

Pushing for Change



**The Role of Disabled
People's Organisations in
Developing Young Disabled
Leaders of the Future**



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Young Disabled Leaders
of the Future

“It's someone that I suppose is able to bring out the best in other people. It's not so much about the individual but what they bring out in others - people who help others to aspire, perhaps. What the person is able to do to enable others brings out the true leader.” Oliver

Contents

Introduction	6
Key Findings and Recommendations	12
Conclusion	16

Research findings in Detail	18
i) Young disabled people	19
ii) Disabled People's Organisations (DPOs)	32
Recommendations in Detail	40

Available Relevant Literature	56
List of Participants	63

Appendix 1	
List of DPOs currently working with young disabled people	65

Appendix 2	
List of disabled people referred to in research findings	68

Appendix 3	
'Big Minds, Big Lives' Event Programme	70

Appendix 4	
List of 'good leader', 'bad leader' qualities	72

Appendix 5	
Questionnaires	74



Introduction

Purpose and Background

This research report has been commissioned by the Alliance for Inclusive Education as the starting point for its *'Young Disabled Leaders of the Future'* project.

The Alliance recognises that unless a new generation of disabled leaders is ready to take up the reins, it will become difficult, if not impossible, to build and sustain the capacity of Disabled People's Organisations (DPOs) and will affect their ability to play a lead role in ensuring full equality and human rights for disabled people. Our young leaders project is an attempt to start addressing this issue and make recommendations for building and developing a new generation of young disabled leaders of the future.

The report looks at some of the ways different organisations are including young disabled people and encouraging their leadership and includes the voices and experiences of young disabled people on leadership matters. It is suggested by our research that DPOs with clear strategic goals and programmes of activities for young disabled people will encourage and inspire them to become the future leaders of social change for themselves and other disabled people.

The *'Young Disabled Leaders of the Future'* project represents a key element of the **Disability LIB (Listen, Include, Build) Alliance**. The Disability LIB Alliance is a partnership of:

The Alliance for Inclusive Education
The United Kingdom's Disabled People's Council
Equalities National Council
Disability Awareness in Action
National People First
Preston Disc
Scope (as the managing lead partner)

The Disability Lib Alliance has funding from the Big Lottery BASIS Fund for three years (2008-2011), to build the capacity of 200 DPOs across England. This effort will support meeting recommendation 4.3 of the government's *'Improving Life*

Chances of Disabled People' report (2005) (a user-led Centre for Independent Living in every area by 2010), enabling organisations to become more effective and sustainable, and acting as agents for social change to ensure the full equality and human rights for disabled people.

The Young Disabled Leaders of the Future project was set up in response to the lack of relevant and inclusive leadership development programmes and opportunities. There are numerous leadership development programmes across the mainstream sector. However, most limit the understanding of leadership to running organisations or groups, or standing for local councils etc. It is also the case that disabled people are discouraged to seek real leadership in their own lives by the way in which services and participation opportunities are often structured so that the power and decision making remains with others.

For leadership to be relevant to and inclusive of disabled people, particularly young disabled people, the definition of leader/leadership needs to be much broader to include the full range of possibilities, including choice and control over everyday decisions about what to eat, where to live, who to have as friends - right through to choices about social, learning and work opportunities. A broader, more inclusive definition of leadership would become relevant to a wider group of people and has the potential to assist in reaching the Government target of 2025 for achieving equality for all disabled people.

The finding of this report will inform the next stage of the Young Disabled Leaders of the Future project, in which two DPOs will put the report findings into practice. The final stage will be to produce a Leadership Development resource that will be rolled out in 2011 across 200 DPOs involved in the Disability LIB Alliance work.

Method of Investigation

Various methods of investigation were used in the process of this research. Representatives of DPOs participated in a questionnaire investigation; young disabled people participated in face-to-face interviews or telephone interviews within a





range of settings and were also asked to fill out questionnaires; groups of participants from one Scope School and two DPOs took part in group interviews; and young disabled people and their allies participated in a one-day consultation event.

What does the term 'Disabled People's Organisation' (DPO) mean?

Disabled People's Organisations (DPOs) are, by definition, organisations OF disabled people, run BY disabled people to promote the rights of disabled people. For the purposes of this report this would include Centres for Independent Living (CILs).

This is in contrast to organisations FOR disabled people, most of which are controlled by non-disabled people and exist in order to 'benefit' disabled people but often do not have disabled people really in control.

DPOs came out of the pioneering and campaigning work of disabled people, many desperate to be released from institutions, who in the 1970s first developed the idea of the 'Social Model of Disability'.

The Social Model of Disability focuses on how and where society fails to value and include disabled people by creating 'disabling' attitudes and barriers. Barriers that effectively exclude us from getting our rights and equality, and from realising our true potential.

When we talk about 'disabled' people, we are talking about people with impairments and health conditions who face these socially created disabling barriers. Disabled people, and certainly all DPOs, who understand 'disability' as a social construct and see it as a political identity, take a rights-based approach to campaigning for social change. Strong DPOs have been shown to be the most effective way of empowering disabled people to take control of their own lives, supporting transition from the margins of society into the heart of the mainstream as equal citizens.

DPOs are places where disabled people can meet, gain and exchange information and use the facilities and services to



access opportunities in the disabled people's community and wider society.

Disabled people's organisations also have an important contribution to make in bridging the current gap between young disabled people and the disability community. Many of the disabled young leaders who were interviewed for this report cited examples of how disabled adults' interest and commitment made a vital difference to their self esteem and aspirations.

The empowerment role that DPOs and disabled adults can play in the lives of young disabled people is key if this and future generations of young disabled people are to have the confidence and interest to take leadership roles in the continuing struggle for our inclusion and equality.

Government Initiatives

Since the early 1980s, disabled people have been lobbying successive governments for the establishment of organisations led by disabled people and centres for independent living in every area of the UK. This goal is now enshrined in the 2005 government report *'Improving Life Chances of Disabled People'* which states:

'User-led organisations

By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing Centres for Independent Living.'*

Prime Minister's Strategy Unit, January 2005

The government's "Every Child Matters" initiative lays out key priorities for every child in the U.K. to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

*Full report can be accessed online at:
<http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>
(Accessed on December 16 2009)



For young disabled people, the absence of adult disabled role models can make it hard for them to imagine themselves making a positive contribution or achieving economic well-being. Currently young people are encouraged to aspire to images of leadership rooted in traditional models, e.g. super-heroes; captains of industry; sporting heroes; wives and girlfriends of football stars; talent show winners; beauty queens; etc. For many young disabled people, these aspirations are images of just what is unattainable. There is no emphasis on the contribution made by the disabled leaders of our country or on the political dimensions of leadership related to social change.

'By the age of 26, young disabled people are more than three times as likely as other young people to agree with the statement "whatever I do has no real effect on what happens to me". Initiatives aimed at promoting social responsibility and active citizenship are more likely to characterize disabled people as objects of voluntary activity rather than participants'. Disability Rights Commission*

Other recent Government initiatives include a multi million pound cash injection to overhaul services for disabled children and their families. The "Aiming High for Disabled Children: Better Support for Families" report focuses on some of the barriers faced by families when trying to access statutory services and the key recommendation is that services should reflect the needs and desires of families rather than be directed purely by budget targets.

The Government missed a huge opportunity in this report to ring-fence money to support effective participation opportunities for disabled children and young people. Participation monies were ring-fenced for parents and families so clearly the same value is not placed on the involvement of disabled children and young people.

DPOs in the U.K. continue to look to the international scene to assist with increasing the right to participate for disabled young

*'Increasing Democratic Participation and Active Citizenship: Creating an alternative future' p3. DRC 2005. Available on ALLFIE website www.allfie.org.uk

people. The United Nations Convention on the Rights of the Child, which was ratified by the U.K. more than 20 years ago, clearly places an obligation on Governments to listen to the voices of children and young people.

The recently ratified United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) presents a brand new opportunity for the disabled people's lobby to seek commitment from Government to recognise and respect the human rights of all disabled people, irrespective of age, to have their voices heard. Although the Government ratified the UNCRPD on June 8th 2009, it chose to place a reservation and interpretive declaration on Article 24, which has the potential to reverse the move towards inclusive education for disabled learners for future generations. The UNCRPD does not give disabled people any new rights, but it does reinforce that existing rights (in other treaties) apply equally to disabled people, of all ages.

Disabled people played a key role in negotiating this important Convention and, in the light of the Government's recent back tracking, the next challenge is to ensure full implementation of the education rights enshrined in it. The Alliance hopes that our recommendations in this report for developing a greater leadership role for young disabled people will assist the push for change to achieve full equality on this and other Government initiatives.





Key Findings and Recommendations

Key Findings

1 Leadership:

In the opinions of the interviews and questionnaire respondents (Young disabled people and disabled peoples organisations), a disabled leader is someone who promotes social justice and empowers themselves and other disabled people.

There are no fundamental differences between adults' and young people's definitions of leadership - both groups identified a disabled leader as someone who:

Promotes Social Justice

Empowers Others

Manages People

Has Specific Personal Qualities/Skills

'Someone who has a vision for change and the ability to influence, who has an understanding of leadership and equality - the social model is a general model of what helps disabled people - followed by the opportunity to participate in decision making'

'This does not need to be an active role, but just going about day to day life and being visible is a leadership role in itself'

59%

of DPOs said young disabled people did not have a leadership role in their organisation

2 Disabled People's Organisations:

DPOs that are working on building leadership skills with young disabled leaders of the future have varying levels of commitment and different ways of engaging with them. There is no apparent consensus on what constitutes good practice.

26% of those DPOs involved in this research are not working directly on building young disabled leaders of the future because they lack:

Funding and resources to support the work

The capacity and sometimes commitment

Experience and expertise with young people generally

Access to young disabled people

3 Young disabled people:

Young disabled people are definitely interested in disability politics.

Young disabled people are readily able to identify disability equality and inequality and are keen to work on challenging it.

Young disabled people have valuable perspectives to bring to the table.

Young disabled people need disabled adult role models.

Young disabled people need disabled adult mentors who will commit themselves on a long-term basis and support them.

Young disabled leaders are important role models for other young disabled people.

'Young people's non-acceptance of things as they are is absolutely refreshing. It's important to have those sorts of ideas put forward'

88% of young disabled people who participated thought young people could be leaders

88% thought you did not have to be able to speak to be a leader

83% thought you did not have to do everything on your own to be a leader

'Someone who is able to take charge - able to manage a group of people and bring everyone's ideas together - like a facilitator. The person at the front - a spokesperson, or a representative of that group. A good leader would be someone who naturally took on that role and was accepted by the others'



"I am very heavily interested in disability rights. I've always been interested since I was a child. I hate discrimination, it gets on my nerves" Kate

88%
of young disabled people thought leadership could be shared



Recommendations

- 1** Government and public bodies need to review and change current mainstream leadership initiatives to make them inclusive of and relevant to young disabled people. This is to ensure the views of young disabled people are included at the highest level.
- 2** Government and local initiatives to support and capacity build DPOs need to ensure that involving and supporting Young Disabled People is a key commissioning priority and is factored into long term funding support.
- 3** DPOs should work towards establishing a definition of the term 'leader' that is inclusive and relevant to young disabled people.
- 4** DPOs should review the culture, and audit practice and procedures within their organisations to ensure that their activities include and do not exclude disabled young people.
- 5** DPOs should develop programmes to inform young disabled people about disabled people's history, the social model, human rights and equal citizenship, and proactively plan to include and find resources to bring about the inclusion of young disabled people within their organisations.
- 6** DPOs should make a concerted effort to promote themselves and their activities/services to young disabled people and their allies, including local community groups, schools and residential settings. They should also liaise with social services and youth services to ensure that they are known and that young disabled people and their parents are referred to them.

76%

of young disabled people thought anybody could be a leader

37%

of DPOs stated that there are no barriers to young disabled people in their organisation

- 7** DPOs should recognise and identify ways of working with disabled young people that promote their leadership.
- 8** The Alliance for Inclusive Education with the Disability LIB Alliance should seek funding to hold a series of 'fun' local consultation and involvement events with young disabled people and disabled people's organisations across the U.K to help capacity building and inclusion.
- 9** More detailed research is needed on young disabled people and leadership - research that looks more closely at the specific needs of young disabled people in looked after settings and that includes an even wider range of backgrounds and young people using a range of communication methods.
- 10** The Alliance for Inclusive Education (ALLFIE) should host a national conference for DPOs to network, to develop guidelines for supporting young disabled leaders of the future and to showcase good practice.



“Involve young people in the process of governance and peer mentoring”
Miro

“Make younger people aware that disability is not about you and what is wrong with you” Oliver





Conclusion

It is clear that much more work still needs to be done to ensure that young disabled people are included in the development and implementation of leadership initiatives. Our research has highlighted that none of the young people we interviewed had ever been asked to consider the issue of 'leadership' before, or how the concept of leadership related to them as young disabled people. They were, however, all keen to think about and discuss leadership.

Many young disabled people are missing out on opportunities for leadership that are accessible to their non-disabled peers. As a result the important contributions of young disabled people to ensuring full equality and human rights of disabled people are not being realised. This needs to change. Many of the disabled young leaders who were interviewed for this report cited examples of how disabled adults' interest and commitment made a vital difference to their self esteem and aspirations.

The reality of the current relationship between DPOs and young disabled people suggests that there is a need to build sustainable and welcoming structures of support for young disabled people within the disability community. Our research showed that:

Only 14 organisations (29%) were offering direct work with young disabled people and had dedicated staff or roles for young disabled people within the organisations.

5 organisations (11%) considered that they provide general services for young people, particularly through benefits advice and help with accessing direct payments, etc. But they were not running any dedicated services for young disabled people.

Only 3 organisations (6%) said there were young disabled people already included in their work.

These are disappointing figures, but create a starting point from which to build capacity. It is clear from our research that there is real commitment from DPOs to find ways to build their capacity and develop a greater involvement of young disabled

people in their work, but they need financial support, motivation, access to expertise and resources to do this.

The potential role for DPOs in providing support to young disabled people is poorly recognised and even more poorly resourced. A huge opportunity exists however, with the capacity building of DPOs, to enshrine working with young disabled people as a key priority with beneficial outcomes for future generations.

The report findings illustrate that more work needs to be done on a definition of leadership that is inclusive of all young disabled people, including young people with learning difficulties who also have communication barriers.

Also it is clear that many DPOs need to reflect on the culture and practice within their organisations to build trust and relationships with young disabled people if they want to benefit from their involvement and wealth of experiences. This will take a long term commitment and a willingness to change.

Importantly, DPOs have a key role to play in building confidence, self esteem and a sense of history in young disabled peoples lives. Such a role will help ensure that the next generation of disabled people are better informed about their rights and are more likely to experience day to day living as equal citizens.

This report will help to support the capacity building of DPOs to include working with young disabled people as a key priority. We hope that the rest of the 'Young Disabled Leaders of the Future' project will give DPOs the knowledge, good practice and confidence to go out and make that a reality.

We hope that these findings create a tidal wave of desire for change across the disability community. The Alliance for Inclusive Education believes that without disabled people and the full inclusion of young disabled people equality and equal citizenship are impossible to achieve - in other words,

NOTHING ABOUT US WITHOUT US!





Research Findings in Detail

Introduction to the Research Project

This report represents the findings from a three-month research project carried out between January and March 2009. The main objective of the research project was to look at and report on ways in which Disabled People's Organisations (DPOs) are supporting the development of leadership in the next generation of young disabled leaders. This involved:

Looking at how DPOs and young disabled people understand the concept of leadership

Identifying both formal and informal ways that DPOs include young disabled people and support the development of their leadership skills and subsequent gaps in support

Identifying what DPOs need to do to effectively support young disabled people into leadership roles

Producing a list of findings, outcomes and priorities that reflect the voices of a diversity of people from a range of backgrounds and experiences.

Research Methodology

In order to meet the objectives of the research, various methods of investigation were combined:

Extensive literature was researched

Representatives of DPOs participated in a questionnaire investigation

Young disabled people participated in face-to-face interviews or telephone interviews within a range of settings and were also asked to fill out questionnaires

Groups of participants from one Scope School and two DPOs took part in group interviews

Young disabled people and their allies participated in a one-day consultation event.

The varying methods that were implemented within the framework of the research intended to look at broad aspects of leadership, to refine the empirical findings and minimise random biases that could be induced by using one single method.



The Young Disabled People's Perspective

Outline

This section of the study intends to provide insight into the way disabled people understand the concept of leadership, as well as the way in which DPOs work practices link to leadership initiatives.

Method

For the present study a total of 34 young disabled people were interviewed either individually or in groups. Interviews were conducted by telephone, email or face-to-face and through a consultation event called 'Big Minds, Big Lives'.

The sample of young disabled people

The young disabled participants of this study had a range of impairments and health conditions. The study included mental health system survivors, people with mobility impairments, people with neurodiverse impairments, people with learning difficulties, people with cerebral palsy, people with epilepsy, people with a hearing impairment, facilitated communication users, as well as people with a range of social identities including Black Minority Ethnic (BME), Lesbian, Gay, Bisexual, Transsexual (LGBT).

Participants' ages varied, the majority being from 11 to 25. However, two disabled leaders over 25 years old were also included in this study. The reasons for this are that a) both had been young disabled leaders when they were under 25 and that b) they represent impairment groups that are often excluded: Mental health system survivors and people with learning difficulties.

Participants in the study had varying backgrounds in terms of participation and involvement in leadership initiatives. Some of



them had previously been involved with DPOs and had gone on to start their own organisations and projects. Some were currently involved with DPOs and were in the process of learning about disability equality or developing skills around campaigning.

Two participants were at a Scope residential college and had taken leadership initiatives relating to their student union and been involved with access audits. Three were at a Scope 'special' school for children 'with physical disabilities'.

Others had developed their leadership skills via organisations for disabled people (e.g. Whizz-kidz) and are now involved with national campaigns and organisations. Some were paid workers and were working as apprentices at Hertfordshire Personal Assistant Support Scheme - a DPO. Finally, some were members of Youth Forums.

The Interviews

The twenty-three young people who were interviewed individually and in groups were all asked the same eight questions but the style of questioning was varied to meet their communication styles and access requirements.

None of the young people had been asked to consider the issue of 'leadership' before and were not used to hearing the three words 'young' 'disabled' and 'leader' in the same phrase or sentence. They were, however, keen to think about and discuss leadership.

Questions for Young Disabled People

1. What does the word 'leader' mean to you?
2. Are there any disabled people that you think of as a leader?
3. Do you think of yourself as a 'leader'?
4. What kind of things do you think a young disabled leader might do?
5. Have disabled adults or DPOs helped you to think of yourself as a leader or to develop leadership skills? How?

6. Have disabled adults or DPOs discouraged you in any way? How?
7. Is there anything that disabled adults or DPOs can do to help you to develop leadership skills?
8. Is there anything else you want to say about young disabled people and leadership?

The eleven young disabled people who came to the 'Big Minds, Big Lives' event were asked similar questions but in different ways (see Appendix 3)

The general outcomes of the interviews are presented below.

Question 1 What does the word 'leader' mean to you?

Three types of leaders were identified in the responses:

Work/task-based leaders

'Somebody that leads a group or ... chairs it... Not only responsible for the job you are doing, you have responsibility for each member of your team. You have to instruct them on what to do.'

Leaders as change agents

'Being a leader means pushing for change, being willing to stand up and do the work that others don't. Seeing the situation and wanting to change it and encouraging other people to do the same, utilising your experience to empower other people and get their own leadership going.'

'Traditional image' leaders

'Strong, powerful and worshipped, adored, fast and furious'.

Question 2. Do you think of yourself as a leader?

Most young people responded positively to this question and readily listed a range of issues they are either acting upon or interested in. Most, though not all, issues coincided closely with the disabled people's movement agenda:

'Yes - I am very heavily interested in disability rights. I've always been interested since I was a child ... I hate discrimination, it gets on my nerves. I have a lot of advocacy experience and I've worked in a disability charity....'



“It’s someone that I suppose is able to bring out the best in other people” Oliver

“I want to contribute toward social change for disabled people”

Miro



Some hesitated to identify themselves as leaders:

'I don't consider myself a young leader; I've not been around long enough. There is a severe lack of young disabled people in the DPOs'.

Question 3. Are there any disabled people that you think of as a leader?

Responses fell into five categories:

Other young disabled people/friends

Examples included: Maresa MacKeith, Lucia Bellini.

'Zara Todd - because she is very passionate about causes, and proactive in seeking out what needs to be done. She is well equipped to act as a representative because that's what she wants to do and she is naturally skilled in influencing people. She has got intelligence on her side.'

Disabled adults in young disabled people's lives

Examples included: Phil Samphire, Owen Parry, Nick Saunders, Micheline Mason, Chrissie Wilson, Chris O'Mahony, Simone Aspis, Richard Rieser, Tara Flood.

Famous Disabled Celebrities / Politicians / Sports personalities, etc.

Examples included: Ellie Simmonds, Oscar Pistorius, Alison Lapper, Bert Massie, Tanni Grey-Thompson, Lara Masters, David Blunket, Gordon Brown.

'Daniel Bentley used to play a lot of bowls round here and he won the gold medal in the Beijing Olympics. He is an inspiration'

Famous Disabled Activists

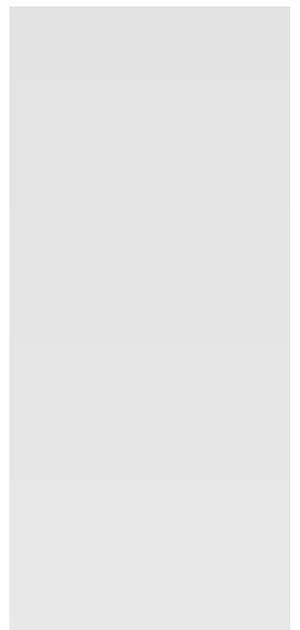
Examples included: Mick Scarlet, Liz Carr, Jacqui Christy James, Rachel Hurst, Mike Oliver, Andrew Lee.

'Someone like Micheline Mason - she started a movement - and Jane Campbell and Anne McDonald'

Organisations of and for disabled people

Examples included: Council for Disabled Children, Priority Trust, 1Voice.

“In Whizz-kidz - there was no such thing as a wrong answer, no one was going to laugh at me, no one was going to say 'you are doing that completely wrong', or 'you are not using the social model properly’” Zara



“They were always giving me menial jobs like cleaning wheelchairs. They wouldn't let me have a staff badge because they always thought of me as a volunteer, they didn't think of me as a staff member” Katie

'People at groups like the Alliance for Inclusive Education have influenced me because they have got so much experience; they know what it is like'

(See Appendix 2 for full details of people mentioned in this section)

Question 4. Have disabled adults or DPOs helped you to think of yourself as a leader or to develop leadership skills?

Responses fell into three categories:

One was adamant that this had never happened:

'Not really, not at all.'

Some underlined the importance of receiving positive affirmation, support, mentoring and encouragement from disabled adults:

'I got lots of encouragement from disabled adults and some also from allies. There were adults that made a difference.'

Some appeared to prefer relying on themselves and their peers:

'I weave my own path and I may have bumps but I'll get there.'

Connections with other young disabled people can be found both to encourage and to dismay young disabled leaders:

'At first it was wonderful but then there were some who talked all the time and some who didn't and it felt like being marginalised again.... I think it is hard for us who can't move on our own to feel we can keep up even with other disabled young people'

Question 5. Have disabled adults or DPOs hindered or discouraged you in any way?

At least one was adamant that this happens:

'Yeah, all the time, kids and adults, bullying me.'

Others tend to feel that disabled adults have not been thoughtful around them:

'When people don't respond to the letters we send out... I start to doubt



myself... Some meetings were awful - they just went over my head without explaining what was going on'

Question 6. What sort of things might a young disabled leader do?

Most people described activities that are part of the disabled people's agenda:

'A young disabled leader should try to represent the views of young disabled people. Young people in general have a goal towards equality; you would be trying to represent their views in general'

'Think independently; build confidence; share ideas; know their rights as young people; inform other young people; be valued, see that impairment is not the problem; inform others about our issue using drama.' (Youth Forum Members)

"I think be a focal point for the voice of young people" Oliver

Question 7. Is there anything that DPOs could be doing better?

Improve communication:

'I was recently approached to join a reference group... But the wording and expression of ideas set out on the application form was incredibly political. They are all valid points but asking young people to sign up to a series of beliefs to get onto a reference group is not realistic'

Avoid personality politics:

'One of the big problems for young disabled people is that there is a lot of personality politics in the DPOs. Some (conflicts) happened before I was born!'

Provide inclusive structures:

'I think I would try and get young people out of the isolation before they can lead'

Be flexible:

'One of the flaws of the current system is that people try to fit young disabled people into whatever the organisation is, rather than letting them know there are different ways of tackling the same issues'

Protect or safeguard personal details, eliminate the reproduction of social stigma:

'If I were to join (a disabled people's organisation) I wouldn't want to disclose anything about my own history. I don't know if I would be happy to go as a mental health system user rather than someone who just works for MIND'

Provide information and better understanding of disability, disability politics, and the social model:

'I think when I was younger it would have been good if they could have helped to make me actually understand what disability was about, make it less of an individual experience. It can be isolating. You almost have to politicise yourself to understand. Make younger people aware that disability is not about you and what is wrong with you'

Orientate towards the actual needs of today's young disabled people:

'Most DPOs do young people's work within the framework of what they needed/wanted when they were young, rather than asking what young disabled people need now'

Employ young disabled people:

'Put money in to employ disabled people to do jobs'

Make involvement with DPOs fun and attractive to young disabled people:

'Too much of what's going on at the moment is trying to fill organisational outcomes rather than providing fun activities for young disabled people - they're giving up free time for free. The least that can be given back is a good time'



“Some are more into direct action - others would prefer to sit round a table - it is completely what the individual makes it” Zara

“The best thing was coming up with ideas to a panel, going to conferences, shouting from the rooftops” Kate



The Big Minds, Big Lives Event

The eleven participants of the 'Big Minds, Big Lives' event were presented with an additional series of 18 questions. The participants' responses are presented below:

Q1 Can anybody be a leader?



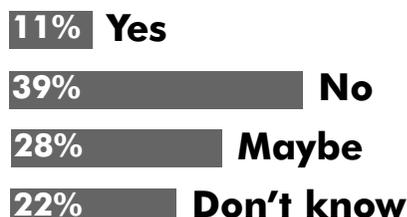
Q2 Do you have to be able to talk to be a leader?



Q3 Does being a leader mean doing everything on your own?



Q4 Do you have to have followers to be a leader?



Q5 Can young people be leaders?



Q6 Is a leader responsible for other people's actions?



Q7 Do you have to know that you are a leader?



Q8 Does the leader have to do all the hard work?





Q9 Is there only ever one leader?



Q10 Can leadership be shared?



Q11 What are the qualities that make good leaders?

What follows below is a summary of young disabled people's thoughts on what makes a good leader. Their responses fall into five categories:

Promotes Social Justice

- Concerned about the community
- Dedicated and committed to the cause
- Fair
- Inclusive
- Represents others, is a voice for the community

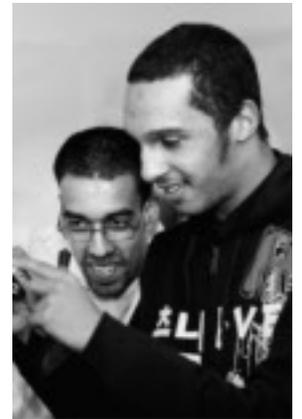
Empowers Others

- Considers and encourages others
- Has high expectations
- Helps others reach goals and objectives
- Helps people reach their potential
- Shares ideas
- Supportive

Manages People

- Encourages initiative

- Good management skills
- Good motivator
- Knows what to ask of people
- Makes something happen
- Recognises team members' strengths and weaknesses
- Thanks and praises people for their efforts



Has Specific Personal Qualities / Skills

- Able to use her/his intelligence
- Decisive
- Determined
- Good communicator
- Good personality
- Has empathy
- Knowledgeable
- Knows where he/she is headed, clear direction
- Listens
- Organised
- Practical
- Reliable
- Flexible
- Polite
- Responsible
- Takes initiative
- Willing to learn
- Works hard

Is Respected by Others

- Gets a response from others
- Someone people look up to

Q12 What are the qualities that make bad leaders?

The responses to this question are summarised below:

Breaks promises; Creates unrealistic goals; Denies people a voice; Discriminates against people because of their disabilities; Communist; Easily led; Excludes others; Fascist; Has a 'Grandad' attitude - a closed mind to new ideas; Has a big ego; Hates and holds back people who are better than him; Is a 'yes' man - can't think for himself; Is a bully; Is big-headed;



Judges people by their colour or race or because of their place in the social or workplace hierarchy; Lies; Promises a lot to get praise (but doesn't deliver) - actions speak louder than words; Racist; Rules by fear - my way or the highway; Selfish; Thinks they are the big 'I am'.

Examples of Bad Leaders: Alfred the Great, George W. Bush; Hitler; Pol Pot; Robert Mugabe; Saddam Hussein; Stalin

Q13 What are the barriers to young disabled people taking on leadership roles?

The responses to this question fell into two categories and are summarised below:

External Barriers

Having to prove yourself to people who are suspicious of your abilities

Ingrained negative attitudes towards young people

Low expectations of people who go through mental health issues

Being ignored - not listened to

Older people thinking they know better - sometimes they really don't

Not being backed by other disabled people when you are right

Being used as a symbol

Being used as a token disabled young person

Organisations that claim to be user-led but are not really

Funding problems

Low aspirations and expectations of young disabled people (from teachers and other adults)

Being isolated at work

Being stereotyped

Lack of access to equipment

Competitiveness from other disabled people

Internal Barriers

Fear of being criticised

Doubting my own ability

Fear of getting it wrong





The DPOs' Perspective: Useful Structures or Unhelpful Barriers

Outline

This section of the study aims to investigate how DPOs look at the concept of leadership, as well as to explore the organisations' practices with regards to leadership initiatives.

Method & Sample

Questionnaires were sent out to approximately 300 DPOs. The questionnaire was designed to find out:

1. What work DPOs are doing with young disabled people
2. How work with young disabled people is funded in DPOs
3. If work undertaken with young people is specifically designed to promote and develop leadership skills
4. Reasons why DPOs do not include young disabled people in their work
5. How DPOs define the term 'leader' to better reflect the range of experiences of young disabled people from different backgrounds and communities
6. What DPOs see as the barriers to leadership for young disabled people within their organisations.

16% of the organisations filled out the questionnaire (49 responses were received).

Results of the investigation

The outcomes of the questionnaire are presented below.

Q1 Does your organisation do any work which includes young disabled people?

Only fourteen organisations (29%) were working directly with young disabled people and had dedicated staff or roles for young disabled people within the organisations.

Thirteen organisations (26%) reported that they did not currently do any specific work with young disabled people.

Eleven (22%) considered that their work on supporting young

29%

of DPOs were working directly with young disabled people

disabled people to become employers, etc. via the use of Direct Payments encouraged them to develop leadership skills.

Five (11%) considered that their general services included young people, particularly through benefits advice and help with accessing direct payments, etc. But they were not running any dedicated services for young disabled people.

Three (6%) said there were young disabled people included in their work.

'We have a few disabled members aged between 19 and 25, who get involved to influence strategies, policies and services affecting their lives.'

Three (6%) were beginning to develop work with young disabled people as a result of successful funding bids for dedicated workers and project.

Q2 Can you describe the kind of work you do which includes young disabled people?

There appeared to be at least four levels of involvement offered by DPOs to young disabled people:

Level 1 - Advice and information, for example on Direct Payments to children and their parents/carers etc. and support to become employers.

Level 2 - Involvement in core activities but no specific activities focused on young people.

Level 3 - Services open to all disabled people including young people, e.g. National Centre for Independent Living:

'All of our activities, information and advice, campaigning, policy and research, are for young people as they are for all groups of people'

- or through a national network representing a particular social identity, e.g. Gemma - a national friendship network for disabled lesbians.

Level 4 - Direct work specifically designed to involve and engage with young disabled people and build leadership skills. (for examples, see Appendix 1)



6%
of DPOs said
there were young
disabled people
included in their
work



Q3 How is this work funded?



Grant giving trusts included City Bridge Trust; Big Lottery, Leonard Cheshire; NSPCC.

Q4 Does the work that includes young disabled people promote/develop leadership skills?



How does this work promote/develop young disabled people's leadership skills?

Respondents suggested the following activities and positive outcomes from those activities could be effective in building young disabled people's leadership:

- Accredited courses
- Advocacy
- Confidence building
- Inclusive organisation
- Involvement in campaign work
- Involvement in decision making
- Leisure activities / sport / events / trips

- Paid employment
- Peer monitoring
- Raising aspirations
- Support to become employers
- Training for independent life skills and employment
- Training opportunities
- User-led organisation



Q5 Is there any reason why your organisation does not include work with young disabled people?

Data analysis revealed that the 13 respondent organisations that do not currently work with young disabled people were positive about the idea of employing young disabled people. The stated reason why they do not offer employment to young disabled people was overwhelmingly a lack of financial resources.

“We are short of funding and have no campaigns in this area at present”

We are now looking to seek funding for a Young People's Development Worker.'

'We recognise that we have a long way to go in terms of actively seeking young disabled people's participation in all the work that we do and would welcome any suggestions or partnerships in how to we take this forward.'

Q6 What is a disabled leader in your opinion?

'There is no difference between a disabled leader and a non-disabled leader other than the fact that disabled leaders may have faced more discrimination and barriers to get where they are'

The preferred definitions of a disabled 'leader' fell into four broad categories. Mainly, a leader was seen as someone who:

- Promotes Social Justice (mentioned by 71% of respondents)



“Disabled leaders are needed at every level of society, and in all areas, not just in relation to disability issues”

Empowers Others (mentioned by 43% of respondents)
Manages People (mentioned by 10% of respondents)
Has specific personal qualities (mentioned by 6% of respondents)

This matched well with the young disabled people's perceptions of the qualities that make good leaders (see question 11 p28)

Some organisations mentioned issues that fell into more than one category:

Promotes Social Justice

Champions equality, diversity, disability rights, independent living & person-centred change
Understands individual needs
Uses social model
Is a change agent
Is an effective activist
Is a campaigner
Speaks up for self and represents others

Empowers Others

Acts as a role model
Motivates
Encourages
Develops
Empowers others
Offers peer support
Inspires others to change the world
Unites others

Manages People

Controls the situation
Takes the lead in a group
Plans
Understands the task and ensures everyone is working to it

Has Specific Personal Qualities / Skills

Enthusiastic
Driven

Passionate
Confident
Motivated
Respected
Listened to



It must be noted that some responses do not fall in the above categories since they represent significantly differing approaches to the concept of leadership. One organisation had a medical model vision of a disabled leader, as being:

'Anyone assisting people with disabilities or promoting the needs of people with disabilities'

Another organisation had a flat hierarchy and disliked the idea of leadership:

'We do not necessarily see anyone as a leader, but prefer to work to a team ethos and respect everyone's opinions'

Some recognised that being a leader did not always have to mean being out in front or being obviously in charge:

'This does not need to be an active role, just going about day to day life and being visible is a leadership role in itself'.

One felt that it was not important to be identified as a 'disabled' leader:

'Someone who takes on a leadership role but does not necessarily identify (as disabled) as such '.

Q7 Are there any young disabled people taking leadership roles within your organisation?

25% Yes

59% No

16% Didn't answer

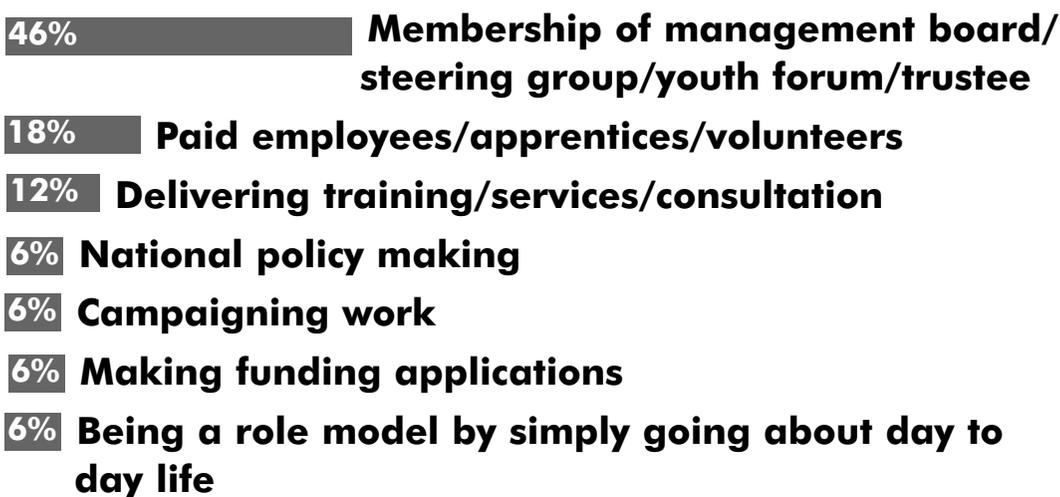
25%
of DPOs have
young disabled
people taking
leadership roles



Ratio of leadership activities undertaken by young disabled people

The following chart presents activities that were mentioned as examples of young disabled people taking leadership roles within organisations included.

In this chart the % frequency with which these activities were mentioned by the respondents is also noted.



37%

of DPOs said there were no barriers to young disabled people in their organisation

Q8 What are the barriers to young disabled people taking leadership roles in your organisation?

37% of the organisations stated that there are no barriers to young disabled people in their organisation.

28% of the organisations which stated that there are no barriers to young disabled people in their organisation are not currently working with young disabled people.

4% of the organisations did not reply at all to this question.

Mainly, the barriers listed by the remaining respondents fell into three broad categories:

Category 1 - Internal Barriers, rooted within the young disabled person

This group of respondents indicated that they felt young people's lack of motivation, confidence, skills, experience,

interest, knowledge, (e.g. not understanding each other's impairment access needs) created barriers to leadership.

'We are an equal opportunities employer. We have little response from young disabled people to our recruitment efforts'

Category 2 - Organisational Barriers

This group of respondents indicated barriers stemming from the organisational structure itself.

'No formal support, planning or process visible to young people who may want to become leaders'

Category 3 - Barriers rooted in societal discrimination

This group focused on barriers rooted in a general social context.

'The usual underpinned discrimination. No resources to train young leaders, etc.'

'In rural locations the lack of public transport causes great difficulties for both workers and volunteers'



“As we are a political organisation I think there are barriers in young people feeling motivated to engage with such organisations”





Recommendations in Detail

This research has been a first step in identifying areas for development so that DPOs can play a more strategic and supportive role in the lives of young disabled people. We have produced 10 recommendations from the findings, which are listed below, with some comment on the issues raised by participants.

- 1 Government and public bodies need to review and change current mainstream leadership initiatives to make them inclusive of and relevant to young disabled people. This is to ensure the views of young disabled people are included at the highest level.**

It is clear from looking at the literature available and our interviews with DPOs and young disabled people that mainstream leadership initiatives have much to do to engage and involve young disabled people as a matter of course (see Relevant Literature list p58).

There are numerous leadership development programmes across the mainstream sector, however most limit the understanding of leadership to running organisations or groups, or standing for local councils etc. It is also the case that disabled people are discouraged from seeking real leadership in their own lives by the way in which services and participation opportunities are often structured so that the power and decision making remains nearly always with others.

Some participants indicated that the barriers to participation in leadership initiatives lie not with the disabled young person but with the way life is set up for them e.g. recognising that most students have high workloads and struggle with trying to keep financially buoyant. Barriers are sometimes created and maintained by 'gate-keepers' in the lives of young disabled people, i.e. people who have responsibility for meeting young disabled people's needs.

Institutionalised discrimination in the benefits system also creates barriers to developing leadership for disabled young

people. For instance, Access to Work funds are not available for Trustees or volunteers, although Trusteeships are a valuable way of gaining and practising leadership skills.

A number of respondents focused on their access issues and discrimination exacerbated by multiple social identities. Disabled young people with additional social identities faced multiple layers of discrimination including disablism, ageism, sexism, heterosexism, racism and educational discrimination, which all play their part in setting up barriers.



'Not being 'out' - there's still much discrimination against Lesbian Gay Bisexual Transgender (LGBT) people of all ages'

'We require more time to learn than hearing peers' (DPO response)

These experiences require public bodies, including DPOs to have in place and promote strong anti discrimination strategies.

2 Government and local initiatives to support and capacity build DPOs need to ensure that involving and supporting Young Disabled People is a key commissioning priority and is factored into long term funding support.

DPOs are constantly under pressure to prioritise, organise and reinvent themselves to external funders to keep going. It is not surprising; therefore, that for many DPOs work with young disabled people has sometimes not been a priority.

Government initiatives, despite an increasingly welcome focus on improving the life chances of disabled people, have not prioritised strategic funding for work with DPOs and young disabled people. Overall organisations expressed or demonstrated that the main barriers for them to include young disabled people as:

DPOs lack funding and resources to support the work

DPOs lack experience and expertise with young people generally



DPOs lack access to young disabled people

DPOs lack motivation to include young disabled people

Those organisations that are working with young disabled people or thinking about working with young disabled people have a number of issues to consider.

The majority of funding received by DPOs came from local authorities, either through local service level agreements or through partnership working with local education and children's services.

Most organisations can only work on issues they are funded for and are constantly managing funding starting or coming to an end for work that needs consistency and development. If we are serious about building work with young people we have to develop long term strategies. We cannot expect, in this instance, that a limited three-year project delivered to some young people at some point in their growing up years will have the desired long-term consequences.

The findings have shown that what is needed is strategic, well thought out programmes of work that will continue with successive generations of young disabled people developing leadership and support rather than short term initiatives with short term goals.

Eight organisations surveyed had no separate funding and offered what they could from their core funding. Five used fees they earned to develop work with young people. There does not appear to be any systematic route of acquiring funding to work with young disabled people that DPOs can apply for.

This makes development work inconsistent and hard to plan and means that young disabled people are not being given adequate access to older disabled people who might be supporters/ role models.

“I got involved in Whizz- kidz because it acknowledged *all* of my identity and most importantly that I was a young person first” Zara

3 DPOs should work towards establishing a definition of the term 'leader' that is inclusive and relevant to disabled young people.

Young disabled people were not happy with the traditional images of leaders as isolated individuals who do all the thinking for everyone. Neither were they happy with the idea that some people are 'more cut out for leadership' than others on the basis of their background, education, or class.

'Say how it really is, not how the adults want it to be'

In the research, they pointed out that many disabled young people have to take leadership initiatives, for instance, with personal assistants, allies and adults, in order to educate them about their needs. They argued that this creates effective leaders for people with every level of impairment or health condition, including those young disabled leaders who do not have verbal communication and/ or have significant learning difficulties. The ability to be able to communicate ideas (by whatever means) and have them taken up by others was the key.

Most young people responded positively to the question **'Do you think of yourself as a leader?'** and readily listed a range of issues that they were either acting upon or interested in. Most, though not all the issues, coincided closely with the issues for DPOs.

'Leadership, definitely by young people gives more opportunities for me as a young person - training, disability action training. Consultations support young people to become leaders'

One participant answered 'no' to this question but then went on to identify a number of examples where they were taking leadership initiatives. It was clear that they had never considered the concept of leadership and this was a common response from participants.

Although one participant wanted to lead on disability equality she hesitated to take on the identity of being a 'disabled leader' because of the perceived stigma attached to her mental health impairment, she felt that her leadership would be undermined.



“A leader takes responsibility, gets all people involved” Patrick



Clearly disabled people from different impairment groups experience discrimination and stigma leading to exclusion at many different levels.

Some people made a distinction between those disabled people who are in the 'limelight' but do not necessarily champion disability issues and those who lead in order to promote disability rights.

'I don't want to be a leader, I want to be a household name'

Disabled leaders are needed everywhere in society - not just in DPOs. Disabled young people do not necessarily all want to lead on disabled people's issues but nevertheless have big ambitions and goals for their lives. DPOs should have a vested interest in supporting the development of their skills and helping them to achieve their full potential.

“Someone who is able to take charge - able to manage a group of people and bring everyone's ideas together - like a facilitator”

Anon

Most young people described leadership activities that are part of the agenda for DPOs. They were keen to take action to varying degrees - sometimes direct action. They were generally aware that a young disabled leader should be wherever possible responsible to the whole community of disabled people and not just represent themselves and their own views.

Although some activities may look small in terms of bringing change, the impact of taking leadership and representing others can be huge for the individual, whose confidence and self-esteem has improved. In a residential school it is not a small issue to challenge practices that have been in place a long time. It can be very daunting to risk upsetting the people you are dependent upon for, for example, personal care.

'I complained at lunch time - I went to the cooks to ask for a different back up meal for me and other people because fish on a Friday is not a very popular meal... They gave us something different whoever asked for something different got something different but whoever didn't just got the Friday fish'

The question for disabled people and their organisations is whether current understanding of leadership and what makes a leader properly reflects the diversity of our community.

For example, disabled people may demonstrate their leadership skills through movement or gestures. Of course, as a community we strive constantly to be inclusive of, and accessible to all and so it must then follow that we focus our efforts on broadening existing definitions of leadership to reflect our shared commitment to equality of opportunity.

The idea that young people are not interested in leadership or politics is strongly refuted in the responses from young people who were asked if they thought of themselves as leaders.

It could be generally concluded from the research that a disabled leader is **'someone who promotes social justice and empowers themselves and other disabled people'**. This is the general consensus of opinion that comes from the research expressed by both disabled adults and young people.

This definition also works well for young disabled people who are non-verbal and have significant learning difficulties. Despite society's lack of recognition of their 'skills', it could be argued that many disabled people are regularly demonstrating leadership initiatives by indicating preferences, choices and aspirations to people around them through movement or gestures.

When their wishes are acted upon and their leadership is followed, it empowers them and can be an inspiration to other disabled people. However a more structured coming together of DPOs and Young Disabled People might shape and sharpen this definition.

There are no fundamental differences between disabled adults' and disabled young people's opinions about general key definitions of leadership.

These findings support at many levels accepted understandings of leadership - from the communication of choice about what to wear or eat, how to spend time and resources to support assistants, etc., to decisions in political office or management of large international corporations.

'I could be like a managing director, maybe even the big boss. I like working in radio. I would like to be the big boss of a radio station'



“A vision for change and the ability to influence. Leadership involves getting co-operation between different groups” Miro



'I hope we get the views of young disabled people coming through. Not just having those voices in an isolated area - not just a disability view. The voices of young people should be heard throughout society. We need to change the structures to make society more inclusive'

4 DPOs should review the culture, and audit practice and procedures within their organisations to ensure that their activities include and do not exclude disabled young people.

A number of respondents indicated not understanding the way DPOs work, or are structured. This excludes or puts off young disabled people from being involved.

For instance, Trustee meetings and Trustees themselves can create barriers if they are not used to having young disabled people decide things for themselves. The young people support these views:

'Most disabled people's organisations do young people's work within the framework of what they needed/wanted when they were young, rather than asking what young disabled people need now. Things have changed quite a lot in the experiences that disabled young people have had since many organisations were set up'

'The idea of being a trustee does not seem to attract young people, or any people for that matter'

Issues that were highlighted included:

Work with young disabled people where they are coming from, not where you would like them to be when you start working with them.

Young people do not always use what adults consider being 'acceptable' vocabulary. Nevertheless it is just as valid as any other communication system.

Cut out the jargon, break things down, use Plain English

Young disabled people felt disempowered by adults who

“They need to explain things like the role of Chair People and Treasurer and all that because I didn't understand what they were on about half the time” Maresa

talked over their heads and did not explain things

Old tensions between disabled adults confuse and dismay potential young disabled leaders of the future. Most of the original disagreements are of no relevance or interest to them but they sometimes feel expected to 'take sides'.

Make sure the organisations structures includes everyone

Be flexible - use a variety of approaches to engage young disabled people

Remember that the issues are not necessarily the same as when you were young

Include everyone, use a non-judgmental approach

Whilst some young people felt that disabled adults had never discouraged them, at least one was adamant that this does happen and others felt that adults were not thoughtful around them.

'Some meetings were awful - they just went over my head without explaining what was going on'

One DPO demonstrated an unawareness of the need to adjust strategies to attract young people, indicating that any young person who wanted to get involved with leadership in their organisation would *'go through the same process as anyone else - a formal approach to the Chief Executive.'*

Such formal procedures are not likely to be accessible to a disabled young person who has not learnt or been taught how these structures work.

Fear of exposure can be an issue for some young disabled people from specific impairment groups who feel overwhelmingly stigmatised.

'I am aware that I can be a member of mainstream society and that I would only be marginalised if I chose to disclose that information'



“All you want to do is to change things but to see disabled people fighting themselves is disconcerting.”

Zara



about me. I can go about my daily life without broadcasting the fact that I am disabled. Someone with an obvious impairment does not have that choice.'

Some DPOs lack commitment to include young disabled people

This is closely tied to issues of funding but also to inherent adultism in our society, which tends to ignore or belittle the concerns of young people. Many adults do not believe that young people are interested in working with them, or interesting to work with.

They do not consider the impact of leaving the next generation to 'just get on with it'. Disabled adults are in general no different from other adults in their attitudes towards young people and will need to consider what gets in the way of their planning for the next generation of disabled leaders.

In addition, DPOs need to reflect on their motivation for including young people to ensure there is a genuine desire to acknowledge and tackle what the real issues are for them. Young people are very good at detecting when adults do not make it clear that their perspectives and skills are being respected.

DPOs lack experience and expertise with young people

Many of the older generation of disabled adults may have been segregated into institutions and strongly discouraged from having children in their lives. Consequently, they may not have any familiarity with growing up in extended families and with young people.

This means that some disabled adults may not connect with young disabled people, particularly where that young person's experiences are markedly different from their own. They may not appreciate the barriers that young disabled people raised in mainstream society encounter and be at a loss to know how to listen to them constructively or to support them. In turn, their lack of contact may impact on young people, making them less communicative and trusting. It may feel easier to both parties to stay away from each other.

“Things have changed quite a lot in the experiences that disabled young people have since many organisations were set up” Zara

In addition, many DPOs are not familiar with Child Protection legislation or policy and lack funds and resources for example to get Criminal Record Bureau checks. This may decrease the likelihood of working with young disabled people.

Most DPOs have no dedicated young people's worker, so any work with young people is left to individual members of staff ability to commit time and resources. Appointing dedicated workers may be a good opportunity to educate and involve the whole staff group on thinking and acting upon the needs of young disabled leaders of the future. However, there needs to be a top down commitment, throughout the organisation to guard against any tendencies to leave the dedicated worker to 'get on with it'.

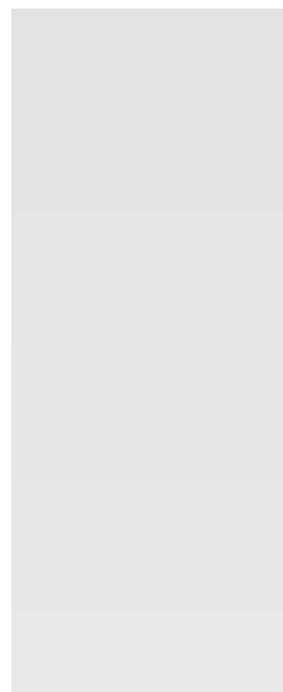
Despite this, there was much evidence that DPOs are keen to consider how to include young disabled people more.

5 DPOs should develop strategic programmes to inform young disabled people about disabled people's history, the social model, human rights and equal citizenship and proactively plan to include, and find resources to bring about the inclusion of young disabled people within their organisations.

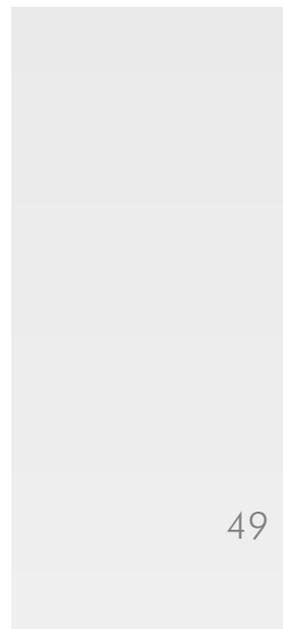
Many organisations that responded did not mention the social model of disability. It is not clear whether this is because it is taken as obvious that organisations have not fully embraced the social model, or whether it is because they no longer consider it to be relevant.

Greater Manchester Coalition of Disabled People have produced a DVD ('**The Young Disabled Peoples Forum - Our life our Say! Peer Mentoring - A Good Practice Guide**') which gives useful information on working with young disabled people.

Young disabled people do not necessarily differentiate between an organisation 'of' disabled people and an organisation 'for' disabled people when looking for supportive adults. DPOs will need to recognise that it takes time and input to convey an understanding of rights, the history of the disabled people's



“You almost have to politicise yourself to understand” Oliver





movement and the social model of disability in a way that is fun and meets people's learning needs.

'I got into disability stuff through a disabled children's' charity, (Whizz-kidz). It was the first thing I was involved with that was explicitly about disability but not specifically young disabled people (just wheelchair users). It got me interested in disability equality - not the extreme end, just young wheelchair users - this pushed me towards leadership.'

The issues are not necessarily the same for young disabled people as they are for disabled adults and not the same as they were when today's adults were young people. However, this does not mean that young disabled people are uninterested in social change - they are just coming from different perspectives at different times.

'Some young disabled people can be hindered in developing leadership skills because they might not have as much information (as older people)'

Many of the 'heroes' of the disabled people's movement have had an upbringing developed in special schools and it could be argued that direct experience of segregated schooling leads young disabled leaders to identify the oppression more easily than those young disabled people who may be isolated in mainstream schools.

'I think when I was younger it would have been good if they could have helped to make me actually understand what disability was about, make it less of an individual experience. It can be isolating and lonely. You almost have to politicise yourself to understand. Make younger people aware that disability is not about you and what is wrong with you'

We can conclude that providing young disabled people with information and knowledge from a social model perspective that relates to their own life experiences would be beneficial in increasing self esteem and facilitating inclusion.

- 6 DPOs should make a concerted effort to promote themselves and their activities/services to young disabled people and their allies, including local community groups, schools and residential settings.**

They should also liaise with social services and youth services to ensure that they are known and that young disabled people and their parents are referred to them.

Many DPOs do not have networks of, or contact with individual young disabled people. Many do not have connections with local schools, 'special' schools, or with young disabled people generally who are in looked after residential settings or the many other community settings where disabled young people might be found.

It is important to develop working relationships with special schools and develop interpersonal relationships with the young disabled people in them. Those young people interviewed in special schools did not have any contact with adult disabled role models.

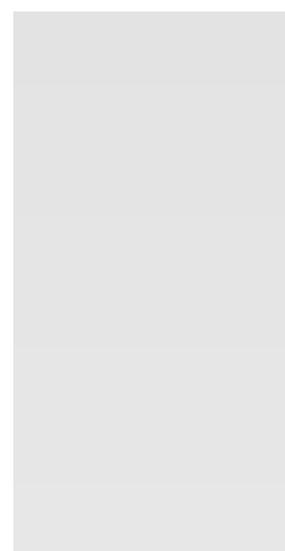
The existence of child protection legislation makes it perhaps more difficult for any adult to form relationships with young people that are not sanctioned by the guardians in young people's lives (i.e. teachers, parents, youth workers, etc).

This poses challenges for DPOs in developing work with young disabled people. Schools tend to be disconnected and at times resistant to interventions from DPOs and non-disabled adults often do not see the relevance of disabled adults in young disabled people's lives.

Other young disabled people might use or be involved in community organisations specifically created to support particular community needs. This issue could start to be addressed through the building of relationships with schools and community based groups, which include DPOs.

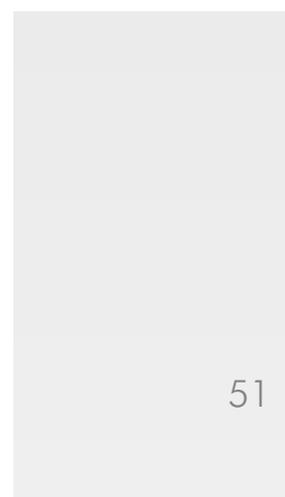
7 DPOs should recognise and identify ways of working with disabled young people that promote their leadership.

It is clear from the research that most young disabled people would like disabled adult mentors who would be able to support them consistently.



“The voices of young people should be heard throughout society. We need to change the structures to make society more inclusive”

Oliver





Young disabled people need disabled adult role models

Young people who responded to the interviews mentioned over and over again that the adults who inspired them were *'just around'* and available to them on a long-term basis. It did not seem to matter that the adult in question had not recognised his or her own importance to the young person.

The main benefit for a young person was one of believing in the young person's skills and abilities and communicating that belief to the young person. It was important that the young person felt they had access to a particular adult even if they did not have any regular contact. Contact may be unplanned or distant, but it seems to make a big difference to young people's confidence in their own leadership if they feel that at least one adult has a relaxed and friendly interest in what they do and can offer advice and support when it is asked for.

“He always asked me to be there to give my opinion on education. He said they couldn't do it without a young person who had struggled in the system and he said I was articulate around it. ” Maresa

Parents of disabled young people are often isolated and may not readily seek out adult role models for their young people. Young disabled people often do not know how to seek out disabled adults. Most of the interviewees had stumbled upon inspirational disabled adults by accident rather than by design. They are not on the whole aware of the existence of DPOs or of what they do.

It was highlighted that connections with other young disabled people can both encourage and dismay young disabled leaders and that they need support when trying to encourage other young people to have greater control in their lives.

'It is very difficult because I don't want young disabled people all to be living the fight for disability rights but (I don't want them to be) ever so grateful for the crumbs that society offers them - they don't want to kick up a fuss - they know their place'

Young disabled people are readily able to identify disability equality and inequality, maybe at different levels, and are keen to work on challenging inequality. However, the same approach to engaging young disabled people will not suit everybody - flexible thinking and fun activities are more likely to attract young people.

Standard DPO committee meetings and many DPO organisational structures are not likely to be attractive options for young disabled people who, after all, are being asked to give up their limited free time for no remuneration.

'Taking a very hard line about what you want from young disabled people rather than going through the process of listening to what the issues are for them and letting them develop their own thinking is off-putting'

DPOs need to encourage young disabled people to design and present activities that are attractive to them and other young disabled people. DPOs are then more likely to produce good leaders.



- 8 The Alliance for Inclusive Education with the Disability LIB Alliance should seek funding to hold a series of 'fun' local consultation and involvement events with young disabled people and disabled people's organisations across the U.K to help capacity building and inclusion.**

It is important that work takes place to stimulate the bringing together of DPOs and young disabled people across the U.K.



in a way that is attractive and engaging for young disabled people. This stimulus needs to be a stepping stone to then building sustainable networks and forums that enable young people to have much greater choice and control in their lives supported by DPOs.

See Appendix 3 'Big Minds, Big Lives' event programme for an example of a programme designed to deliver effective and fun consultation with disabled young people. Young disabled people are equally responsive to and as capable of action for change as older disabled people.

- 9 More detailed research is needed on young disabled people and leadership - research that looks more closely at the specific needs of young disabled people in looked after settings and that includes an even wider range of backgrounds and young people using a range of communication methods.**

It was not possible within the time constraints of this work to develop the necessary relationships with some young disabled people in the above groups to systematically get their views but this should definitely be followed up in any future research on young disabled people and leadership.

This research was a limited piece of work but it was clear that many young disabled people in the above groups are often invisible to their local communities and experience higher levels of isolation and exclusion.

- 10 The Alliance for Inclusive Education (ALLFIE) should host a national conference for DPOs to network, to develop guidelines for supporting young disabled leaders of the future and to showcase good practice.**

ALLFIE recognises that DPOs that are working on building leadership skills with young disabled people have varying levels of commitment and involvement. However, there is no apparent consensus on what constitutes good practice.

Thirteen organisations from our survey were working on building young disabled people's leadership but they were all using different models. This in itself is not a problem, but it would be helpful to have across-the-board discussion and debate about methods used and how local situations inform the development of different models.

ALLFIE will be holding a national conference at the end of the Disability Lib project in 2011 to deliver this recommendation.

ALLFIE has awarded two grants in July 2009, to Darlington Association on Disability and Norfolk Coalition of Disabled People to test out the findings of our research and to develop their leadership work with young disabled people.

We will be making a 3rd grant in Autumn 2009 supported by Scope which will target leadership work with young disabled people who attend a Scope residential school and college. These new developments will build on ALLFIE's existing work developing young people's forums in the London Boroughs of Lambeth and Newham.



'Just because young people don't communicate the same way as the person on the other side of the room, doesn't mean they don't have anything to say or shouldn't be heard. That is why it is so important to have young people's voices come through.'



Available Relevant Literature

What follows is a list of literature that may be useful to future researchers.

It was difficult to find any literature that directly referred to 'young', 'disabled' and 'leadership' in the same sentence. Most work on leadership relates to adults and most work on young people's leadership relates to sports leadership or leadership in terms of gender, culture or interests. The following literature was identified as being of relevance.

Significant texts from the literature search were rare. However, the following were considered as matching the search parameters.*

Basis Partnership Work Phase 1 (May - July 2007) Aspis, S. (2007).

Career Success of Disabled High Flyers Shah, S. (2008), Jessica Kingsley Press.

Defying Disability Wilkinson, M. (2007), Jessica Kingsley Press.

Disability and Diversity: New Leadership for a New Era Walker, S., Turner, K. A., Halle-Turner, M., Vincent, A., Miles, M. D. (1995), Presidents Committee on Employment of People With Disabilities and Howard University Research and Training Centre.

DRC Leadership Strategy DRC, (2006)

Equalise It! A Manifesto for Disability Equality in Development Cooperation UKDPC, (2008)

(<http://www.leeds.ac.uk/disability-studies/archiveuk/ukdcp/Equalise%20It%20final.pdf>)

Leadership by People with Disabilities in Self-Determination Systems Change Powers, L. E., Ward, N., Ferris, L., Nelis, T., Ward, M., Wieck, C., & Heller, T. (2002), Journal of Disability Policy Studies

(<http://dps.sagepub.com/cgi/content/abstract/13/2/126>)

Leadership Development Programme will support Disabled People to influence Public Life RADAR, The disability Network, (2008)

(<http://www.radar.org.uk/radarwebsite/RadarFiles//Documents/Press%20Releases/20080806-press-release-Radar-Leadership-Development-Days.doc>)

Our Movement needs Leaders Rickell, A. (2007)

(<http://www.disabilitynow.org.uk/have-your-say/andy-rickell/our-movement-needs-leaders>)

General disability issues that need to be raised and considered when promoting leadership in disabled people's organisations for young people

The Glass Ceiling and Persons with Disabilities Braddock, d. & Bachelder, L. (1994), Federal Publications.

Barriers to Independent Living: A scoping paper prepared for the Disability Rights Commission Morris J. (2003)

(<http://www.leeds.ac.uk/disability-studies/archiveuk/morris/independent%20living%20scoping%20paper%20final%20edit.pdf>)

Carbon: Appointing Britons with Disabilities Grayson, D. (2007)

(http://www.carbonsearch.com/thecarbonreport/CF_Diversity_DavidGrayson.asp)

Citizenship and Disabled People Morris, J. (2005)

(http://www.leeds.ac.uk/disability-studies/archiveuk/morris/Citizenship_and_disabled_people_final.pdf)

Disability, Identity and Difference Shakespeare, T. (1996) in 'Exploring the Divide' Barnes C., & Mercer, G. (Eds.), Leeds: The Disability Press, pp. 94 - 113.





Disability Politics: Understanding Our Past, Changing Our Future Campbell, J., & Oliver, M. (1996), Routledge.

Disabled People's Organisations and Developments: Strategies for Change Hurst, R. (1999) in 'Disability and Development: Learning from action and research on disability in the majority world', Stone, E., Leeds: The Disability Press pp. 25-35.

Disabled Students in London. A review of higher and further education, including students with learning difficulties Greater London Authority, (2007) (<http://www.london.gov.uk/mayor/education/docs/disabled-students.pdf>)

Effecting Change: Disability, Culture and Art Barnes, C. (2003); Paper presented at the Finding the Spotlight Conference, Liverpool Institute for the Performing Arts, University of Leeds.

Including Disabled People Breakthrough UK Policy, Think Tank, ODI Consultation - Equality for Disabled People, (2007) (<http://www.leeds.ac.uk/disability-studies/archiveuk/breakthrough/ODI%20Consultation-final.pdf>)

Fighting for a slice, or for a bigger cake? Campbell, J. (2008), The 6th Annual Disability Lecture, University of Cambridge St John's College

Independent Living for People with Disabilities: from patient to citizen and customer Ratzka, A. (2007), Invited Presentation at the Convergencia Conference, Barcelona; (<http://www.leeds.ac.uk/disability-studies/archiveuk/ratzka/2007%2010%20Barcelona%20final.pdf>)

Internalised Oppression: How it seems to me Rieser, R. (1990), in Rieser, R. & Mason, M. (Eds.), 'Disability Equality in the Classroom - A Human Rights Issue', London: ILEA.

Leadership and Self-Determination Johnson, J. R. (1999), Focus on Autism and Other Developmental Disabilities, 14 (1), pp. 4-16.

Leadership of disabled people in Australia Leadershipplus (2009)

The Positive Action Leadership Programme National Disabled Police Association (<http://www.ndpa.info/Home/palp.html>)

One Northeast Disability Equality in Skills and Leadership Action Plan 2006-2007 (<http://www.onenortheast.co.uk/object/download.cfm?lib=liDownload&id=10511>).

Public Policy and Organisations of Disabled People Gibbs, D. (2005), Text of seminar presentation, Centre for Disability Studies (<http://www.leeds.ac.uk/disability-studies/archiveuk/Gibbs/Leeds-0504.text.pdf>)

Leadership Radar, The Disability Network (<http://www.radar.org.uk/radarwebsite/tabid/217/default.aspx>)

Examples of participatory decision making of disabled people and young disabled people

Access to Youth Work for Disabled Young People Policy Document Wiltshire Youth Development Service, Wiltshire County Council (<http://www2.wiltshire.gov.uk/high/access-to-youthwork-for-disabled-young-people.pdf>)

A View from the Balcony: Leadership Challenges in Systems of Care Heifetz, R., Linsky, M. & de Carolis, G. (2005), Brown Books Publishing Group.

Developing Disabled Leaders in Essex Adams, M. (2007)

English Federation of Disability Sport (<http://www.efds.co.uk>)
Listening and Responding? Children's participation in health care within England Franklin, A., & Sloper, P. (2006), in Freeman M. (ed.), 'Children's Health and Children's Rights', Martinus Nijhoff Publishers, pp. 11-29.





Moving Forward: Progress in global disability rights:

Lindqvist, B. (2007), Disability Rights Promotion International (DRPI)

(<http://www.yorku.ca/drpi/files/MovingForwardFINAL.pdf>)

Supporting the Participation of Disabled Children and Young People in Decision-making

Franklin, A. & Sloper, P. (2007), Social Policy Research Unit, The University of York; (<http://www.york.ac.uk/inst/spru/pubs/rworks/jan2007-01.pdf>)

Participation of disabled children and young people in decision making within social services departments: A survey of current and recent activities in England Franklin, A. & Sloper, P. (2006), British Journal of Social Work, 36 (5), pp. 723-41.

Participation of disabled children in individual decisions about their lives and in public decisions about service development Cavet, J. & Sloper, P. (2004), Children & Society, 18 (4), pp. 278-90.

Participation of disabled children and young people in decision-making within social services departments in England Franklin, A. & Sloper, P. (2004), Research Works 2004-02, Social Policy Research Unit.

Supporting the participation of disabled children and young people in decision-making Franklin, A. & Sloper, P. (2009), Children & Society, 23 (1), pp. 3-15.

Sync: Disability Leadership Development Programme Deaf Forum (2008)

(<http://www.deafforum.co.uk/index.php?showtopic=1998>)

The education and employment of disabled young people - frustrated ambition Burchardt, T. (2005), Bristol: Policy Press.

The National College for School Leadership's commitment to good practice in employing disabled people



The participation of children and young people in decisions about UK service development Cavet, J. & Sloper, P. (2004), *Child: Care, Health and Development*, 30 (6), pp. 613-621.

User Driven Hertfordshire PASS Workability, (2008) (<http://www.hertspass.com/workability.shtml>)

Young Disabled People Aspirations, Choices and Constraints Shah, S. (2008), Jessica Kingsley Press.

Inspirational' disabled people - auto/biographical Whilst not directly considered leaders, the following may be positive role models as high achievers in their fields:

The Blunkett Tapes: My Life in the Bear Pit Blunkett, D. (2006), Bloomsbury.

Blade Runner Pistorius, O. (2009), London Virgin Books.

Blood and Sand Gardner, F. (2006), Bantam Press.

Four Fingers and Thirteen Toes Moriarty-Simmonds, R. (2007), La Fontaine Media.

It's Not About the Bike: My Journey Back to Life Armstrong, L. (2001), Yellow Jersey Press.

Lucky Man: A Memoir Fox, M. J. (2003), Random House.

Moving Violations: War Zones, Wheelchairs, and Declarations of Independence Hockenberry, J. (1995), Hyperion Books.

My Life in My Hands Lapper, A. & Feldman, G. (2006), Pocket Books.

Nothing is Impossible: Reflections on a New Life Reeve, C. (edited by K. Parkin) (2002), Century.



Seize the Day: My Autobiography Grey-Thompson, T. & Broadbent, R. (2002), Coronet Books.

The Diving-Bell and the Butterfly Bauby, J.-D. (1997), HarperPerennial.

Examples of Projects for young leaders

The Football Association

(<http://www.thefa.com/GetIntoFootball/School/NewsAndFeatures/2007/YoungLeadership07.aspx>)

Northern Leadership Academy The Sixth Yorkshire Leadership Conference 2009

Scotland Leadership for Girls

(<http://www.youthscotland.org.uk/training/girls-on-the-move-leadership-courses/girls-on-the-move-leadership-courses.htm>)

Sports Leaders Programme (<http://www.sportsleaders.org/>)

The Churches for All Partnership

(http://www.churchesforall.org.uk/all_organisation.html)

Young Muslims (<http://www.da.mod.uk/spotlights/young-muslim-leadership-course-20th-may-2008/>)

Young People Leading Change

(www.teachernet.gov.uk/publications)

*Web-pages visited on December 16th, 2009

List of Participants

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Young People:

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Appendix 1

List of participating DPOs that are currently working with young disabled people

Central England People First Ltd. include young disabled people with learning difficulties in advocacy and consultation events. www.peoplefirst.org.uk

Darlington Association on Disability employ young disabled people as Experts by Experience, link with the local youth parliaments, develop Young Ambassadors in identifying and engaging rights-based information and advice work, peer mentoring and many other activities and services specific to young people. www.darlingtondisability.org

Disability Cornwall have a match-funded disability sport community coach working with special needs schools, day centres and disabled children in mainstream education. They also have plans to support young disabled people to exercise choice and control through the establishment of a young people's partnership board. www.disabilitycornwall.org.uk

Essex Disabled People's Association Ltd. offer training for office work and involvement as volunteers in 120 local disability clubs in Essex. www.disabilityessex.org

Hammersmith and Fulham Action on Disability have an Agenda for Youth programme which provides leisure, education and access to social opportunities; promotes inclusive services and develops progression routes; provides support for families of disabled people; training for independent life skills, etc. Young people have been successful in making funding applications and have launched an accessible recording studio. www.hafad.org.uk

Hertfordshire Personal Assistant Support Service (PASS) employ three young disabled people as apprentices to run Workability, a user-driven project providing work experience opportunities for young disabled people. They have taken on





leadership roles in much of the work they are required to do. PASS has produced a book - 'User Driven' which carefully details the work of Workability, including processes involved in appointing staff, working in the community and what it means to be a user-led organisation. See Literature Search for details. www.hertspass.com

Ideal for All has a dedicated staff member who works specifically with 16 to 25-year-olds to enable them to access the job market. The project aims to reduce benefit dependency, through empowering young people to become socially and economically active and independent and develop leadership skills pertinent to running an organisation: 'Our young people's project mirrors the user-led philosophy of Ideal for All which is achieved through a steering group comprised of young disabled people. The Chair is a 25 year old disabled woman.' www.idealforall.co.uk

Manchester Coalition of Disabled People has a young disabled people's forum that hosts a range of activities designed to empower young disabled people and build leadership skills, e.g. Group meetings; peer mentoring; independent living training; information and advocacy; and issue-based drama presentation. They also have 3 young people on their management board. www.gmcdp.com

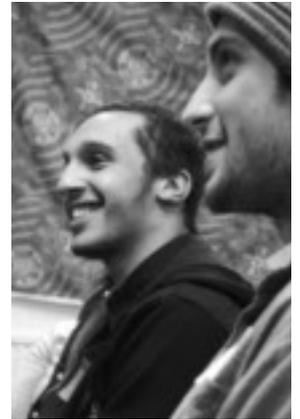
Marigold Training offer training courses designed to encourage development of leadership skills. www.marigoldtraining.com

Portsmouth Disability Forum offer work placements to young disabled people. www.p-d-f.org

Shape is in the process of assembling a Steering Group of young people with learning difficulties (16-25) to drive their 'Articulate' programme. www.shapearts.org.uk

Vision Sense offers aspirations workshops; young trustees' training; work experience and apprenticeships; training in DPOs' history; disability rights and choices, independent living; and advice and information. They also support local youth groups to be inclusive and accessible. www.visionsense.co.uk

Warrington Disability Partnership has a dedicated Young Person's Development Worker (a young disabled person herself) and offers a range of opportunities for young people to become involved in leadership development activities, including a Young Ambassadors Project, Leisure, Recreation and Sports provision and a youth club. They work with a range of funders and partnership organisations, including local schools and colleges. www.disabilitypartnership.org.uk





Appendix 2

List of disabled people referred to as role models

Maresa MacKeith - Young disabled activist for non-verbal people using facilitated communication, former member of Young and Powerful, co-founder of One for All.

Lucia Bellini - Young disabled activist, former member of Young & Powerful.

Zara Todd - Young disabled activist, Vice-Chair of Equality 2025.

Phil Samphire - Project Worker, Greater Manchester Coalition of Disabled People.

Owen Parry - Chair of Hertfordshire Personal Assistant Support Service.

Nick Saunders - Disability Equality and Inclusion activist.

Micheline Mason - Founder of the Alliance for Inclusive Education, inclusion activist.

Chrissie Wilson - Disabled inclusion activist.

Chris O'Mahony - Disability equality and inclusion activist.

Simone Aspis - Disability equality and inclusion activist.

Daniel Bentley - Paralympic athlete.

Ellie Simmonds - Paralympic swimmer.

Alison Lapper - Artist/TV personality.

David Blunkett - Labour MP.

Gordon Brown - Prime Minister of UK.

Bert Massie - Chair, Office for Disability Issues, Commission for Equality and Human Rights.



Mick Scarlet - Disabled TV presenter/DJ.

Oscar Pistorius - Paralympic athlete.

Liz Carr - Disabled actress/comedienne.

Dame Tanni Grey-Thompson - Paralympic athlete/sports personality.

Lara Masters - Columnist /TV presenter.

Mike Oliver - Disability rights activist, author and academic.

Baroness Jane Campbell - Equality & Human Rights Commission Commissioner.

Anne McDonald - Australian disability rights activist for non-verbal communicators.

Jacqui Christy James, MBE - Co-director and founder of the International Disability and Equality Agency.

Rachel Hurst, CBE - Director, Disability Awareness in Action.

Tara Flood - Disability rights activist, Director of the Alliance for Inclusive Education.

Richard Rieser - Director, Disability Equality in Education, inclusion activist.

Andrew Lee - Director, National People First - national advocacy organisation for people with learning difficulties.

Council for Disabled Children - Government national umbrella organisation for disabled children's sector in England.

The Priority Trust - Charity promoting disabled children's independence.

Whizz-Kidz - Charity helping disabled children throughout the UK via provision of mobility aids etc.

1Voice - Network of support and information for children who use communication aids, and their families.

Appendix 3

Big Minds, Big Lives Event Programme Feb 2009

TIME	ACTIVITY	RESOURCES
10.30	Set up	Lights, fabric, images, blue tac, tacks etc.
11.00	Registration	Release Forms Registration Forms
11.11	Intros with drum beat + opportunities to experience leading the drumming and saying what that feels like	Drums
11.30	What is a leader? - draw round bodies - identify good and bad types of leaders	Flipchart paper, tape, pens etc. Collage images
12.00	Are there any disabled people that you think of as a leader? Divide into 2 or three groups, thought storm - write on flipchart paper, compare with each group	
12.30	Do you think of yourself as a 'leader'? 'Yes, No, Maybe' Exercise - see questions	Questions and room to move
1.00	LUNCH BREAK	Food, drink, plates, cups, cutlery etc.
1.30	Have disabled adults or disabled people's organisations helped you to think of yourself as a leader or to develop leadership skills? How?	

TIME	ACTIVITY	RESOURCES
cont.	<p>Have disabled adults or disabled people's organisations discouraged you in any way? How?</p> <p>Is there anything that disabled adults or disabled people's organisations can do to help you to develop leadership skills?</p> <p>Forum theatre - issues: adults talking in jargon - inviting you to meeting just to tick a box for fundraising. Ancient conflicts between disabled adults confusing young disabled people. Sent to work experience - ignored, misused, etc.</p>	
3.00	Anything else you want to say about young disabled people and leadership?	Flipchart, pens etc.
3.45	Goodbyes and Evaluation (Balloon images)	

Yes, No, Maybe Questions

1. Can anybody be a leader?
2. Do you have to be able to talk to be a leader?
3. Does being a leader mean doing everything on your own?
4. Do you have to have followers to be a leader?
5. Can young people be leaders?
6. Is a leader responsible for other people's actions?
7. Do you have to know that you are a leader?
8. Does the leader have to do all the hard work?
9. Is there only ever one leader?
10. Can leadership be shared?

Appendix 4

List of 'Good Leader', 'Bad Leader' Qualities

Disabled young people identified a 'good' leader as someone who:

<p style="text-align: center;">Promotes Social Justice</p> <p>Is concerned about the community</p> <p>Is dedicated and committed to the cause</p> <p>Is fair</p> <p>Is inclusive</p> <p>Represents others - a voice for the community</p>	<p style="text-align: center;">Empowers Others</p> <p>Is considerate to others</p> <p>Encourages others</p> <p>Has high expectations</p> <p>Helps other people to reach goals and objectives</p> <p>Helps people reach their potential</p> <p>Shares / Shares ideas</p> <p>Is supportive</p> <p>Supports people who need help</p>
<p style="text-align: center;">Manages People</p> <p>Encourages initiative</p> <p>Has good management skills</p> <p>Is a good motivator</p> <p>Knows what to ask of people</p> <p>Makes something happen</p> <p>Recognises other team members' strengths and weaknesses and offers appropriate support</p> <p>Thanks and praises people for their efforts</p>	<p style="text-align: center;">Has Specific Personal Qualities/ Skills</p> <p>Is able to use her/his intelligence</p> <p>Is decisive</p> <p>Is determined</p> <p>Is a good communicator</p> <p>Has a good personality</p> <p>Has empathy</p> <p>Is knowledgeable</p> <p>Knows where he/she is headed - clear direction</p> <p>Is organised, practical, reliable, flexible</p> <p>Listens / Is polite</p> <p>Is responsible</p> <p>Takes initiative</p> <p>Is willing to learn</p> <p>Works hard</p>

Disabled people's organisations identified a disabled 'leader' as someone who does one or more of the following:

<p style="text-align: center;">Promotes Social Justice</p> <p>Champions equality and diversity</p> <p>Disability rights</p> <p>Independent living</p> <p>Person centred change</p> <p>Understands individual needs</p> <p>Uses social model</p> <p>Change agent / Campaigner</p> <p>Effective activist</p> <p>Speaks up for self and represents others</p>	<p style="text-align: center;">Empowers Others</p> <p>Role model</p> <p>Motivates</p> <p>Encourages</p> <p>Develops</p> <p>Offers peer support</p> <p>Inspires others to change the world</p> <p>Unites others</p>
<p style="text-align: center;">Manages People</p> <p>Controls the situation</p> <p>Takes the lead in a group</p> <p>Plans</p> <p>Understands the task and ensures everyone is working to it</p>	<p style="text-align: center;">Has Specific Personal Qualities/ Skills</p> <p>Enthusiastic</p> <p>Driven</p> <p>Passionate</p> <p>Confident</p> <p>Motivated</p> <p>Respected</p> <p>Listened to</p>

Appendix 5

Questionnaires

Questionnaire for Centres for Independent Living and Disabled People's Organisations

Your name:

Position:

Organisation:

Address:

Email:

Tel: no.

1. Does your organisation do any work which includes young disabled people?
Yes - go to Q.2
No - go to Q.5
2. Can you describe the kind of work you do which includes young disabled people?
3. How is this work funded?
4. In your opinion, does the work that includes young disabled people promote/develop leadership skills?
How?
5. Is there any reason why your organisation does not include work with young disabled people?
6. What is a disabled 'leader' in your opinion?
7. Are there any young disabled people taking leadership roles within your organisation?
8. Can you list any barriers to young disabled people taking leadership roles in your organisation?

Questions for Young Disabled Participants

1. What does the word 'leader' mean to you?
2. Are there any disabled people that you think of as a leader?
3. Do you think of yourself as a 'leader'?
4. What kind of things do you think a young disabled leader might do?
5. Have disabled adults or disabled people's organisations helped you to think of yourself as a leader or to develop leadership skills? How?
6. Have disabled adults or disabled people's organisations discouraged you in any way? How?
7. Is there anything that disabled adults or disabled people's organisations can do to help you to develop leadership skills?
8. Anything else you want to say about young disabled people and leadership?

Notes

“Being a leader means pushing for change, being willing to stand up and do the work that others don't. Seeing the situation and wanting to change it and encouraging other people to do the same, utilising your experience to empower other people and get their own leadership going” Young Participant

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