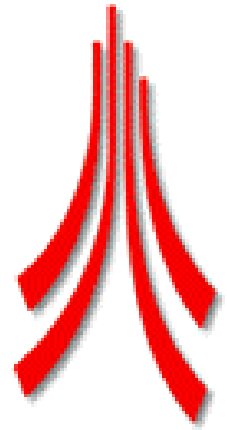


Monitoring the Life Experiences of Adults with Intellectual Disabilities in England

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The Project

- Government commitment in 2001 White Paper (*Valuing People*)
- Aim
 - To describe what life is like for adults with learning difficulties in England
- In order to ...
 - Provide a baseline against which to judge future progress
 - To inform current policy



Adults with Learning Difficulties in England 2003/4



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First Research Team





Five Issues

- Conceptualising & measuring 'quality of life'
- Design issues
- Headline results
- Dissemination
- Key issues for future policy and practice

Starting Point: Utilisation Focus



- Importance of providing information/data in a way that maximises the chances of it having an impact on improving the life opportunities of people with intellectual disabilities
- Engaging with all key stakeholders in ...
 - Conceptualising and operationalising 'life experiences' or 'quality of life'
 - Designing the survey
 - Analysing, reporting and disseminating the results

Starting Point: Essential Aims



- Key question
 - Better than?
 - Satisfaction of personal aspirations?
 - Characterising nature and extent of social (in)justice?
 - Disability discrimination
 - Equality of outcomes/life experiences

Conceptualising 'Quality of Life'



- Social indicators (life experiences and opportunities)
 - Domain selection
 - through consultation with people with intellectual disabilities, carers, policy makers
 - Item selection
 - where possible, borrowed from existing population-based surveys
- Well-being
 - Overall life satisfaction
 - Psychological well-being
 - Satisfaction with services/supports

Reference Points:
utilisation

social justice (equality
of outcomes)



Domains

- Accommodation
- Work
- Education & training
- Money/poverty
- Relationships
 - Contact with families & friends
 - Caring for others
- Being part of the community
 - Neighbourhoods
 - Participation
 - Transport
 - Citizenship
 - Crime & bullying
- Health & well-being
- Support



Choice & Control

Design Issues: Who Takes Part?



- Target population: adults (16+) with intellectual disabilities (including people who may not be known to ID services)
- Sample: Just under 3,000 people
 - Living in private households
 - Living in supported accommodation
- People we did not reach
 - Homeless
 - Correctional facilities
 - Treatment facilities

Design Issues: Supporting Participation

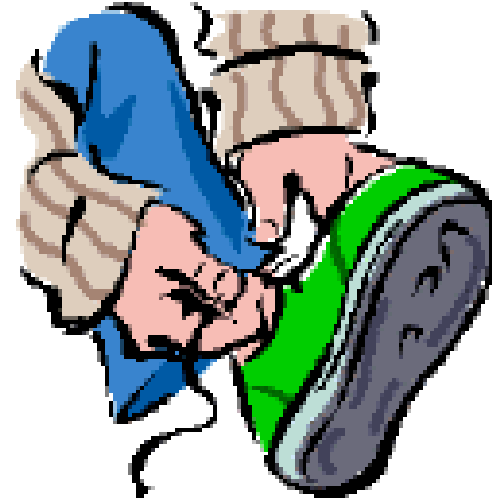


- Interviews
 - Face-to-face computer assisted structured interviews
 - In own home
 - All interviewers trained by Central England People First
 - Support person present if requested
 - Encourage participation through accessible wording, rephrasing, visual aids

Do you need help to ...?



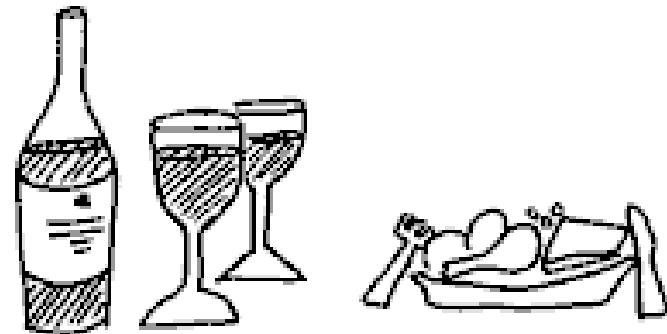
Get dressed



Put on shoes



Have a shower or
bath



Order food at a cafe

This year, have you been ...?

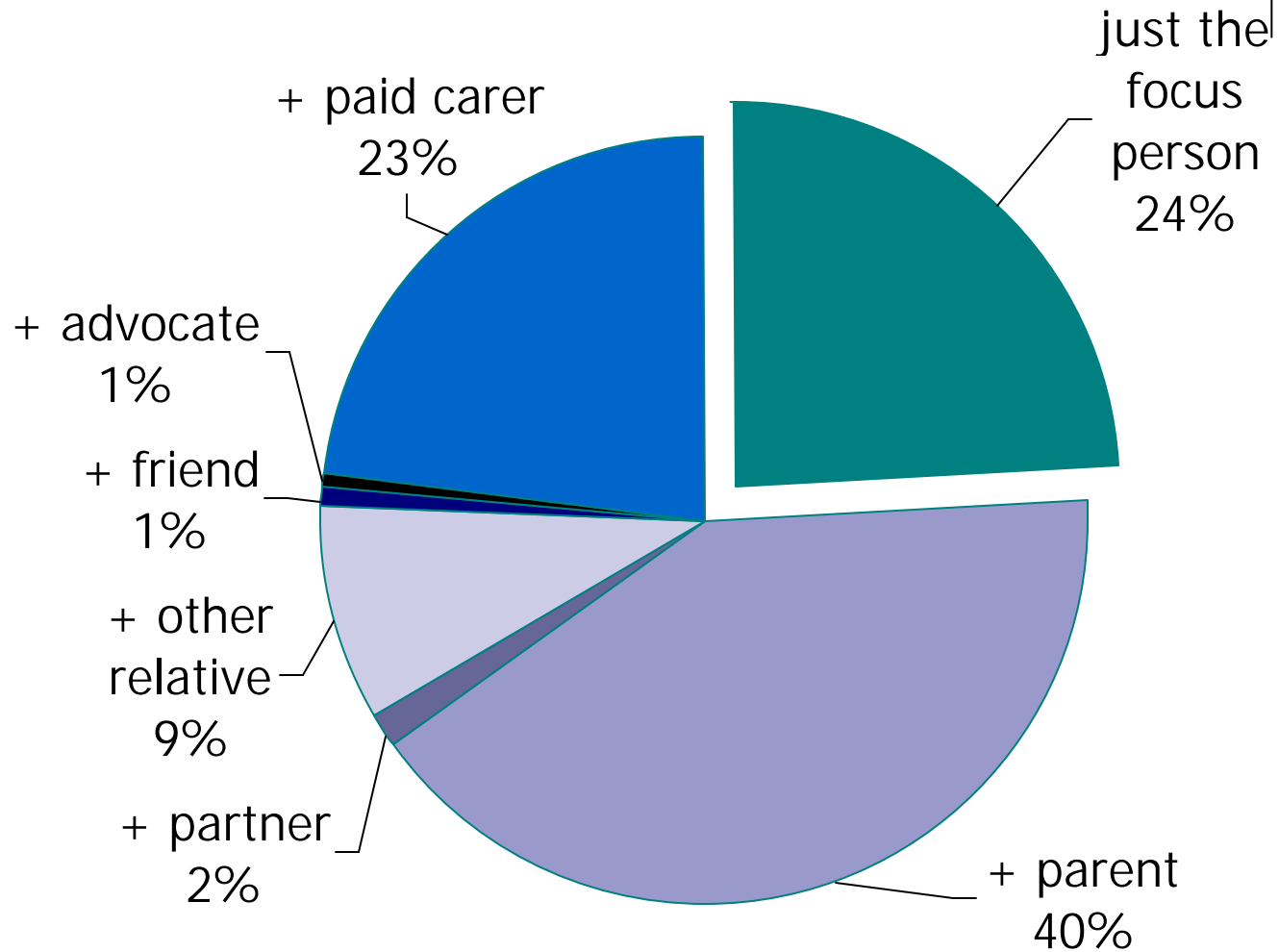


For a cervical
smear test



To have your
breasts checked
for lumps

The Interviews



Headline Results


- Social exclusion
- Choice & control
- Independence
- Systemic inequalities




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Adults with Learning Difficulties in England 2003/4



Full Report

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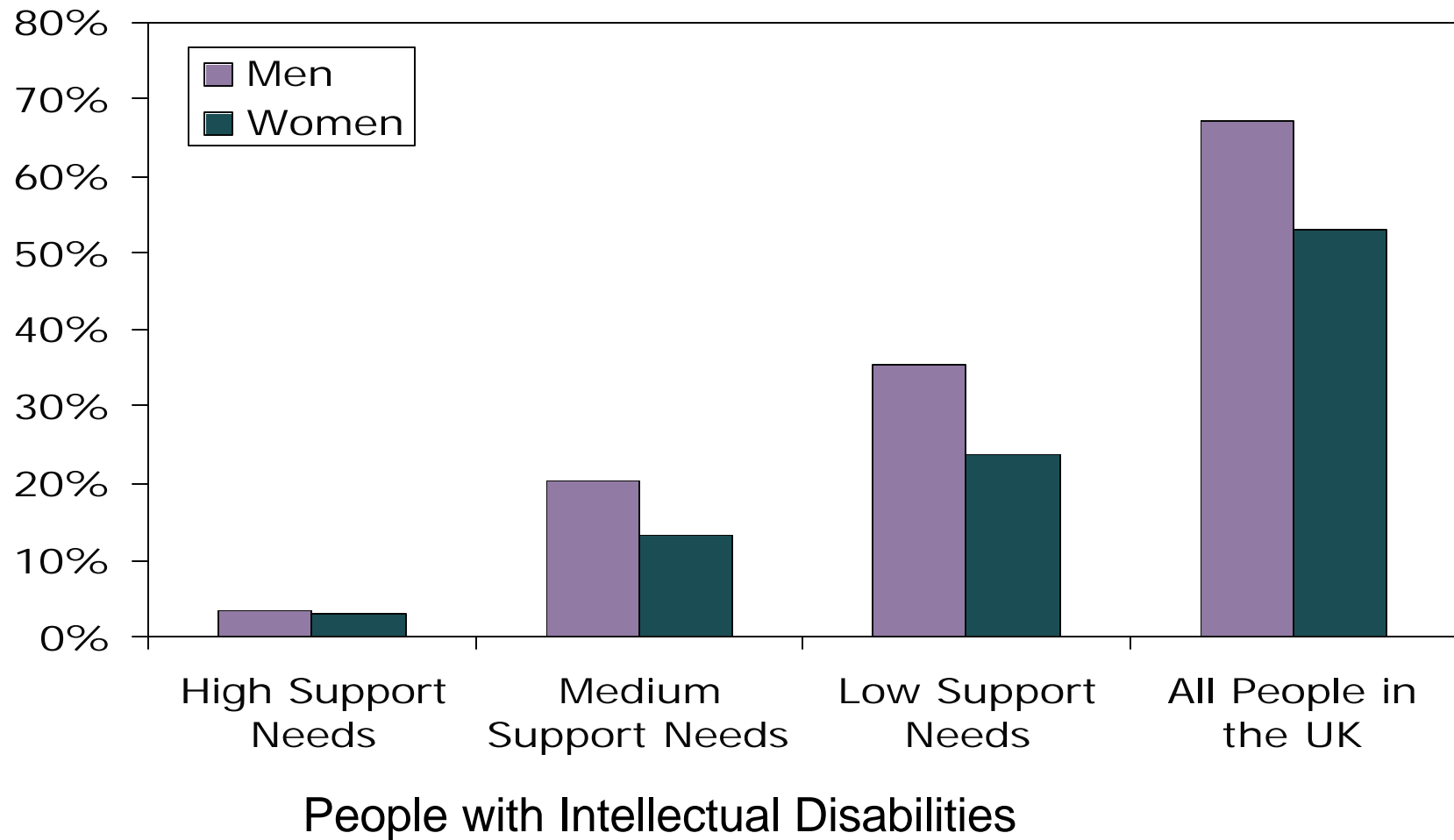
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Social Exclusion

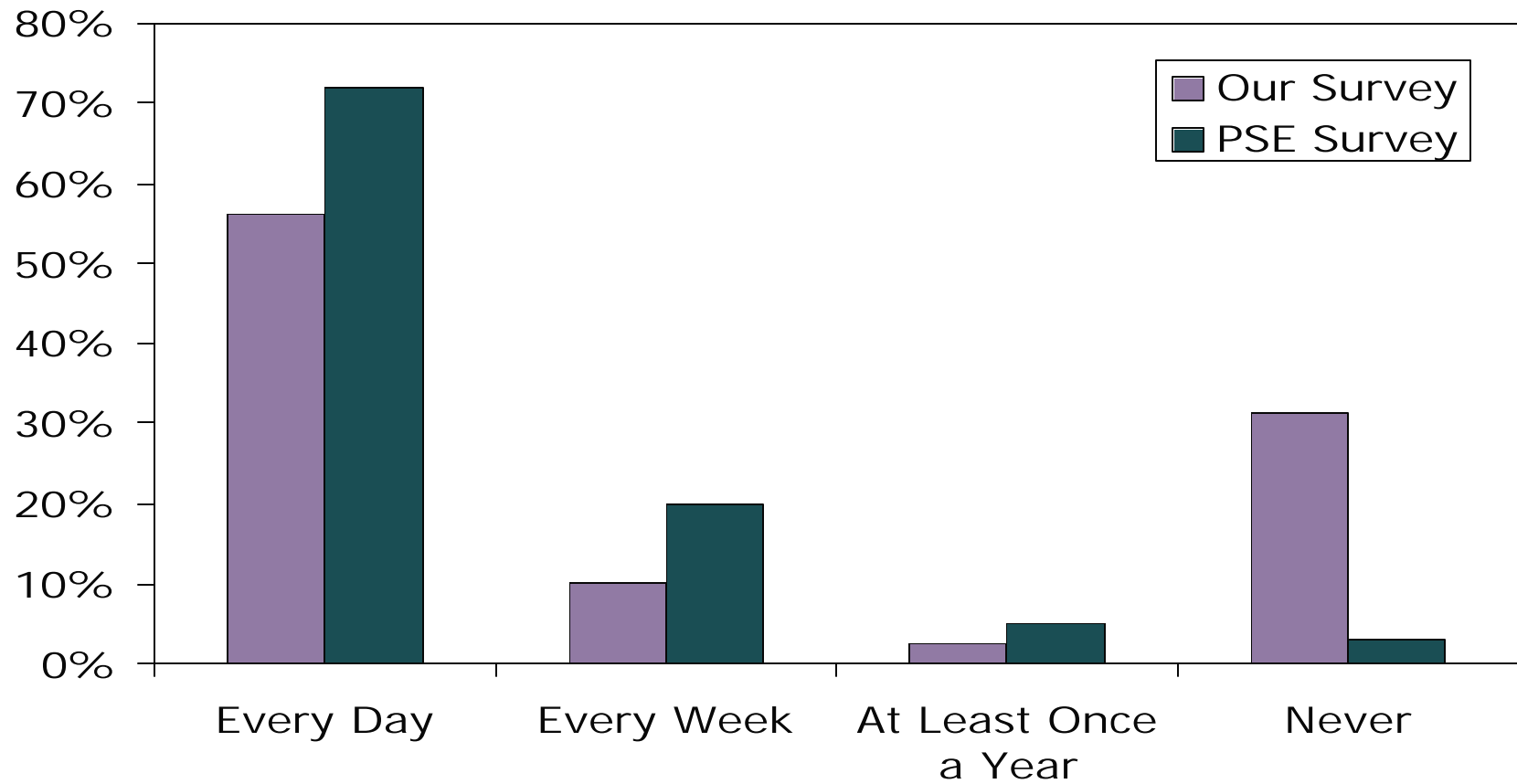


- Segregated education
- Low rates of employment
- Few inclusive relationships
- Significant minority were socially isolated

Exclusion from the Workplace



Exclusion: Contact with Friends



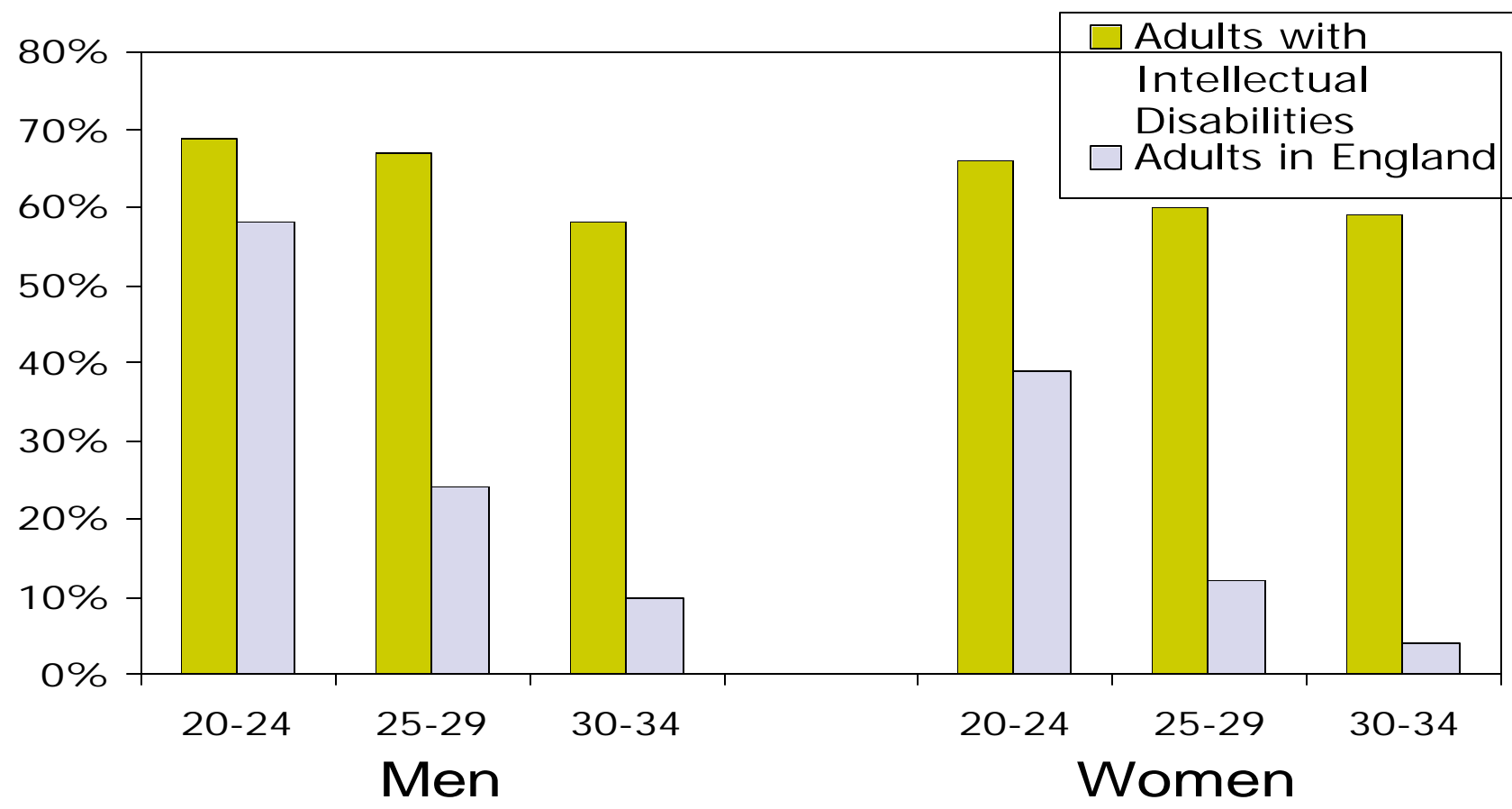
Choice & Control



- 2/3 people in supported accommodation had no control of either where they lived or who they lived with
- Over half had no control over their money



Independence: Leaving Home



Systemic Inequalities: Poverty & Neighbourhood Deprivation



- Living in unsuitable accommodation
- Having less privacy at home
- Unemployment
- Not having a voluntary job
- Not having enjoyed school
- Being bullied at school
- Not taking a course
- Not attending a day centre
- Not having control over money
- Less likely to see members of their family
- Being an unpaid carer
- Seeing friends less often
- Doing a smaller range of community activities
- Not having voted
- Not knowing about local advocacy groups
- Feeling unsafe
- Being bullied
- Being a victim of crime
- Having poor health
- Having a long-standing illness or disability
- Smoking
- Not being happy
- Being sad or worried
- Feeling left out
- Feeling helpless
- Not feeling confident
- Having unmet needs
- Having wanted to complain about the support they receive

Systemic Inequalities: Support Needs



- People with **higher support needs** were more likely to
 - be living in supported accommodation
 - to have less privacy
 - to have less choice
 - to be unemployed
 - to feel helpless
 - not to have a voluntary job
 - not to have gone to a mainstream school
 - not to be taking a course
 - not to receive Direct Payments
 - not to have control over their money
 - not to see friends who do not have learning disabilities
 - not to feel safe
 - not to feel confident.
- People with **lower support needs** were more likely to
 - be poor
 - be a victim of crime
 - be unhappy
 - to have been bullied at school



Well-Being?

- 71% of scale maximum (very similar to the general population)
- Higher SWB related to
 - personal characteristics (older age)
 - living circumstances (no hardship)
 - relationships (being single & more contact with family – for women)
- High levels of satisfaction with existing support

Dissemination

- Aim: Accessibility of information
 - Maximising accessibility of main report(s) to all stakeholders (supplemented by technical appendices)
 - Free public access to materials and anonymised data

The People



We interviewed 2,074 people. Of these, 76 probably did not have learning difficulties.¹ This left us with 2,000 interviews with people with learning difficulties.

Sex



Of the people we interviewed, there were more men (53%) than women (47%). You would expect this as there are more men than women with learning difficulties.²

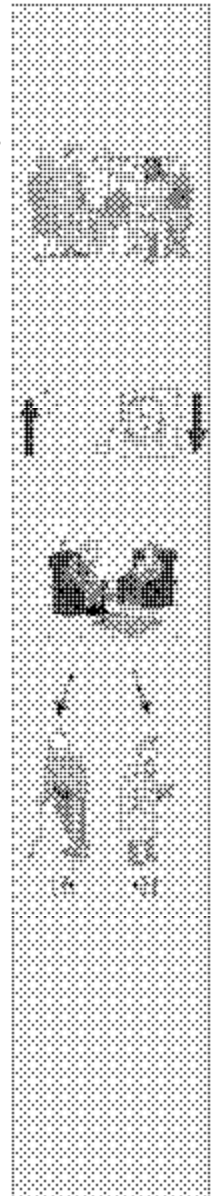
Age



The youngest person we interviewed was 10 years old the oldest was 81. About half of the people we interviewed (45%) were under 30. Figure 2 shows how many men and women we interviewed at each age group.

We compared the ages of the people we interviewed with our best estimates of the ages of people with learning difficulties in England.³ We found that we were more successful at finding younger people with learning difficulties to talk to than older people.

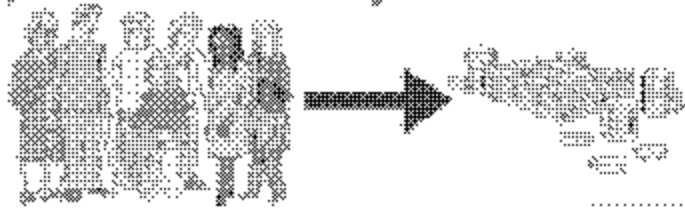
We found that this was true for people living in private households and for people living in supported accommodation.



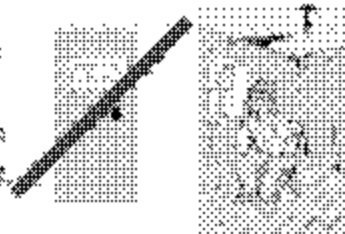
What did the survey show?

Being poor or living in a poor area.

- Being poor or living in a poor area had an impact on just about every aspect of peoples lives. This is important because people with learning difficulties are much more likely to be poor than people who do not have learning difficulties.



- People who were poor or lived in poor areas were more likely to live in unsuitable accommodation and to have less privacy at home.



- They were also more likely to be unemployed, not have a voluntary job, not have enjoyed school, be bullied at school, not be taking a course and not attend a day centre.



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Adults with Learning Difficulties in England 2003/4



Summary Report

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ALDE - Charleston

Friendly Reports - ...

Key Issues: Defining & Measuring 'QoL'




- Describing life experiences and opportunities highlights the inequalities and social injustices faced by people with intellectual disabilities
- ... but people are only slightly less satisfied with their lives overall than the rest of us (and are very satisfied with the services and supports they receive)!


Key Issues: Design & Dissemination





- Value of linking into general household omnibus surveys
- Hard to reach groups
- Strategies for maximising participation and access to information


<http://www.ic.nhs.uk/pubs/learndiff2004>



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