

"If you've got summat
to say, you've got
summat to say, it dun't
matter how old you are"

Young Disabled People - Moving into Adulthood

A report from the Conference

Leeds - 24th February 2000



Introduction

The idea for the conference came about because some people recognised that work needed to be more co-ordinated and that a lot of changes needed to happen if disabled children were to have more equality.

The groups involved in organising the day were (see appendix 4 for contact details):

- The Commissioning, Implementation and Performance Management Team - Services for Disabled People - who wanted services to work together more effectively.
- The Disability Research Unit at Leeds University - who wanted to let staff and disabled children know about recent research into the lives of disabled children.
- The Development Officer for Disabled Children who works for Social Services and Health - who wanted more effective support and co-ordination for young people going through changes in their lives (the transition to being an adult).
- Save the Children - who wanted to help make sure that disabled children get the same rights as other children.
- Leeds Centre for Integrated Living - who wanted to make sure that their services were appropriate for young disabled people.

All the organisers wanted three important things:

- For disabled children's views to be heard by those providing and responsible for services
- For professionals and services to understand some of the barriers to independence, inclusion and equality that disabled children face
- For the conference to be more than just a 'talking shop', and for real change to come out of it.

To achieve this we did a number of things in planning the day:

1. We made the conference 'invite only', so we could make sure that it was made up half of disabled children and half of workers. Invites were sent to disabled children who had taken part in the research project and to workers in various organisations involved in services that affect disabled children's lives (see delegate list - Appendix 1).
2. We planned workshops during the day, to make it easy for as many people as possible to contribute (see outline of the day - Appendix 2).
3. We invited disabled adults who had grown up with disability to run the workshops.
4. We provided transport and personal assistance for disabled young people so that everyone could come
5. We tried to use language that everyone could understand and relate to.
6. We held the conference at Elland Road football ground, so that people could have a look round. This was partly to thank disabled children for all the time they had put in.

"Given that disabled children have limited chances to play football, a football ground was an ironic choice of venue!"



Aims for the day

"...at the moment I am not as independent as I would like to be and I obviously need to get more independent if I'm going to have a life when I grow up.."

These are the aims and outcomes that we sent out to everyone who was coming to the conference, so they knew what we were trying to do:

Aims: (what we are trying to do)

- For people who work in services to hear what young disabled people want and what they have to say.
- For people who work in services to be able to find out what stops young disabled people being independent and being part of things on an equal level.
- For people who work in services to say they will work in a way that stops that happening.
- For young disabled people to be able to help change services and what is decided about them.
- To help make the change from being a kid to being an adult better for disabled children/young disabled people.

Outcomes: (what should happen on the day)

- Mark Priestley will talk about what the research found out.
- Young disabled people will feel better about themselves and their friends.
- We might be able to set up a young disabled people's group to look at other stuff that we care about.
- To make it so that the change for young disabled people becoming adults becomes more important for the people who provide services.
- We will write down what happens and what is said at the conference.
- What is said, and any good ideas, at the conference will be followed up by the people organising it and the people who work in services, so that things get better.

What happened on the day?

The conference started with Christine Barton, a disabled woman from Sheffield, who has worked in Education in Leeds.

She welcomed everybody and introduced the speakers. She explained what would be happening on the day, as well as the important things like where the toilets were and when lunch was.

Christine talked about the many changes that take place in our lives as we become adults. The change from being a school student to being a young adult, with a role in the community, is an important time. More 'independence' is a goal for all children, but for some people it is harder to achieve than for others. For disabled people the barriers can be huge.

Christine explained that disabled people's organisations have identified seven needs towards independence in their community. They are:

- information
- peer counselling
- equipment and adaptations
- personal assistance
- housing
- transport
- access

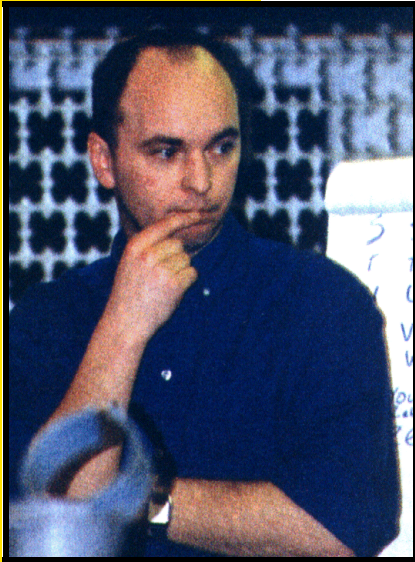
Meeting those needs helps to break down barriers and enables young disabled adults to gain independence.

Christine stressed that to give young people greater control over their own lives workers must listen to what they say and work towards improving the transition from school to adulthood.

She hoped that the conference would provide an excellent opportunity for the voices of young disabled people to be heard.

'Life as a disabled child'

This was presented by Mark Priestley, from the Disability Research Unit at Leeds University. He was a member of a research team who were finding out more about the lives of disabled children. He talked about the things that children said to the research team, which covered nine topics:



- Family
- Friends and relationships
- School
- Attitudes and bullying
- Going out
- Who is disabled?
- Hospitals and doctors
- Work and work experience
- The future

Mark said that most of the children were very aware of changes as they grew up.

"...As I've grown up I've found it quite difficult, because obviously I'm getting stronger viewpoints and getting older and all that...I just seem to have found, sort of these last few years, quite difficult... With parents, because I think it's accepting, you know, that I am changing..."

Many of the older children had a clear vision of their future, particularly in relation to work. They had hopes and ideas about careers and they could think about how to move towards these goals. However, a significant minority had little knowledge about the world of adulthood. That was particularly the case for children labelled as having 'severe learning difficulties' and for those who went to special schools.

When it came to ideas about participation, age did not seem to be a factor at all. There was a clear feeling that all children should be involved.

Mark said that most of the children they met spent large amounts of time with adults both during their school day and at home. For some children, all their social contacts were with parents.

"I mean now, I only ever go out with me parents, I never go out any more..."

Children with few contacts outside the family sometimes had the chance to socialise with other adults, such as volunteers, respite carers or professionals. For many children the school day was dominated by interaction with adults - especially with classroom assistants (SNAs). Sometimes these relationships extended beyond school.

"Like the teacher goes out and the SNA has to like tell everyone to be quiet, they all blame it on me...I can't sit next to anyone 'cos my SNA has to sit on the same table as me...And I can't really talk, when she's there."

Mark also described some of the things children said about the barriers to growing up.

"I find it difficult to get out, have a good time and disappear off."

"When you're younger...you seem to think that's the only life. But when you're older you see other people and you think that life could be better"

Mark finished by explaining how people could get more information about the research (see appendix 3) and saying that listening to what young people say leads to a better understanding of their lives

"It was good to listen to bits of research which related to you"


The Workshops

There were three workshops. Each workshop was run twice, so people could go to more than one of them. The topics were:

- Leaving School
- Going Out
- Friends and Relationships

Leaving School (led by Peter Pearse)

Peter wanted people to talk about leaving school, to feel it was safe to speak out, and to listen to other people in the group. People worked in small groups to discuss their experiences, and then shared their conclusions with the workshop. Things that were raised in the group included:

- mixed feelings and ambition
 - uncertainties about leaving school
 - future opportunities such as further education
 - careers guidance should be more specific
 - interventions needed at the right time
 - lack of employment opportunities
 - difference in encouragement from parents
 - special needs assistants can be effective and helpful
 - there should be honesty about what is available
 - continuing education
 - more appropriate college courses
- 
- people want independence of mind as well as body
 - professional workers not understanding disabled perspectives
 - availability and accessibility of information
 - safety
 - disabled young people are prevented from taking risks
- discrimination in work experience
 - people's low expectations.

"Peter was good and knew what he was talking about"

Going Out (led by Sonali Shah)

"...after school and in the holidays you just stay at home at night...Too difficult to do it and nowhere to go...And finding a friend is difficult."

Sonali provided information about the Disability Discrimination Act, and organised group exercises that encouraged discussion about going out and the barriers that prevent disabled people from taking part.

1. Group members worked in pairs and told each other about their best and their most embarrassing outing. Each person then introduced their partner to the larger group and described their outings.
2. Group members worked in threes or fours to think of somewhere they might like to go and the barriers that might prevent them. They then used role-play to suggest how the barriers could be dismantled.



"There's loads of stuff but we can never go to it 'cos of taxis, we can never go...I mean I want to do that martial arts but it's after school, and there's no way I could stop on and then get picked up... There's nobody can come and pick me up."

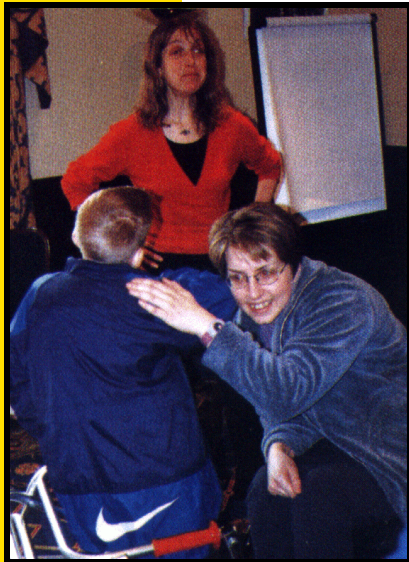
The exercises were followed by discussion about overcoming barriers. Suggestions included:

- planning ahead
- telephoning ahead
- seeing whether somewhere is accessible
- having a strategy
- knowing the Disability Discrimination Act

"There was a feeling of everyone going through the same thing - 'you're not alone'"

Friends and Relationships (led by Ailsa Fairley)

"Some people like call me like "spastic", "broken legs" and all sorts...it isn't as bad at home is it, because they understand."



Ailsa's workshop started with lots of different 'warm up and getting to know each other' exercises such as -

moving around the room to commands of stop and go, and then the commands mean their opposite

magic carpet - where would you go and who would you take?

people to people - move around the room and, when you are told, find a friend and join bodies, e.g. hand and elbow.

One exercise looked at who surrounded a young disabled person and then used role play in the following situations:

1. Strangers, Distant Friends and Acquaintances
2. Friends/Family, people you want around you
3. People who are too close - uncomfortable
4. People on top of you - smothering

Group members were asked to think of a time when they felt so small and to explore the relationship.

For example, being sent to bed early by nurses.

Then, think of a thought bubble (what you would like to have said), e.g. "shut up you stupid nurses".

Partners choose scenarios of someone being put down and act out changing it - changing the reply and body language.

The group produced an 'A - Z' for Young Disabled People:

A-Z for Young Disabled People

A	= Access
B	= Brotherly love, bullying
C	= Caring, cursing
D	= Dancing
E	= Enjoyment
F	= Family and friends
G	= Good life, gritting teeth
H	= Happiness, health, harassment
I	= Intelligence
J	= Joking, joy
K	= Kicking, knowledge
L	= Loving, laughing
M	= Mad, merriment
N	= Naughty, nice
O	= Optimism
P	= Pleasure, power
Q	= Quality, quilt
R	= Resilience
S	= Strength
T	= Tenacity
U	= Unique
V	= Victory
W	= Winning
X	= Xylophone
Y	= Yourself, young
Z	= Zest, zebra

"Ailsa, who ran the workshop, was enthusiastic..."
"It was a good way of expressing yourself"

Feedback and Summing up

The conference ended with people talking about what happened in their workshops (including shouting out the A-Z !) and asking questions.

"I'm dreading growing older, 'cos I know my mum will still be there but I've got to be independent at some point in my life, and I'm scared that I'm not going to be able to, and that I'm always going to need somebody."

Some of the important things that came up were:

- Disabled young people spend more time with adults than non-disabled young people.
- The presence of adults limits the relationships that disabled children are able to form, both at school and in their home environment.
- Schools reinforce the difference between disability and "normality" and focus too much on children's impairments.
- Young people identify with disability in many different ways. Some see themselves and other people with the same impairment as being disabled, while some think that everyone is disabled. Some young people think they are more disabled in some situations than in others.
- Young disabled people need to know more about the Disability Discrimination Act - what it means and how to use it.
- A Conference just for disabled young people could be held.
- Disabled young people experience barriers that limit their relationships with peers. These include physical, attitudinal and communication barriers.

What would Service Providers Do About This?

People were reminded that the aim of the day was to bring about changes, and staff were asked to say what they would go away and do. These are some of the specific promises that were made:

- The Disability Research Unit will put the research findings on a website (including this report).
- The Commissioning, Implementation and Performance Management Team (CIPMT) - Services for Disabled People will work on making assessment procedures easier to understand and for disabled people to have more control over the process.
- The CIPMT would look at how to get Disability Equality Training into schools.
- The Community and Mental Health Services Trust (part of the Health Service) will ask a member of the research team to come and talk to them about what young disabled people said.
- Leeds Centre for Integrated Living will tell people about the research and take its findings into account when developing services.
- The Development Officer for Disabled Children would work with Leeds Centre for Integrated Living to assist young disabled people in setting up a group to discuss the things that are important to them, and to influence the way that things happen. Support will include appropriate funding from the CIPMT.

The CIPMT would take overall responsibility for chasing up those and other broader commitments made by agencies on the day.

Conclusion

The overriding view from the day was that things can change for the better. It needs agencies to:

1. Listen to what young disabled people are saying
2. Understand the barriers that young disabled people face
3. Work better together in ways that begin to dismantle those barriers.

"....in some situations I'm not, we're not, always disabled".

Thank You

Although a range of organisations were involved in the planning and running of the day the following individuals need a special mention for their contribution:

Christine Barton, Sonali Shah, Peter Pearse, Ailsa Fairley, Linda Boadle, Suzanne Triggs, Mark Priestley, Amanda Clarke, Mick Ward, James Woodhead, Sarah Robinson-Burke, Heather Vickers, Joe Sullivan, Helen Lumb, Pria Bhabra

We would also like to thank all those who attended on the day, especially all the disabled children who gave up a day of their holiday to take part.

Appendix 1

Invited Delegates to the Conference ('professionals')

Ronel Bekker Leeds Education Social Inclusion Division	Gill Crawshaw Equal Opportunities Unit	Nicki Isaacs Nursing Team Manager Children's Disability Team
Jean Baker Acting Clinical Unit Manager - Child Health	Robert Richmond Highways Department Assistant Access Officer	Mohammad Shabbir Implementation Manager Asian Disability Network
John Wells Senior Education Psychologist - Leeds Education Special Services Division	Gill Keighley Barnardo's	Peter Hardman First Key
Eva Kemecsel Barnardo's Young Carers Project	Dr S Yellin Public Health Consultant - Leeds Health Authority	Joe Kent Department of Housing and Environmental Health Services
Jeanette Sargent Planning and Development Officer - Metro	Ruth Woodhead Assistant Director Community Services	Rob Winette Leisure Services
Linda Randall Social Worker Young Adult Team	Meryl Wilford Social Work Manager Children's Disability Team	Judith Kahn Health Team Manager Leeds General Infirmary
Susan Morrell Leeds Centre for Integrated Living	Gordon Kerr Specialist Careers Service	Helen Ridsdale Pinfolds
	Lucy Muir Leeds/Sheffield University	Denise Joseph General Manager East Leeds Primary Care Group

Invited Delegates to the Conference ('disabled children')

Amy Stannard	Kieran Forde	Rachel Flint
Ida Adams	Nayab Fatima	Kelly Shine
Dominic Trigg	Paul Ambler	Sean Senior
Nan Boulton	Emma Pearson	Linda Briggs
Phillip Topley	Ciaran Gilligan	Lisa Padgett
Vicki Manley	Gavin Murphy	Richard Chiltern
James Johnson	Jenny Dodds	Simon Bendelowe
James Aylward	Paul Russell	

Note takers

Sarah Robinson-Burke	James Woodhead	Pria Bhabra
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Appendix 2

Young Disabled People

Moving into Adulthood

24th February 2000

Elland Road Conference and Banqueting Centre.

- 9.30** Coffee and Registration
- 10.00** Welcome and Introductions from the Chair - Christine Barton
- 10.15** Presentation on Research Findings - Mark Priestley
- 11.00** Workshops:
- | | |
|---------------------------|-----------------|
| Leaving School | (Peter Pearse) |
| Going Out | (Sonali Shah) |
| Friends and Relationships | (Ailsa Fairley) |
- 12.15** Lunch and Tours of Elland Road Stadium
- 1.45** Workshops (repeated from morning)
- 3.00** Feedback
- 3.30** Questions, Summary and Closing Comments
- 4.00** Finish

This event has been jointly organised by the Commissioning, Implementation and Performance Management Team (Services for Disabled People with Physical Impairments), Disability Research Unit (University of Leeds), Development Officer Disabled Children (Social Services and Health), Leeds Children's Rights Service (Save the Children) and Leeds Centre for Integrated Living.

Appendix 3

The 'Life as a Disabled Child' research project was carried out by researchers at Leeds and Edinburgh Universities, funded by a grant from the Economic and Social Research Council.

Copies of the report and more information about the research will be available from the following web page:

www.leeds.ac.uk/disability/projects/children.htm

...or contact:

Mark Priestley
Disability Research Unit
University of Leeds
LEEDS
LS2 9JT

Telephone : Leeds (0113) 233-4417

e-mail : m.a.priestley@leeds.ac.uk

Details about the young persons group set up as a result of this conference can be obtained on the website set up by the young people involved at:

disabilityyouth.homestead.com/nan.html

alternatively you can contact Suzanne Triggs at:

Department of Social Services
Strategic Services
Merrion House
110 Merrion Centre
Leeds
LS2 8QB

Telephone : (0113) 224-3342

e-mail : suzanne.triggs@leeds.gov.uk

Appendix 4

Suzanne Triggs
Development Officer - Disabled Children
Leeds Social Services
Merrion House
Leeds 2

Telephone : (0113) 224-3342
e-mail : suzanne.triggs@leeds.gov.uk

Mick Ward
CIPMT
Thoresby House
2a Great George Street
Leeds
LS2 8BB

Telephone : (0113) 24-76769
Minicom : (0113) 24-74731
e-mail : mick.ward@leeds.gov.uk

Amanda Clarke
Save the Children
Leeds Children's Rights Service
1 Eastgate
Leeds
LS2 7LY

Telephone : (0113) 222-2544

Mark Priestley
Disability Research Unit
University of Leeds
LEEDS
LS2 9JT

Telephone : (0113) 233-4417
e-mail : m.a.priestley@leeds.ac.uk

Linda Boadle
Leeds Centre for Integrated Living
Armley Grange Drive
Leeds
LS12 3QH

Telephone : (0113) 214-3599
Minicom : (0113) 214-3598
e-mail : info@leedscil.org.uk

Further copies of this report are available from: Suzanne Triggs - Leeds Social Services (see inside cover for contact details).

This leaflet is available in large print and braille, and on tape and computer disc.

