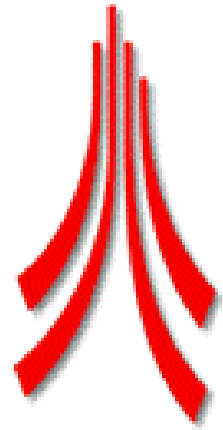


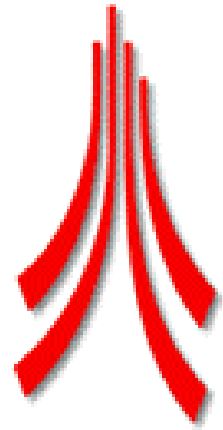
Innovative Ways of Making Outcome Data Accessible to All

Eric Emerson & Chris Hatton
Institute for Health Research
Lancaster University, UK



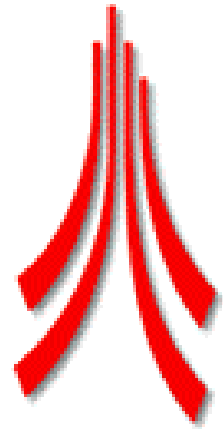
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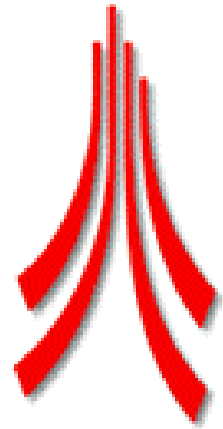
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~~Ir National~~ ~~Ways of~~
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Relevant to All

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The Plan

- Overview of current approaches to collecting national data on provision and outcomes of services/supports for adults with intellectual disabilities in England
- Outline some principles that should underlie future data collections
- Describe a recent attempt to put some of these principles into practice
- Key issues/lessons

The State of the Nation



- What do national statistics tell us about people with intellectual disabilities in England?

The State of the National *Statistics*



- What do national statistics tell us about people with intellectual disabilities in England?
- What do national statistics reveal about policy makers' assumptions?

Never Mind the Quality, Feel the Width



- We identified almost 100 'indicators' collected nationally on a regular basis
- Almost all about service expenditure and service activity, not about outcomes
- Validity/reliability of the data collected can be questionable

Don't let the Right Hand Know What the Left Hand is Doing



- Collected for at least four Government departments, with no cross-referencing:
 - Dept of Health
 - Dept for Education & Skills
 - Dept of Work & Pensions
 - Office of the Deputy Prime Minister
- Focused on the activities of specific services rather than the life experiences of people

Causing Offence is the Best Form of Defence



- Terms and definitions used include:
 - Learning difficulties
 - Learning disabilities
 - Mental handicap
 - Mental retardation
 - Mental impairment
 - Mental illness

Don't Ask, Don't Tell



- Information is irrelevant to current policy aims
- Information is irrelevant to the priorities of people with intellectual disabilities and their families
- Information not designed to evaluate inequalities in access or outcomes
- Information is inaccessible to people with intellectual disabilities and their families (and policymakers!)

Some Personal Favourites



- Proportion of expenditure on day/domiciliary services for people with learning disabilities to expenditure on residential provision for people with learning disabilities
 - 0.71% in 2000/01; 0.90% in 2003/04
- Number of people waiting as 'ordinary' hospital inpatients for the 'mental handicap' hospital speciality
 - 5 in first quarter of 2001; 7 in first quarter of 2004
- Number of adults with learning disabilities aged 18-64 receiving social services by ethnic group
 - 2003/04 128,000 total; 96,000 White; 7,100 Other; 24,900 not known/declared

National Statistics in England



- Current national statistics largely based on historical policy assumptions:
 - ‘Total’ service systems provide all the support the person will receive
 - There are ‘preferred’ service models that are associated with better outcomes, so no need to assess outcomes directly
 - Services should meet professionally assessed needs rather than the aspirations of people with intellectual disabilities

From Total to Complex Support Systems



- UK moving from 'total' support systems to more fragmented, integrated and individually driven support systems
 - Person centred planning
 - Direct payments
 - Self directed support/individual budgets
- Over time, less and less support should be provided by specialist services
- Information collected by specialist services will become less and less relevant

Service Models as Proxies for Outcomes



- Little evidence that ANY service model will be a guarantee of a high quality service for an individual
- Little evidence that resources or service activities are reliably associated with outcomes for individuals
- Increasing emphasis on self-determination: extremely unlikely to be universally ‘preferred’ service models
- Policy aims increasingly framed directly in terms of outcomes, rather than in shifting service models

Whose Priorities?



- In a consultation exercise:
 - Priorities of people with intellectual disabilities and family members very similar to policy outcome domains
 - Information priorities of professionals very similar to the information already collected (and not similar to the priorities of people with intellectual disabilities or family members)
 - Virtually no current national statistics map on to the priorities of people with intellectual disabilities or family members



Three Principles

- All stakeholders (e.g. people with intellectual disabilities, family members, policy makers) should be involved throughout the process, from setting the agenda to using the findings
 - National statistics should reflect current Government policy aims and
 - the aspirations of people with intellectual disabilities and their relatives and those who support them



Three Principles

- National statistics should prioritise outcomes, not resources or service activities
 - Data systems should capture the life experiences and opportunities of people with intellectual disabilities, not the activities of specific services



Three Principles

- National statistics should be able to document potential areas of inequality within the population of people with intellectual disabilities

An Example

- 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



NHS
Health and Social Care
Information Centre

Adults with Learning Difficulties in England 2003/4



Eric Emerson
Institute for Health Research,
Lancaster University



Sally Malam
BMRB



Ian Davies & Karen Spencer
Central England People
First Research Team





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A Participatory Approach

- The commissioning process
- The research consortium that won the tender
 - Academic researchers
 - A market research company (BMRB)
 - Self-advocate researchers (Central England People First)
- Our steering group





A Participatory Approach

- Defining what to measure and how to measure it
 - Search conferences
 - Interviews and focus groups
 - Analysis of documents



The Key Question

- Better than?
- Satisfaction of personal aspirations?
- Characterising nature and extent of social (in)justice?
 - Disability discrimination
 - 2006 UN Convention on the Rights of Persons with Disabilities
 - UK Disability Discrimination Act
 - Equality of outcomes/life experiences



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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

Amartya Sen



- ‘Concentrating on happiness or desires can be particularly restrictive when making interpersonal comparisons of well-being and deprivation. Our desires and pleasure-taking abilities adjust to circumstances, especially to make life bearable to adverse situations. the deprivation of the persistently deprived may look muffled and muted’

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A Participatory Approach

- Defining what to measure and how to measure it
 - Search conferences
 - Interviews and focus groups
 - Analysis of documents
- Training interviewers
- Making sense of and disseminating the information

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

Money



Being poor is a very important reason why people with learning difficulties can't have choice, be independent and have control of their lives. The survey shows how big an issue this is. Too many people who choose to live independently are poor. Things such as not being able to go on holiday, not having new clothes, not being able to go out and being able to go for a pint really affects our lives.

In our experience as people with learning difficulties Direct Payments for our support should help. People need support with Direct Payments. We need to be careful that this support is not used as a way of controlling people with learning difficulties. The survey shows that this is an issue too.

Ian Davies & Karen Spencer

- In this part of the interview we asked people about:
- whether they had enough money to pay for things they might want
 - the benefits they received
 - the control they have over their money.

Poverty & Hardship

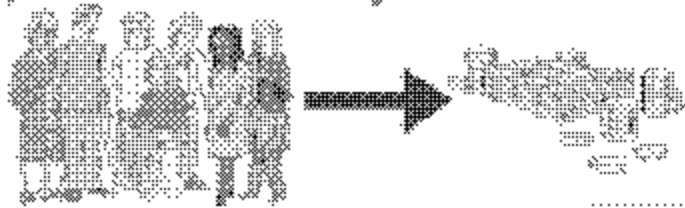


First we asked people whether they could afford nine things that people in England think people should be able to have²¹. The things that people could not afford are listed below. The list starts with the things that more people cannot afford, and finishes with the things less people cannot afford.

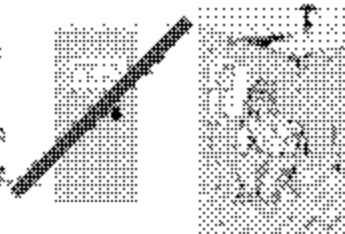
What did the survey show?

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 - ...



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Well-Being



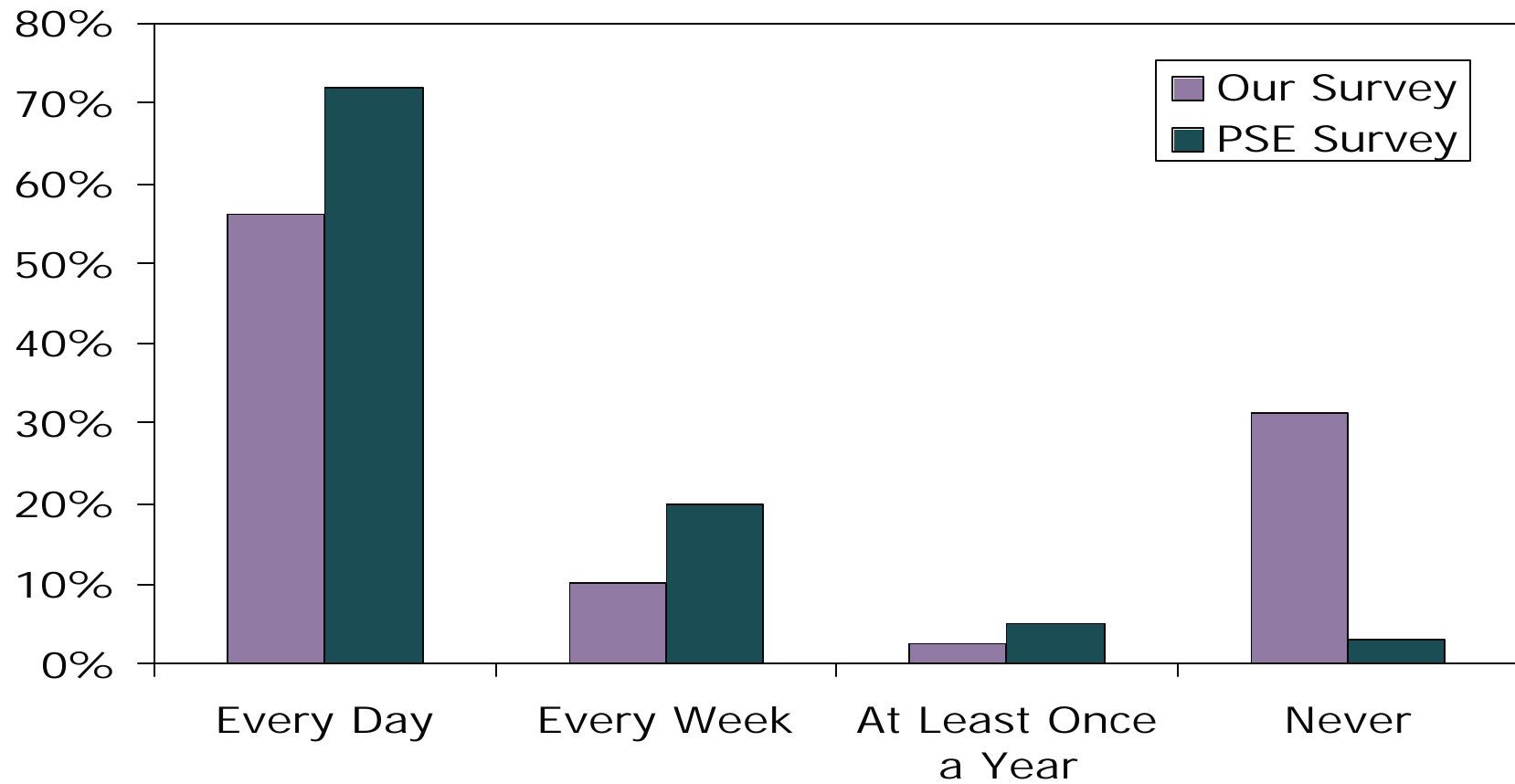
- 71% of scale maximum (very similar to the general population)
- High levels of satisfaction with existing support



Headline Social Indicators

- Social exclusion
 - Low rates of employment
 - Few inclusive relationships
 - Significant minority were socially isolated
- 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

Exclusion: Contact with Friends



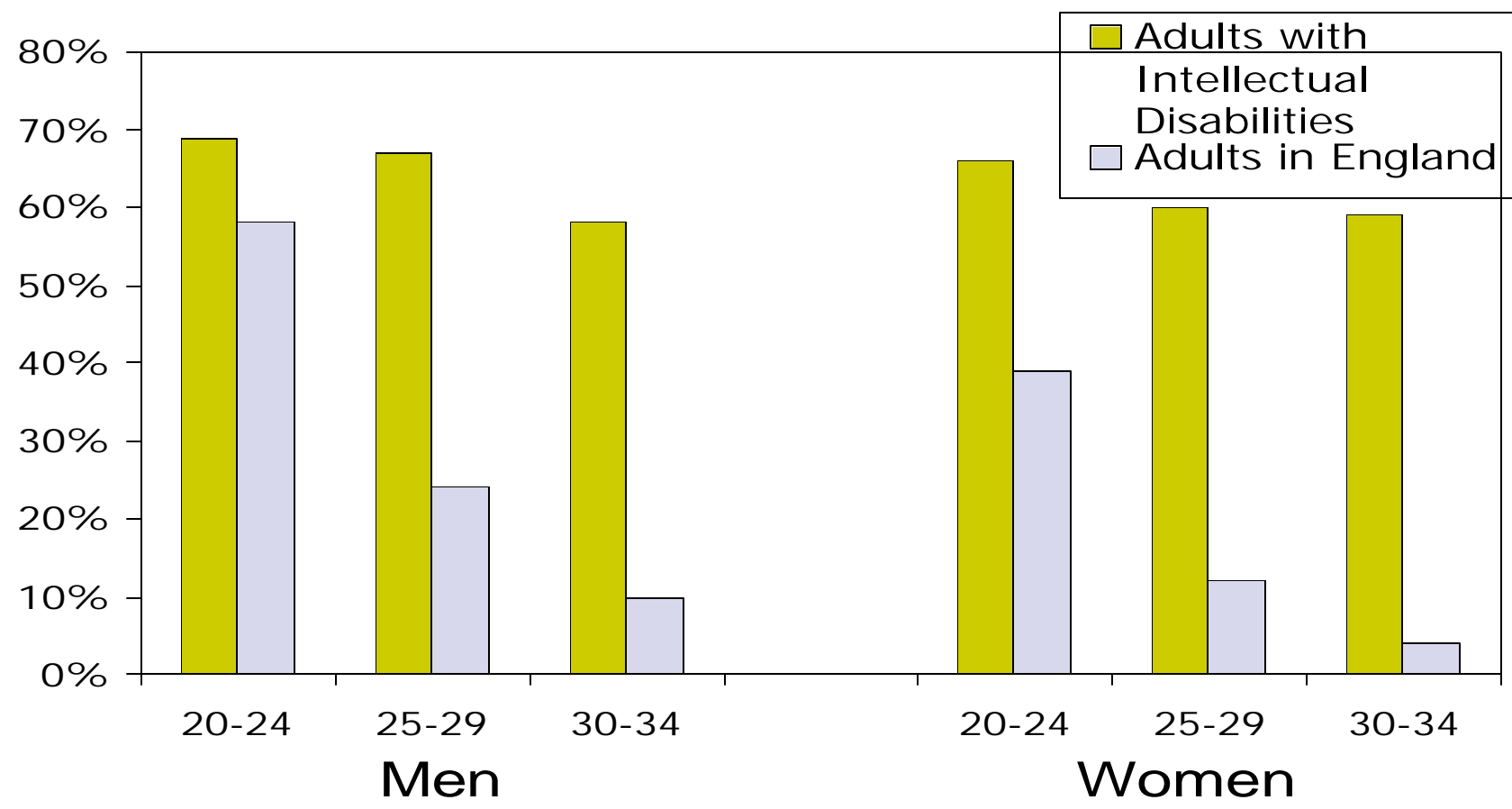


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Independence: Leaving Home





Three Principles

- National statistics should be able to document potential areas of inequality within the population of people with intellectual disabilities

Systemic Inequalities



- **Gender**
 - **Men** were more likely to have less privacy in their home, see friends who have intellectual disabilities less often, be a victim of crime and smoke.
 - **Women** were more likely to be unemployed, have been bullied at school, attend a day centre, not exercise, feel sad or worried.
- **Ethnicity:** People from minority ethnic communities were more likely to
 - be unemployed
 - be poor
 - see their friends less often
 - have poor health
 - be sad or worried a lot
 - less privacy
 - feel left out
 - not feel confident

Systemic Inequalities: Support Needs



- People with **higher support needs** were more likely to
 - Not be living with their families
 - have less privacy
 - have less choice
 - be unemployed
 - feel helpless
 - have attended segregated school
 - not be taking a course
 - not receive Direct Payments
 - not have control over their money
 - not see friends who do not have intellectual disabilities
 - not feel safe
 - not 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

Systemic Inequalities: Household & Neighbourhood Poverty



- 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

Key Issues/Lessons

