articulated in any cohesive or direct manner by its proponents. The medical model is an implicit one, so those who use it, be they professionals or the general public, are not usually aware of doing so. To its adherents, the model seems common sense, the only natural way of seeing things. It is this unspoken, seemingly natural, quality of the medical model that renders invisible the crucial distinction between *impairment* (a part of the body that does not work well) and *disablement* or *disability* (such as when a public building provides no ramp for wheelchair users).³

The medical model of disability underpins and reinforces, in ways direct and indirect, all of the obstacles discussed in the previous section. This next example speaks of exclusion from a physical activity – in this case swimming – but the confusion of impairment with disability typifies exclusion wherever it is encountered, whether the barriers are attitudinal, structural, environmental or a mix of all three:

I wanted to go to the swimming lessons down at our local club. All my friends from school were going. They wouldn’t let me join in.
(Lee, 12)

Lee would love to go to swimming lessons. The pool won’t take him because he needs extra support in the water ... he probably will never swim very well but he loves it.
(Lee’s mother)

Not being able to participate in the swimming club denies Lee the opportunity to take part in an activity enjoyed by many young people. His absence renders him invisible to his non-disabled peers, teaching them that 'Lee is different', 'Lee can't do the same things as us' and, most crucially, 'it's OK if Lee is not there'.

For other young people the impact of medical model thinking centres not so much on the right to be present in places, but on the right to be heard:

Daniel: I was taught by my speech therapist to do facilitated communication at school and I did it with everyone and then I went into the leavers' class and they didn't want to do it with me but they said that I wouldn't cooperate and I was so angry that I refused to communicate with anyone including the speech therapist because she backed up the staff.

Mother: Shall I add something?

Daniel: Yes.

Mother: A highly respected professional taught school how to do facilitated communication. School learnt. Then Daniel went into the leavers' class and it's clear that they do not want to do it and when I go into school they discourage me from doing it. School says that head of class was untrained. Daniel wrote a letter to school saying how unhappy he is about it. School said that the standard of the letter was much higher than communication produced at school. We showed them a video we have of Daniel communicating at home, but it didn't make any difference. They didn't believe that Daniel could communicate.

(Daniel, 21)

Daniel faces this same struggle time and again. During his transition review, social workers listened to his hopes for the future, then sent in a final report that contained none of his wishes. When his mother questioned the report, she was told the social workers did not believe her son was directing his communication – that she was pretending. Such experiences abound in the lives of disabled young people and show a deep-seated cultural conditioning, driven by a model long past its sell-by date.

The social model of disability

The social model of disability, which makes clear the distinction between impairment and disablement, is an explicit challenge to the dominant but implicit medical model. With this distinction out in the open, the whole picture changes:

From this viewpoint, society is at fault, that is a disabling society that is geared to, built for and by, and controlled by non-disabled people – a society that excludes disabled people. This exclusion is created and constructed in every aspect of living, including ways of thinking, language, the built environment, power structures, information, values, rules and regulations. Whether you are disabled or not, you are living in a disabling society.

(Swain *et al.*, 2003, p. 2)

When young disabled people discussed experiences like Lee's exclusion from the swimming class – and they are all familiar with such experiences – their response was unanimous:

Leisure centres should change their rules and adapt to new ideas and inclusiveness. They should start by finding out what people want.

(Group statement by young disabled people in Swansea, 2003)

The plea from young people is to start exploring the issues, to question why disabled people are largely absent from the mainstream and to take measures to change the status quo. In other words, they are asking us not to take the implicit messages of the medical model for granted.

Impairment does indeed mean 'something does not work right', making it difficult if not impossible to do certain things. But to conclude from this that exclusion is inevitable is to introduce a non sequitur, made possible through the medical model's failure to distinguish impairment from disablement. Seeing impairment as 'one of those things', exclusion as the product of a disabling society, paves the way for change. To put this another way, a far wider understanding and acceptance of the social model of disability – starting with professionals but extending to the wider public – is the key to dissolving the barriers that exclude young disabled people from the mainstream.

And there are grounds for cautious optimism. Over recent years, the social model's influence on legislation and policy has slowly but steadily increased:

Society creates many problems and poses many challenges for disabled children and their families ... There is a compelling body of evidence from research and inspection reports that disabled children and their families face many barriers to full participation in society.

(Department of Health, 2001, p. 30)

But such words imply change is afoot, raising expectations that they will carry over into the delivery of services. Clearly, this can happen only if those responsible for the latter share the social model approach, which increasingly shapes declared policy. Currently, that is not the case and a key conclusion of this report is that expectations raised by statements like the one just cited cannot but lead to disappointment when large numbers of professionals – and the vast majority of the general public – adhere, consciously or otherwise, to the medical model of disability.

The rhetoric of social model understandings, running alongside service provision informed by medical model thinking, leaves young disabled people in the unenviable position of being told they have rights to full inclusion in their communities, while having to rely on services based on the view that they are ‘a problem’ to be feared and avoided. This project provided abundant evidence that the gap between promises of rights, independence, inclusion and choice on the one hand, the daily experience of exclusion on the other, generates cynicism and deep dissatisfaction:

I want to say that I am not able to live without a great deal of support ... I am aware that I am a curiosity for many people but I believe that I should be given the same opportunities as others ... I also think that it is important that people realise that disabled people have something to contribute to their community, and it is high time that our abilities are appreciated for what they are. We wearily allow ourselves to be herded into institutions by people who have no idea of our misery.

(Sean, 21, personal correspondence, 2002)

Where the social model is implicit

So far, I have spoken of the medical model being implicit, the social model explicit. On the whole, this is true and echoes the fact that, throughout history, dominant models tend to be implied, leaving to their challengers the tasks both of articulating alternative models and of teasing out the hidden models these seek to displace. The emergence of the social model, product of concerted attempts by disabled adults to make sense of their experience of exclusion, follows this pattern precisely.

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What this project has uncovered, however, is the extent to which young disabled people – who may never have heard of anything so ‘highfalutin’ as the social model of disability – display a keenly intuitive grasp of its essentials. One young woman brought resounding silence to a project workshop when, with halting speech, she told the gathering of young disabled people, support workers and service providers why she had chosen to bring a candle with her:

When the candle is alight and burning brightly I am being allowed to be myself, when it is dark around me, when I am stopped from being who I really am, then the candle is down.

(Kelly, 17)

As the workshop developed, Kelly explained how she could be herself when she was fully included in a situation. Impairment did not prevent her from ‘burning brightly’. It was on the occasions when she was excluded that the ‘candle went down’.

This intuitive grasp of the social model is only one aspect of a wider theme, the wisdom and expertise of these young people, that we will pick up again in Chapter 5. Meanwhile, the next chapter explores the significance to this project of a concept alluded to at various points in this chapter: *ordinariness*.



Finding out what young people want

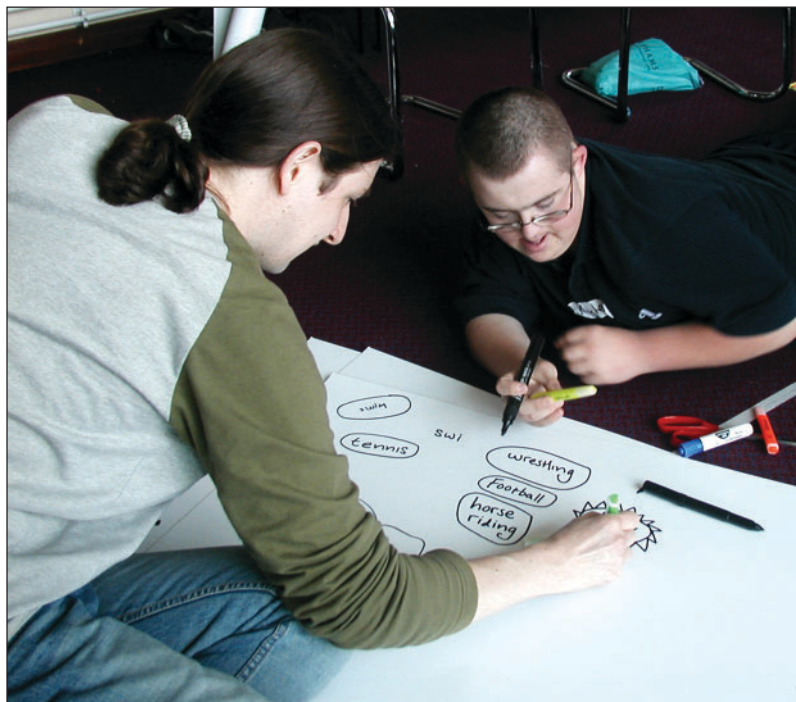
4 Ordinariness

Disabled children have the right to be included in their local community and to do the kinds of things that non-disabled children do. They have the right to support to help them do this.

(Department of Health, 1989, Schedule 2, Paragraph 6; United Nations, 1989, Article 23(1))

Ordinariness is by definition invisible, taken for granted. Only when something occurs to disrupt it, when exception comes along to prove the rule, is the ordinary made visible. So the barriers to inclusion described in the previous chapter – ensuring, as we will see, unusual levels of parental dependency – bring home to us the fact that, as a rule, the teenage years are marked by growing independence from family and a fierce desire to belong to peer groups.

Having the wrong haircut, listening to the wrong music, wearing the wrong clothes, being unable to go places without one's mother – the thought of standing out in these ways fills the teenage heart with dread. Since impairment, as the stories in this chapter reveal, alters none of this, the socially constructed barriers outlined in the previous chapter can be seen as obstacles to ordinariness and therefore, as the above UN Convention on the Rights of the Child (UNCRC) passage implies, denials of a fundamental human right.



There are many different ways to listen to young people

Impairment as ordinary

People say that it must be so hard for me and that, but I don't think it is. It's my body and this is how it's always been, it's nothing difficult to me.

(Caroline, 16)

There is nothing extraordinary for Caroline about her body. It simply is as it is and her impairment is part of who she is. When impairment is recognised in a straightforward way as being something within our body that 'doesn't work right' – and we acknowledge how few of us have bodies that work perfectly – it is possible to understand Caroline's viewpoint. Within the wider context of human frailty, impairment appears unremarkable: a perfectly ordinary part of the human experience.

Caroline's preoccupations and aspirations are those of the majority of teenagers. Again and again, this project showed disabled young people as no different from non-disabled peers in their desire to lead fulfilling lives, their need to be valued in relationships and their hopes for the future. Nothing brought this home to us more clearly than the responses of workshop participants invited to bring an artifact, something of importance to them, as a way of introducing themselves to the group. Though what each individual brought had personal significance for them, all reflected the ordinariness of their interests: family photographs, presents given by families, teenage magazines, CDs, photos of pop stars and sporting personalities. In this way, they showed themselves, first and foremost, to be what of course they are: the youth of today.

My name is Kitty Gilbert and I'm 20 years old nearly 21 in October the 22nd. I have Down's Syndrome. I go out with my sisters, Molly and Letty, sometimes. I go swimming with them or go down the shops checking out the latest clothes or other items like that. I have friends who have the same disability as me and we either go to the cinema or we have parties letting our hair down and going wild. I do lots of things with friends or with relatives. I go out with my mum a lot usually going to parks, pubs, shops or theatres. I rarely see my dad but when I do we usually go to pubs or we eat out or we go to the cinema. I have local friends who are at university now. I live in Wandsworth. I see my local friends when they come back from university and we go out together. Sometimes I work at Battersea Art's Centre and I have friends who go there to see shows sometimes. I also make friends at work. I also am a member of a local dramatic company called The Magdalene Players. I have done three pantomimes there so far. I go bowling sometimes either with family or friends.

(Kitty, 20)

Disablement as extraordinary

Friendships, family, work, college, going out and engaging with the world – all part and parcel of growing up today. Listening to accounts like Kitty's makes clear that young disabled people aspire to exactly the same experiences as their non-disabled counterparts.

Sadly, though, the stories told by participants were of lives made extraordinary by others' reactions to impairment:

Whenever I go out, I hear people saying, 'Who is that guy? He looks so funny.' and I want to roar like an MG car.
(Josh, 15)

For Josh, looking 'different' means he is treated differently. He finds himself the butt of cruel jokes and has difficulty making friends. He has no one to go out with, no peers with whom to share experiences and have a laugh.

Even for those young disabled people, like Kitty, who do succeed in finding a niche for themselves in the outside world, things are far from plain sailing:

I do have a few problems sometimes. For a start my mum worries about me coming home late. I find it hard to find a boyfriend suitable for me. I have had incidents because of my disability.
(Kitty, 20)

The effect on family relationships

The difficulties young disabled people have in making friends, going out and taking part in ordinary life have a knock-on effect on family relationships. Without friends to go out with, more time has to be spent at home. Reliance on family, even to the extent of being trapped in relationships with parents, is often a daily feature of their lives rather than an occasional inconvenience when no one else is around. Besides its negative impact on self-image, and so on opportunities for developing peer relationships, this thwarting of the ordinary pattern of growing independence through the teenage years has effects on family relationships that go largely unrecognised:

Mostly I go out with my family, sometimes with friends. I want support to get on with my friends and family. I don't want to have to be asking them for help all the time.
(Caroline, 18)

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I'm stuck with Mum, I'm always on the buses with my mum, that's the only place people see me.
(Leanne, 17)

The issue for Leanne is not that she dislikes being with her mother, rather that she longs to be with her peers. Lack of access to them denies Leanne, Caroline and many other disabled young people an ordinary teenage experience.

Becoming an adult

The transition from childhood to adulthood requires us to 'leave childish things behind' and become independent. But what do we mean by these things?

Hi my name is Kim
I like football the grate of all.
Television is my best thing.
But I like singing
I don't like school because people think I'm a fool
But I'm not.

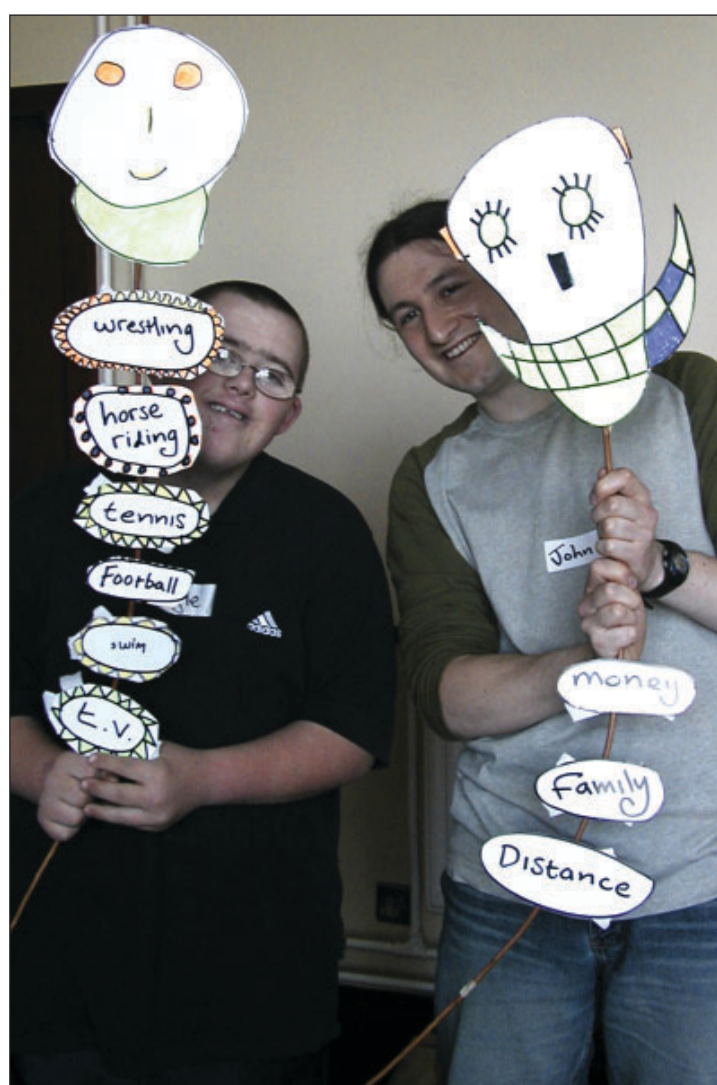
I would like to be a footballer
and win lots of dollars.
And go to America for my holidays.
I would like to go for a long walk.
But I would like to talk to Blue.
But people think I'm a baby because I like Winnie the pooh.
(Kim, 16)

Kim eloquently describes how she suffers under the common misperception that having learning difficulties means she will never grow up. Unable to achieve independence in the same way as non-disabled young people, she is seen as an eternal child. Other participants told similar stories of how such perceptions exclude them from ordinary activities because appropriate support is not readily available, or the desire for ordinariness is not taken seriously. But, when these barriers are transcended, the results can be encouraging. Acknowledgement of Liam's right to ordinariness, coupled with provision of appropriate support, enabled him to do what young men are supposed to do – hang out with their mates in town:

when I was young I used to play a lot and I went to a few kids play's and I liked going to a kids theatre like sooty, Rainbow, Fireman Sam, Postman Pat and I used to run round a lot and being giddy and I act like an adult now because I go

out with my mates to the picture's and we go round town. And I like traveling and go lot's of places like America, Spain, Caribbean, South Africa. And basically I go out with the Barnardos group like bowling pictures meals interview (Liam, 17)

It is worth noting that for Liam, as for many of the participants, it is only through youth organisations providing leisure opportunities tailored to young disabled people that he is able to access an ordinary experience. Time and again, participants told how such organisations, most from the voluntary sector, were their 'lifeline'. Though it is not possible here to do full justice to the subject of empowerment through 'segregated' provision, it is worth taking the opportunity to point out the advantages of such provision when the context is one of recognising the need to move towards inclusion. These advantages can include greater self-esteem, companionship, shared experience and relative independence from family (Murray, 2002).



Wanting an ordinary experience

Ordinariness summarised

Ordinariness is not a difficult concept, nor are the issues discussed here. But the concept does have a sufficient number of important aspects to have warranted its own chapter. The first of these aspects, that the very nature of ordinariness makes it easily overlooked, was stated at the outset.

The second is that human beings have a highly developed need to live ordinary lives because we are social animals. This need for ordinariness is at no time more acute than during the transition from childhood to adulthood, one of the most striking features of that transition being a horror of standing out, of being different from our peers.

The third aspect, a direct result of the dominance of the medical model of disability, is that we grow up learning to see impairment as extraordinary. How do we learn this? By the way those who happen to have an impairment are treated to a very separate experience through attending different schools, exclusion from mainstream activities, and a legacy of fear and avoidance passed down from generation to generation. It is not their impairments that deny Caroline, Kim and Leanne an ordinary experience of adolescence, marked by lessening dependence on parents and corresponding increase in engagement with peers. Rather, it is our failure to see them first and foremost as young people that underpins this denial. Viewed from this perspective, that simple acceptance by Caroline – ‘It’s my body and this is how it’s always been’ – and the messages from all the others whose typical teenage interests speak volumes for the fact their impairments are perfectly ordinary to them, needs to be heard loud and clear.

That last point, on the ordinariness of impairment and extraordinariness of disablement, can help us see an aspect of inclusion rarely discussed. To the extent that the medical model of disability and the exclusion it fosters encourage us to see impairment as extraordinary, we are all alienated from our own humanity. This and its corollary, that inclusion benefits everyone, is the theme of the next and final section of this chapter.

Ordinariness and the case for inclusion

In this and the previous chapter, we have seen how exclusion diminishes the lives of young people who happen to have an impairment. Chapter 3 glimpsed at a matrix of denial, barely visible to those it does not shut out, which condemns in ways gross and subtle those it *does* to the margins of social existence. That chapter also showed how an inadequate model of disability so confuses the effects of impairment with those of disablement as to see the one as cause of the other.

In this chapter, we have viewed exclusion from the perspective of our need to be ordinary, a need basic enough to have received UN recognition as a human right, and felt most keenly in adolescence. And we have seen that the marking out of disabled young people – special schools, exclusion from mainstream activities and ‘a legacy of fear and avoidance passed down from generation to generation’ – renders extraordinary not just the *experience* of those who have an impairment but also, in the eyes of many who do not, their very existence.

The case for inclusion on grounds of social justice is so overwhelming it hardly needs to be made – other than by describing, as we have, the terrible isolation ensuing from its opposite, exclusion. This being so, my intention is to take that case as read and argue for inclusion on the less familiar grounds that it is in the (enlightened) interests of those without obvious impairment, and who are therefore not directly disabled by this excluding world. My motive in doing so is not to prop up existing arguments of social justice, for those arguments need no propping up, but to deepen our understanding of the dynamic of exclusion.

Inner fear, outer projection

A society that excludes some of its citizens from full participation on grounds, not of what they have done but of who they are, will live in fear of those excluded. That this is a universal law can be seen from the many examples history has to offer. Jews, black people, gay men, women – wherever a social grouping has been excluded, that grouping has also been feared in equal measure.¹

These fears, focused on easily identifiable groupings, tend to be outward projections of the dominant group’s innermost anxieties. Misogyny and homophobia are cases in point. It takes no great understanding of psychology to see that men secretly in doubt of their masculinity, as defined by prevailing models, might deflect their fears through a hatred of women and gay men. Similarly, societies that exclude will attribute to the excluded, often in caricature, the very qualities the excluding group cannot face in their own hearts. From this perspective, that widespread fear – whether or not admitted – of impairment acquires a new significance. Are not vulnerability and dependency the most obvious qualities of impairment? And are not most of us trying to hold at bay the facts that we are all vulnerable, most of us will become dependent and we will all die?

Vulnerability, dependency and death are *ordinary* – part and parcel of being alive. To deny it is to deny life itself. When we find the maturity to accept those who remind us of our frailty we embrace our own humanity. And, as we found in the previous chapter with the move towards listening, in doing this we move from vicious to virtuous circle: for just as inner and outer fear fuel one another in a downward spiral, so will inner and outer acceptance fuel one another in the opposite direction.



We learnt what difficulties we come up against like doing and organising outings.



Young people find their own way to give their messages

5 Respectful relationship

The Government has set out its commitment to designing policies and services around the needs of children and young people ... [we are] ... committed to giving children and young people a real say and real choices about the government policies and services that affect them. We want children and young people to feel they can influence the services they receive. We want to see them contributing to and benefiting from their local communities. We want them to feel heard and valued and to be able to make a difference.

(John Denham, Minister for Young People, 2001)

You must listen to us and listen to what we have to say. Listen up and listen now!

(Group statement by young disabled people in Swansea, 2003)

From the start of the Leisure Project, inclusion was seen not just as a desired outcome, which this report might play some part in bringing about, but also as guiding principle for how the research should be done. The idea of 'path and goal being one' expresses the spirit of this approach and the proposition that ends should here be reflected in means informs the rest of the chapter, whose focus is the process of what I shall call 'inclusive consultation'.

At the heart of inclusive consultation is respect, a recurring theme of this investigation. The frequency with which participants told of its absence from their lives suggests that respect – or, as I prefer, respectful relationship¹ – is so central to their aspirations that it can serve as a benchmark definition: one that allows us to draw a clear distinction between accessibility and inclusion, with the former a necessary but insufficient condition of the latter. Only when accessibility (structural, legal, financial or other) is accompanied by respectful relationship do we have a truly inclusive space.

Building and maintaining respectful relationship is a simple proposition, but no easy thing to pull off. It challenges a core assumption of a disabling world: that disabled people count for less. In Chapter 3, we heard of Lee's exclusion from swimming lessons and Lloyd's difficulty in getting service in a pub. We saw exclusion embedded in buildings, buses, clubs and the layout of shops and restaurants – all restricting the opportunities of young disabled people to seek relationship beyond their immediate families. Underpinning all of this is the unspoken premise that it is *reasonable* to subordinate the human rights of Lee, Lloyd and countless others to considerations of convenience, public expense, private profit or even – echoing arguments once used to justify exclusion on racial grounds – the sensibilities of those who might be offended by their presence. In short, that Lee and Lloyd do not matter.

To repeat: meaningful consultation with young disabled people has to have inclusion not only as its desired aim, but also as the means of getting there. That entails building respectful relationships with a grouping for whom respect is definitely not the norm. But what makes this really challenging is the fact that we are *all* products of a disabling world: how could it be otherwise? This being so we can expect to come up against this core assumption, that disabled people count for less, not only 'out there' but also in our own deeply conditioned thought processes.

We need to be wary of ourselves. Above all we need to be mistrustful of any assumption that *we already know* how to 'do' respect.

But here, too, we can learn from the very people we need to respect. During the course of the current project, a number of observations on the theme of meaningful consultation were made by participants. Many of them have fed into the final chapter of this report, while the principal observation – the crucial importance of listening – is explored in the next section.

Listening

It's all about listening, asking and acting. They all come together. You have to listen in order to ask the right questions; you have to be willing to act on what you hear. Listen, ask and act. Listen, ask and act. It's as easy and as difficult as that.

(Nathan, 19)

The importance that young disabled people place on listening can be fully appreciated only when the experience of not being listened to is recognised as one of the many disabling barriers they face. Time and again participants told of the disempowerment they feel as a result of not being listened to. One young man described the experience as leaving him with the sense of trying to communicate with someone whose eyes, mouth and ears are tightly closed. For him, the result is depression and withdrawal.

Understanding listening as a creative activity based on empathy is the first step towards dismantling the socially constructed barriers we saw in Chapter 3. If we are to take that step, we have to move beyond our common understanding of listening as something passive, and confined to messages given and received through the spoken word:

Listening is more than pointing your ears in someone's direction and computing the words which come out of their mouths. Listening can mean going for a walk with someone and noticing what captures their interest. It can mean learning to recognise situations in which a person becomes upset, or becomes animated; it can mean watching a person's movements, or the activities they choose over others; it can mean creating opportunities for that person to experience new things and observing their response. It can mean holding a person when they cry.

(Mason, 2000, pp. 77–8)



Listening is more than pointing your ears in someone's direction

The participants of this project demonstrated their own capacity for creative listening, at times responding with grace and subtlety to unpredictable turns in workshop situations. On one occasion, a subgroup of young people with a range of impairments chose to present, to the wider group, the main thrust of their messages as the outline of a book, *Improving the Environment for Leisure in South and West Wales*.

When the group took the stage to present their work, it seemed a foregone conclusion that Owen, a confident young man, able to read aloud fluently, should take the lead. And Owen did start the presentation but soon noticed another member of the group jumping up and down at his side, clearly wanting his turn. On reaching the end of the first outlined section, Owen passed the book to this person who, as

became immediately clear, could not read well. Instead of returning to take his seat, Owen stayed behind his friend, quietly coming in from time to time when help was needed with a difficult word. At the end of the second section, a third member of the subgroup took over, then a fourth – each person having their turn secure in the knowledge Owen was standing just behind, helping out as and when required. During the performance, the rest of the workshop participants listened intently, giving no indication of impatience at the slow pace of delivery. When the concluding message summarising the framework was read out – ‘We want to be treated the same as everybody else’ – the audience showed its appreciation with loud clapping and cheering. The message hit a note of common concern, but more compelling still was the simple dignity and natural ease with which this demonstration of respectful listening had been given.

How do we listen to those who do not use language?

I really enjoyed your talk this morning and was very impressed by your communication through your letter board but, without being unkind to others, how do I consult with them if they don't have a similar means of communication?
(Service provider)

Sometimes the consequences of impairment can make it hard for a person to take part in the process of consultation. At the same time, the dominance of language as our prime medium of communication means those unable to use it are widely perceived as having nothing to contribute. The question asked in the above quote is one many have asked – and many more have wanted to but have dared not.

Though he seems unaware of it, the interest shown by this particular service provider *is* the starting point. It proved stronger for him than the fear of appearing ‘non-PC’. When natural interest, rather than horror of ‘being seen to do the wrong thing’, is allowed to take the lead, we have already made a huge leap forward:

You need to find out about my way of thinking, like what interests me and what makes me spark, how I communicate with the world and how to communicate with me.
(Nathan, 19)

There is no one technique, or even approach, whose application will guarantee ‘finding the spark’. But we can speak of a general attitude that entails being prepared to look for it and, when we think we may have found it, checking we are on the right track. The story of Rebecca, a young woman unable to communicate through language, illustrates the point.

During one workshop, Rebecca chose to remain in the room but her expression and disengagement from the group suggested discomfort. Clearly, we were not quite hitting the mark with her. When a facilitator tried to draw her in with one-to-one attention, she did not reject these approaches, but neither did she give any definite response.

At lunch, Rebecca ate separately from the group before returning to the workshop room ahead of time. As the others slowly made their way back in, she picked up several puppets, using them to act out different scenarios, occasionally taking up pen and paper to draw pictures. Again, a facilitator went over, this time sitting quietly for a few minutes in close observation before using puppets, pens and paper herself as a way of communicating with Rebecca, who now responded with smiles and animation.

When the workshop resumed, the young people split into groups to explore their experience through a range of media – music, puppets, artwork, writing and drama. Rebecca chose the puppets group but almost immediately began to withdraw again. Noticing this, the facilitator invited her into a space of her own, providing her with a flip chart, paper and felt tip pens, which Rebecca used to create an intricate and accomplished picture of two puppets dancing. As she drew, the facilitator commented on the drawing, ascertaining through Rebecca's body language whether she had 'got the story right'.

Having completed their work, each subgroup fed the main story of their presentation back to the larger group. When it came to Rebecca's turn, she walked proudly to the chart with her drawing, smiling at the group. As the facilitator pointed out key features of the drawing – Rebecca wearing a lovely dress, a beautiful necklace, a rose in her hair, dancing with an adoring partner – the whole group listened with interest and enthusiasm. They showed every sign of empathy with the messages so articulately expressed of an ordinary teenager longing to be in a caring relationship; to be seen as beautiful, special to someone; to go dancing and be happy.

Afterwards, Rebecca continued to be slightly separate from the other young people, but she had clearly found her place within the group. She looked radiant for the rest of the afternoon and seemed fully aware of what was going on around her.

A striking aspect of this story is the way non-verbal media of one kind or another – Rebecca's choices of location and proximity to others, and her use of puppets, drawings, smiles, frowns and even blank expressions – provided critical information at various turning points. That is an important point given how helpless many of us feel when called on to respond to another human being who does not speak. But

Making connections

also important is the way the unfolding situation highlights a number of important principles, applicable whether or not those consulted use language. These are as follows.

- 1 *Being 'on the ball'* – the facilitator noticed Rebecca's withdrawal from the group. Without this basic level of professionalism, none of the rest could have happened.
- 2 *Reading the situation* – Rebecca looked uncomfortable but not distressed. This suggested something was not right, but also that she probably did not wish to leave.
- 3 *Finding out what is going on* – the facilitator's one-to-one engagement not only elicited information (in this case ambiguous) but also demonstrated to Rebecca that she is valued.
- 4 *Making sense of the information* – Rebecca did not reject the facilitator's approach, but neither did she give any positive response. Taken together, these facts tended to support the initial assessment as given in principle 2.
- 5 *Keeping an eye on further developments* – Rebecca's behaviour at lunch and after was watched. What happened next shows that observing her was not done in a negative spirit (Rebecca as problem) but to find a way in that could enhance her experience and ensure she became a contributor (a valuable one as it turned out) to the consultation process.
- 6 *Being opportunistic* – something that calls for flexibility. Rebecca's use of puppets and drawing after lunch suggested a way of reaching her, an opportunity the facilitator did not let slip.
- 7 *Being patient* – though patience and opportunism may appear opposites, here they were two sides of the same coin. Rebecca's use of puppets and drawing did indeed suggest a way in, but the facilitator chose not to rush things. She sat quietly with Rebecca, thus creating a space that made it possible for her to check Rebecca was at ease with her presence and gave her a chance to develop an informed idea of what Rebecca seemed to be getting at, before making an intelligent response.
- 8 *Checking that one has understood* – the ensuing communication was now on Rebecca's terms, allowing her to indicate whether or not the facilitator was 'getting it'. Here the form of communication, drawing, was shared by both parties.

But Rebecca's subsequent presentation to the whole group demonstrated a further possibility – with Rebecca using one medium (drawing), the facilitator using another (verbal comments) to which Rebecca then responded with a third medium (body language) to indicate whether those comments showed a correct understanding.

- 9 *Respecting the other* – the story does not culminate with Rebecca embracing the group. But, by the end, she has contributed, that contribution has been warmly received and she has shown every sign of being happy. With the two primary aims (her well-being and her contribution) fulfilled, no further attempt was made to alter her decision to be separate. Being included, we might say, is a right – not an obligation.



Speaking out



Listening and learning

6 Conclusions and recommendations

Introduction

The first JRF-sponsored Leisure Project was an audit whose aim was to establish, in light of the growing acceptance by policy makers of inclusive thinking, the experiences of disabled children and young people in accessing mainstream leisure. Its findings gave a mixed picture – showing encouraging signs of good practice but also the persistence in many areas of a wide gap between rhetoric and reality. The continuing existence of that gap is what informed the current Leisure Project, whose overall context is the need to close it.

Siting consultation within that context is simple in theory. On the one hand, we have leisure policy speaking increasingly of inclusion and of empowerment through participation. On the other, we have the stubborn reality of young disabled people still excluded in many ways from both leisure activities and involvement in their planning. The point is to do what can be done, however narrow the focus of a given consultation and however small the available resources, to bring practice closer to policy. It is not a difficult idea to grasp – the tricky bit is to apply it.

‘Inclusion’, ‘empowerment’, ‘participation’ – these have become ‘buzz terms’ that lack precise definition. This is not a criticism of those who must use them, but an acknowledgement of the difficulties faced when we try to give them meaning in the real world. With consultation of disabled young people still in its infancy, those who engage in it find themselves at the foot of a steep learning curve. No one knows quite how to do it, but the four broad areas addressed here – clarity of context and purpose, communication of same, flexibility of means and valuing the process – seem fundamental. This chapter does not offer anything so grand as a philosophy of inclusive consultation, nor so mechanistic as a checklist of procedural steps. Its aim is to direct attention to issues that need thinking through with care. With this in mind, the examples used, though taken for the most part from the current project, are intended to illustrate points of wider significance and applicability.

Context and purpose

What are we trying to achieve when we engage disabled young people in consultation? The answers to this question need not be complex but they do need to be made explicit. We will want them at those times when we aren’t quite sure what to do next and when the fine detail obscures the big picture. We will also need them when, having invited disabled young people to tell of their experience and give their views, they ask the question: *why?*

The context of this project has been that overarching need to narrow the gap between policy and practice in the provision of leisure services. Within that context, the aims were threefold. In the first place, I set out to facilitate real dialogue between young disabled people who use or wish to use leisure services and those charged with delivering such services. This, as we have seen, called for a little more than simply booking a venue and inviting both sides to turn up! Many things had to be done to get that dialogue started and the way these things were done had to advance my second purpose: that the running of the project would itself be inclusive.

The third purpose was to produce a report that, besides giving an account of the project, would explore some of the issues shown to be central. This was never conceived as a merely academic exercise, but in the belief that a deeper understanding of the current situation could help us move towards something better.

With context and aims made explicit, useful questions can be asked.

1 Are the aims defined clearly enough to enable assessment, at close of consultation, of whether they have been fulfilled?

The idea is not to reduce everything to the level of ticklists and checkboxes. It is difficult, for example, to see how the second aim of the current project – that it should itself reflect inclusion – could be so reduced without trivialising and/or distorting the concept. But that aim is sufficiently specific to allow independent assessment. It opens up the possibility that someone might declare: ‘you said the project would be inclusive, but what you did in that workshop was not inclusive at all!’

The practical questions raised by our aims are not always simple and the example just given demonstrates that fact. I tried hard to make inclusion a central feature in the running of the project. I did not, however, ask workshop participants to design the newsletters produced afterwards. Did this compromise my aim of inclusive consultation? My view is that to have involved participants in this way would have been desirable, but only achievable by spending time I thought best invested in furthering other aims. Some might take a different view but, because the aim was made explicit, debate on the matter can at least be focused. Clarity of purpose does not guarantee we will always be successful, or even that everyone will agree on whether or not we were. What it can do, however, is direct people’s attention to the relevant issues. And, as this particular example shows, even a difference of opinion about the extent to which an aim has been fulfilled can – precisely because the bone of contention is clear – open up fruitful avenues of thought that might well inform future initiatives.

2 Are the aims mutually compatible and relevant in light of the context?

This should be a simple question to answer, but is worth asking all the same. With aims and context out in the open, ambiguity and uncertainty become detectable. In this project, the aims were straightforward in principle, as were their relationships to one another and to the context of narrowing the gap. Facilitating dialogue between providers and users, working in an inclusive manner and producing a report that would explore issues crucial to inclusion – these aims are mutually compatible and reconcilable with that broader context. But this may not always be the case – especially where responsibilities are shared; and even more especially where those setting the agenda, and those charged with seeing it through, are not the same people. By questioning the relationship between aims and context – something we can do only when both are made explicit – it is possible to identify and resolve at an early stage any flawed, hidden or inconsistent assumptions about purpose.

3 Are the aims, taken together, commensurate with available resources?

Here, too, the obviousness of the question does not alter the fact it is worth raising – though it may not be clear until projects are well under way whether we have bitten off more than we can chew, or for that matter taken sledgehammer to walnut! The fact that resource needs may be overestimated or underestimated does not do away with the necessity to give *some* estimation. Questioning the ‘fit’ between resource and intention can go beyond good housekeeping – important as that is – and take us again to a consideration of exactly what we are trying to achieve.

These questions of context and purpose are useful because their careful consideration should lead to the kind of clarity that allows independent scrutiny.

- Are context and aims sufficiently clear?
- Are all the aims relevant given the context?
- Are the aims mutually compatible?
- Are all the aims realistically achievable within the available resources?
- Do the aims, taken together, justify those resources?

Enabling such scrutiny to take place, and making it as easy as possible, is always important because it renders those responsible for managing consultation projects accountable to the other stakeholders. But the issues considered here have a more

immediate usefulness to the managers themselves. Only by being clear on them will they find appropriate responses to the situations envisaged at the start of this section: when they don't know quite what to do next, when they can't see the wood for the trees and when the young people invited into the consultation process ask why, and to what end.

Communication

The young disabled people who took part in the current project indicated very clearly that they want change. Understandably, they do not want to enter into consultation only to see nothing happen afterwards. This raises questions of professional ethics whose importance can hardly be overstated. It becomes imperative that those doing the consulting are at pains to spell out the limits of their own powers, as well as making clear that being listened to and taken seriously do not necessarily mean every demand can be met. When those consulted are young and vulnerable, the need for the highest standards, backed by clarity of purpose and readiness to be innovative in its communication, is all the more pressing.

The first aim of this project was to facilitate dialogue between providers and users of leisure services. The exuberance with which the latter, as participants on project workshops, came up with wish lists ranging from the prosaic to the exotic was a delight to witness. But it is not within my power to guarantee that Tony Blair, Kylie Minogue and David Beckham come to Ipswich to hear young people voice their concerns, and I was at pains to say nothing that might imply such an outcome was likely. More than this, I had to do all I could to communicate just what I did hope to achieve. Professionalism in this context means more than taking care not to send the wrong signal. It means ingenuity in applying all appropriate media to the communication of aims whose boundaries and outer limits are clearly defined.

But how could I signal the second aim of the project – that it should exemplify inclusion in the way it was managed? Young people are acute in judging others by what they do, rather than by what they say. Inclusive consultation can be conveyed only by the very essence of our approach, and perhaps we should not even try to speak of it to the young people we consult. Integrity, respect for the other, attention to the small details of a welcoming accessibility – these are the 'media' through which the intention to practise inclusive consultation will be manifested, or shown to be empty rhetoric. However imaginative we are in finding communicative forms appropriate to our audience, these will be of no help if we fail to walk the talk – a theme explored in some detail in the final section of this chapter, 'Valuing the process'.



Young people want change

Flexibility of means

Being clear about the aims of consultation does not necessarily equate to neatly prescribed methods of carrying it out. Of course we will have ideas about how to proceed, but these are best regarded as provisional – subject to change in light of circumstances on the ground.

An example from Chapter 2 highlights this. The aim of facilitating dialogue between service providers and young disabled people gave rise to two objectives in the Dudley strand of this project: to make contact with locally based young disabled people and to find local examples of good practice that could help move forward the dialogue when it began. Both objectives were foreseeable given the higher-level aim. But it was only when these were combined with information on the ground that we were able to derive a strategy for Dudley: we would pay visits to a youth club believed to be used regularly by disabled young people, observe what was happening and try to formulate generally applicable principles of ‘best practice’.

As it turned out, our information was flawed: disabled young people had indeed used the club during a summer scheme, but had not returned afterwards. We were forced into a major rethink whose first product had also to be abandoned on the untimely death of someone we had reckoned on as a vital ally. The methods that ultimately won out – presentation to the Orchard Parent Partnership in Dudley, use of the

Disability Register and visits ‘on dark November evenings’ to the homes of disabled young people – though still informed by that higher aim of facilitating dialogue, had been equally determined by events on the ground we could never have predicted.

Many other examples from this project show the need for flexibility in the face of factors we cannot anticipate. In Chapter 5, we saw how Rebecca’s withdrawal at a workshop called for an on-the-spot response. (It worked, but might not have done: the point is to try.) In a different way, the chance discovery, after the project had begun, of someone with skills and willingness to produce newsletters opened up a new approach to documenting workshops and giving back to participants. Flexibility is needed at all levels and not just because situations change. More importantly, in a world where rigid refusal to adapt to those seen as different is one of the main drivers of exclusion, simple willingness to respond – spontaneously, as one human being to another – is nothing less than inclusion in action.

Which brings us neatly to the next and final section.

Valuing the process

This chapter has referred several times to my aim of demonstrating inclusion: an aim I do not regard as unique to my project, but one all consultations with excluded groups should embrace. This section, which can be seen as a more detailed extension of themes begun in Chapter 5, starts from the belief that the process of consultation is as important as its material objectives, and probably more so.

Chapter 5, which spoke of respectful relationship and creative listening, also referred to access as a necessary but insufficient condition of inclusion. Only when it is accompanied by respect do we have a truly inclusive situation, and that equation – *Access + Respectful Relationship = Inclusion* – gives the structure for much of this final section. Valuing the process of consultation means attending to the details of access and respect but, through keeping in mind the goal of inclusion, not getting lost in those details.

Access

When consultations are planned, it is of course essential to consider the suitability of venues. Will everyone invited be able to get into the building chosen? Once in, are the facilities up to scratch? Toilets are an obvious issue, as is mobility within the premises. Split-level floors, for example, may pose a problem for some.

Other aspects of physical access are not quite so obvious but may still be crucial. The most important of these concern the sensory environment. Nobody likes being in a room that is too hot or cold, is ill ventilated, has poor acoustic qualities (extraneous noise, echo, a sound system inadequate for the space), or is dimly/harshly lit. But, while such adverse factors will mar the experience for most people, impairment may make it impossible for some.

The point is not to build up a detailed and prescriptive picture of the perfect venue, one that would enable every human being, regardless of impairment, to attend in total comfort. Few if any buildings could satisfy such exacting criteria, and in any case we would be in danger of missing the point – of getting lost in the details. This is about inclusion, not scaring the pants off those sincerely trying to reach for it!

The point is that the organisers of consultations have to take responsibility for ensuring the venue is, or can be made, suitable for the people who *will* be coming, which means taking responsibility for finding out from those people what is and what is not suitable. Invitations should always – and these days usually do – gather such vital information as whether or not there are wheelchair users, or people with hearing or visual impairment. Besides checkboxes (yes, they do have their uses!) for the most common needs, reply forms should always give space for a ‘catch-all’ where attendees can give information about a need not specified as a checkbox item.



Listening has to be followed by action

Nor do I see it as helpful to be too prescriptive about *how* any particular need is to be met. Should a proposed venue, eminently suitable in other respects, be abandoned in light of the difficulties it might pose for one individual? Possibly. But perhaps there is some other way to address that person's requirements. Provided it is backed by both a genuine desire to include and the highest standards of responsibility (including professional and legal), there is usually room for creative thinking in solving problems. That's what human beings are good at.

Respectful relationship

Inclusion by definition means everyone. A consultation where disabled people were treated with the greatest respect, but service providers were rebuked or scorned for 'non-PC' views, or cleaners and catering staff were treated as though invisible, would not be inclusion – just inverse exclusion. Respectful relationship is for everyone, or it means nothing at all.

In Chapter 5, we referred to the problem being not fear of impairment but its denial. When people are sincerely reaching up for something better, but anxious and unsure of the way, the last thing needed is to have them shot down – or staying silent through fear of being shot down – for saying the wrong thing. An inclusive event gives a safe space where all questions can be asked, all concerns raised.

Initial impressions count for a lot. When people arrive, will they be made welcome? Will there be clear signs around the building; a reception point where everyone is met with a smile and willing help? With all the work that has gone into making an event happen, it is easy to overlook the fact some of those coming will never have been in such a situation before. Everything that can be done should be done to convey, in those first few minutes, that this is a welcoming space in which their presence is valued.

This is as good a place as any to point out the value of having the right amount of help on the day. Since too many helpers can cause as many problems as too few, we have a further reason, if one were needed, for careful planning of the event. With all tasks identified and in some detail, we will have a good idea of how many helpers are required, each of whom can be given a clear brief on role(s) and responsibilities. And if, to continue the subject of the previous paragraph, one or more individuals are given the job of welcoming people and providing a first point of information, for the time they are doing so, that should be their sole responsibility. Relaxed alertness is one of the key qualities needed and frantic distractions as last-minute crises unfold – which they probably will – are not conducive to that state.

In many cases, volunteers can be found. Who would be most appropriate for a particular job? Staying with the reception example, at the Dudley action-planning day everyone was met on arrival by young disabled people. A fine job they did too and what better signal could we have sent to non-disabled people unsure about what inclusion means?

(One of the reasons those young people did such a good job on reception points to a more subtle aspect of inclusion. Many of us have had the experience, on attending an event of any description, of feeling like an outsider. This can be conveyed not through being met with coldness but through a *relative* lack of warmth. Seeing the guy in front greeted as a long-lost buddy, with hugs and prolonged chit chat – ‘and how is so-and-so doing?’ – can be very effective in reinforcing the idea that ‘I am a stranger here: *they* all know one another’. It may be true, but why parade the fact? The total absence of cliquishness – easily signalled without any intent to do so – helped foster the sense everyone was valued, and in equal measure. For whatever reason, the young people at Dudley did not have to be told this, but why not spell it out? Those on reception have an important job to do and should focus on doing it democratically – which here means inclusively. There will be time later in the day for catching up on news about old friends and colleagues.)

While attention to the details of a welcoming space is important, what that will mean in practice at any given event will vary with people, purpose and, of course, budget. Maybe lunch is to be provided. If so, what would be appropriate? At Dudley, we chose a finger buffet, provided by a firm employing disabled young people. It was attractively laid out in a spacious and (this definitely cannot be prescribed for any UK venue) *sunlit* area tastefully decorated with murals, pictures and large leafy plants. Tables had flowers and the spaces between them were generous because we saw lunch as a big opportunity for professionals, disabled young people and relatives to move about and get to know one another in an easy and natural way.

Does this mean all consultations must offer free lunches, flowers and sunlit, aesthetically pleasing spaciousness? Clearly not, for it will not always be possible within budgetary or other constraints. But does it mean that, where circumstances do permit, to do so will give a sure-fire guarantee of genuine, 24-carat inclusiveness? Again, clearly not. The details always matter, but only within the wider picture.

To give a small example of the subtlety involved here, I recently attended a conference where a great deal of attention had been paid to detail. Clearly motivated by the desire to make the conference space pleasant and welcoming, every room contained a large bunch of flowers. Unfortunately, the only places to put these were

on the tables in front of the speakers, where they neatly obscured the audience's view and so had to be moved virtually out of sight. The thinking had been there alright – it just wasn't fully joined up.

The conference was a failure then? No, it was a great success – for the good and simple reason that the desire to include was a sincere one and that was what showed. Everyone felt valued, so a safe space for debate and enquiry was created. With the right motivation, mistakes can usually be carried. It isn't that the details are unimportant; just that they are always subordinate to the goal of inclusiveness.

Before closing this sub-section on respectful relationship, I want to say something about giving back. Those present, disabled or not, will have given something of value. What do they get in return? On this question, I am even less inclined to be prescriptive: no goodies lists here! It *may* be right to give something tangible. Workshop participants at Dudley, Ipswich and Swansea received CD tokens and seemed to take real pleasure in the newsletters sent out after these events, care having been taken to ensure everyone's face featured at least once!

(Incidentally this raises a separate point. When photographs are taken at an event – and these can be extremely useful – what measures are needed to get permission? At the first Dudley workshop, no one was asked. Everyone seemed happy to be photographed and we assumed – wrongly, as we discovered when one young man took exception to seeing his picture in one – that the results could be used in flyers for the subsequent event. That assumption was inexcusable and I will not repeat the error. Learning from it, we established ground rules at the outset of the Dudley action-planning day: a photographer would be present, everyone was told, but anyone seeing a camera pointing their way and not liking it could signal with a raised hand. Either the picture would not be taken or, if it already had been, the offending digital image would be erased.)

Free lunches, tokens, newsletters and photographs may be suitable in some contexts. But demonstrating appreciation need not, and in some situations probably should not, take tangible forms. Attention to matters already raised, regarding a welcoming respect in safe and conducive environments, may be all the giving back that is required. As long as those who organise consultations stay mindful of the fact that participants are giving something, appropriate ways of expressing gratitude will surely be found.

Sustainability – and documentation

Throughout this entire section on valuing the process, I have referred to the bigger picture within which details of access and respect are seen. My assumption so far has been that this bigger picture is the whole consultation, but here I want to go wider still and look – albeit briefly and, of necessity, speculatively – at the overall context within which any consultation takes place. Specifically, I wish to encourage raising of the question: what next?

That is not always a question the organisers of a consultation, who may have been brought in to do a clearly defined job, have the power to decide. But at the very least some kind of documentation should be prepared of the outcomes. Whether the form this takes is a lengthy report, newsletter, two-sided summary of recommendations and key issues, or all of these things, post-consultation documentation offers the opportunity both to feed back to participants and suggest future initiatives.

It also offers an opportunity for reflection. Documenting what happened not only puts it on record but also creates space for a deeper understanding. And the process of doing so should be not only valued but also value-adding. By circulating drafts among participant representatives and other stakeholders, or, where this is impractical or impolitic, actively soliciting feedback on finished documents, we see inclusion at work – its momentum sustained and even accelerated.

The production of this report has been an intense and enriching activity. Though it gives as faithful an account of what I did and found as I know how, it represents more than a simple record. For one thing, my own thinking – on issues as broad as models of disability and as narrow as flower arrangement – has moved on as a result of writing it. For another, the involvement of others in commenting on the drafts has made it an inclusive experience.

This focus on documentation is important in its own right for the reasons just given. But, since it exemplifies the one aspect of sustainability over which those responsible for a consultation will always have some degree of control, it serves as a way into considering that widest picture of closing the gap between current realities and a better world for all. In sum, when the only obvious contribution we can make to keeping the inclusion ball rolling is to offer an informed opinion on what should constitute the next step, what excuse could we have for not grabbing the opportunity with both hands?

Notes

Chapter 3

- 1 This is a good place to remind ourselves that the different categories of barrier are separated here simply so that we may see them clearly. In reality, they operate in mutually reinforcing combination.
- 2 One of the fringe benefits of this project has been the wealth of contacts made with professionals, many of them charged with developing local strategies for implementing national policy, who contacted us for guidance in moving towards inclusion.
- 3 This example is used solely to make the distinction clear. As the previous section showed, disabling barriers can be far more complex than simple failure to provide wheelchair access.

Chapter 4

- 1 The worst aspect here is not the fear itself, but its denial. As one disabled woman told me, '*I* can handle people's fear of impairment but *they* can't. They won't admit to that fear, inevitable in a disabling world, because they think it betrays a personal defect in them. But the problem is in the society not in them: nothing about this is personal.'

Chapter 5

- 1 The latter term suggests we view inclusion as ongoing rather than static. Since relationships grow or wither in real time, the very word suggests something dynamic and therefore not reducible to a set of 'checkboxes' to be ticked off by those eager (whether through naivety or cynicism) to demonstrate political correctness. Checkboxes and ticklists have their place but, when powerful ideals are thus reduced, the result is all too often the preservation of form at the expense of essence.

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Appendix: Sample workshop summary

THE WORD FROM SWANSEA...

“...we just want to be treated like everybody else...”

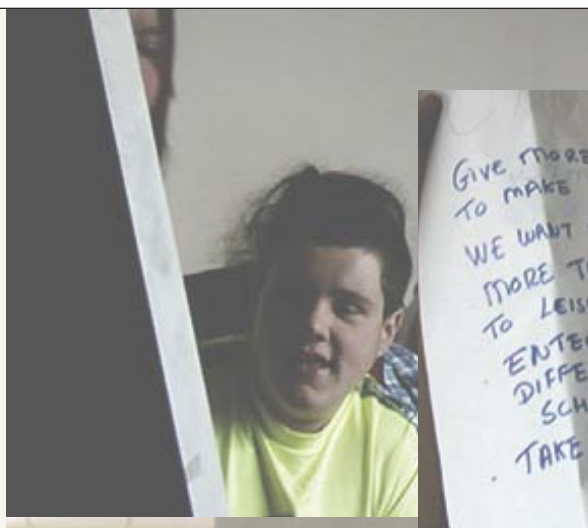


May 28th, 2003 - twelve of you from Interplay met with Dynamix, Interplay staff, Phil (the photographer) and Pippa to talk about your leisure time. Pippa is going to write a report telling other people about the experiences young disabled people have during their time out of school, college or work.

You told us how much you like living in Swansea. Many of you love being able to go for walks in the countryside; going to the beach (some of you said you liked playing games on the beach, others said you preferred to watch the boys); going to the cinema; bowling; going out with Interplay; playing and watching sports (especially rugby).

While most of you said there was a lot to do in Swansea, some of you told us there is not enough to do now that you are a bit older.

All of you told us how difficult it was to do the things you wanted, in the way you wanted. All of you wanted to have more opportunities to go out with your friends. You told us that there were **four main obstacles to this...**





1. Having friends to go out with
 Many of you told us how difficult it was to make friends because of 'bullies'. Bullies were people who laughed and made fun of you. You think they do not realise the horrible effect their behaviour has.

2. Money
 You told us that it was difficult to get a job, so that you never have any money to go out with - 'If I haven't got any money, then I can't go anywhere.'

3. Transport
 When you talked about making public transport accessible, you made it clear that you were not just talking about physical access but also about the way you were treated on buses, and how the price of travelling by train or bus put them out of your reach.

4. Parents
 Whilst you all loved being with your families, like all teenagers, 'being stuck with mum' was not always what you wanted. You wanted a choice about when you spent time with your families. Instead, many of you are very dependent on your families for company, money and transport. You also said that your families worried a lot about you going out on your own. You understood their worries (bullying is something you often come up against) but you still want to go out on your own.



changing things

You had lots of ideas about how to change things. In order to do these things though, you stressed how it was important that people in power and authority took you seriously and listened to you. When you talked about listening, you did not mean just hearing the words or messages you give but actually doing something about the things you were saying.

You had very clear ideas about what has to happen to make things better. You wanted to see improvements in...

Planning of services. You told us that services should keep up to date with new ideas of inclusion and should be based on what people actually want

Management of services (especially better management of public transport).

Physical access

Behaviour - not just with 'bullies' and people you met when you were out, but also from staff in public services.

