

*Access in Mind: a review of
approaches to making ideas
and information accessible*

Jan Walmsley

A talk in three parts

- Part 1: looking back – how far have we come?
- Part 2: different ways of making ideas accessible
- Part 3: questions to ask about accessible ideas

How Far Have We Come?

A long way

- Policy
- Access to Services
- People speaking out
- Research

Policy 1971 to 2005

Then (1971)

- Civil Servants wrote the policy
- People with Learning Difficulties not asked
- Information not accessible

Now (2005)

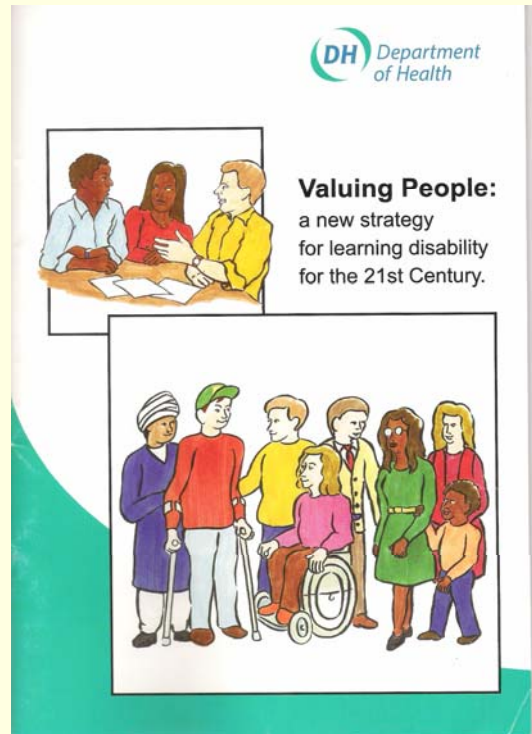
- Civil servants write policy with help from people with learning difficulties, families and carers
- Accessible versions on tape and in print

2001 White Paper 'Valuing People'

Produced in consultation with users and carers
Accessible version on tape and in print

Accessible Policy documents

Valuing People 2001



Access to Services

Then

- Everyone got the same
- Users and carers not asked about how good it was
- No one asked about the type of services people wanted

Now

- Information about how to get better services
- Direct Payments / Individualised Budgets
- Choice
- Consultation and involvement

Research

Then

- Researchers decided on the questions to ask, and the methods
- People with learning difficulties were the objects of research
- Reports not accessible

Now

- People with learning difficulties help decide the questions, and methods
- People with learning difficulties do research
- Accessible reports

Learning Disability Research Initiative

2003

Newsletter issue 1 September 2003


the learning disability research initiative

People with Learning Disabilities Services, Inclusion and Partnership

❖❖❖ **Editorial**

We are delighted to be sending out this first newsletter about research funded by the Department of Health in relation to people with learning disabilities. Ken Simons, a lead researcher on one of the funded research projects passed away suddenly earlier this year. Ken committed his working life to people with learning disabilities, to supporting people with learning disabilities and to making research meaningful to them. We are therefore particularly proud to be presenting this newsletter in plain as well as technical language.

For many people research is not easy to understand. It is not easy to see when it is relevant or useful. We have been employed as co-ordinators of the Learning Disability Research Initiative by the Department of Health and, as part of our role, have been asked to inform people about the research projects and their findings. This will last until all the projects are completed in three years time.



❖❖❖ **So, what is the Learning Disability Research Initiative?**

Valuing People (para 10.15) committed £2m to research aimed at providing an evidence base to inform the planning, management and delivery of new services designed to improve the lives of people with learning disabilities and their families. The Research and Development Division at the Department of Health has managed the resultant research programme titled, People with Learning Disabilities: Services, Inclusion and Partnership and funding has been directed through the Policy Research Programme.

❖❖❖ **How were projects chosen?**

A Commissioning Group made up of people from the RDD, policy divisions of the Department of Health and government departments relating to education and transport, academics, people with learning disabilities and their supporters helped to decide: the most important areas for research; how to send out invitations for researchers to apply to undertake research; how each proposal was to be assessed including external assessment by people with learning disabilities; and what research proposals would be selected. There were 144 proposals altogether! Ten of these have been funded to date. In a follow up bid relating to health needs and to assessing the impact of Valuing People two more projects have been funded and another on participation in research is planned. More news of these will appear on the LDRI web site shortly.

We expect that initial findings will very soon begin to emerge from the projects and it should not therefore be long before the findings are being converted to practice. To provide advice on how this might be handled a new Reference Group has been set up with a composition reflecting government, service provider, academic and service user interests.

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Speaking Out

Then

- Very little until 1960s
- Life Stories published in 1960s and 1970s
- Campaign for Mentally Handicapped Conferences 1970s

Now

Self advocacy and user controlled groups
Conferences
Books and leaflets
Websites, dvds and videos

A rare example of 'speaking out'

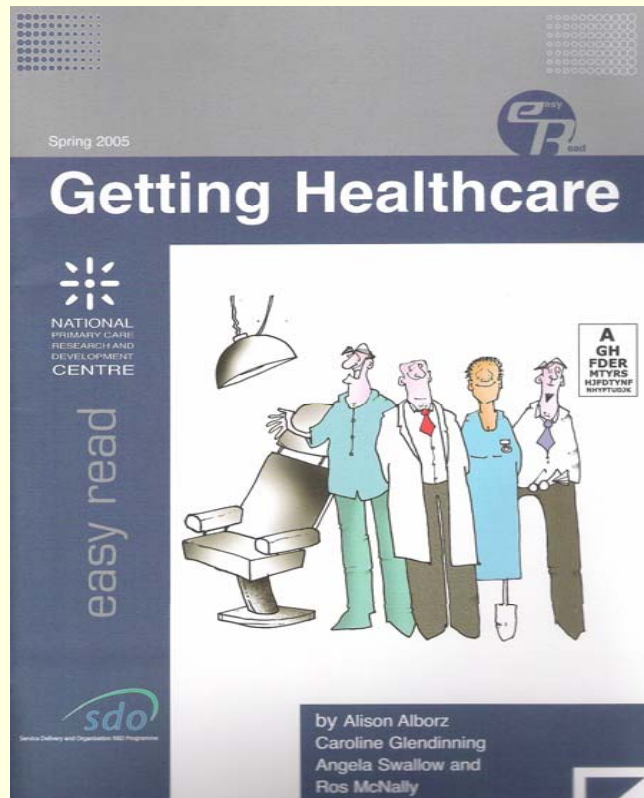
Dear madame or sir

I wonder if you would in any way do me a great favour. All I want to ask you is could you by any means help me to get discharge from the care and control. As this is my 21 years I done under your care and control. I am 36 years old. This is the first time I have written to you. Nothing like sticking up for yourself.

Ruth Gammon, 1943

People with learning difficulties have led the way for others

Accessible information on healthcare



People with Learning Difficulties have led the way

Example

Adult Health and Social Care Green Paper in
accessible format

Approaches to making IDEAS accessible

- Policy Documents
- Education
- Research
- Conference Reports and Consultations
- Research by People with Learning Difficulties

Different Approaches

- Parallel texts – easy to read summaries of full report
- Easy to Read Text sometimes with line drawings or photos
- Story So Far and Summaries
- Short plain language summaries of longer reports and chapters
- Video, audio, websites

Parallel text – easy to read summaries of full report

Valuing People White Paper

Valuing People Accessible Version

What it says about Rights

Having Legal and Civil Rights “People with learning disabilities are citizens too”

Page 3

Valuing People: Full Version

Legal and Civil Rights: The Government is committed to enforceable civil rights for disabled people in order to eradicate discrimination in society. People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary. The Government is committed to providing comprehensive guidance for electoral administrators on helping disabled people, including those with learning disabilities, through the whole electoral process – from registering to vote until polling day itself.

All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. People with learning disabilities will also receive the full protection of the law when necessary

(p. 23)

Educational Approaches: Equal People (Open University 1996)

- Produced in partnerships with People First
- Easy to read pages
- Story So Far Boxes
- Summary Boxes
- Use of audio and video

Research

- Accessible summaries eg British Journal of Learning Disabilities
- Parallel Texts eg Learning Disability Research Initiative
- Short summaries of longer chapters eg Rannveig Traustadottir and Kelley Johnson's book on Deinstitutionalisation
- Websites with audio commentaries eg Government's Survey of People with Learning Disabilities 2005

Conferences and Consultations

- People First Conferences eg Devon People First's Valuing People Conference
- Consultations eg Mental Health Foundation's Building Expectations
- Leaflets eg Open University / Cambridge Mencap's Oral History Workshop

Research by People with Learning Difficulties

- Autobiographies eg Past Times (1993)
- Research Commissioned by funders eg Swindon People First on Direct Payments (2002)
- Co-writing with academics eg Jackie Downer and Jan Walmsley 'Speaking the Loudest' (1997)
- Books and pamphlets eg Wyre Forest Self Advocacy Book (2005)

Questions to ask about accessible ideas

- Who decides what to make accessible?
- Who wrote it?
- Who is it for?
- How well does it work?
- What's lost in translation?
- Can we do it better?

Conclusion

- There isn't a single "solution" – one size does not fit all.
- Selection of what to say is as important as how it is presented.
- Not all ideas can be made accessible. Make things as simple as possible, but no simpler
- Accessible information is not a substitute for good support and education.

Key Questions
