

## Health Inequalities and Learning Disabilities

### *The same as you?* evaluation – consultation event. 26.9.12

The consultation event was chaired in the morning by Phil Hanlon, Professor of Public Health, who explained that its purpose was to consult on Scottish policy for people with learning disabilities. The event was then opened by Jean Maclellan, Deputy Director - Adult Care and Support Division, who gave an overview of the Scottish policy context. She outlined the successes of *The Same As You?*, which included the closure of Scotland's long-stay hospitals. She then stressed the importance now of progressing further by developing new policy, a component of which should be to address the health inequalities experienced by people with learning disabilities. Nick Watson, Professor of Disabilities Studies, then described the challenges presented to society due to the media giving negative representations of disabilities and of people who need benefits, and suggested that the current times of austerity were influencing this. He also presented contrasting examples of people with learning disabilities being highly valued in society. This set the scene for the presentations on health inequalities. Eric Emerson, Professor of Disability and Health Research, discussed the many reasons why people with learning disabilities might experience health inequalities, which is a way of considering how policy and other initiatives could be developed to start to tackle this. Gyles Glover, the Director of the English Learning Disabilities Observatory, talked about the work of the Observatory, and how, by actually identifying what the health inequalities are that are experienced by people with learning disabilities in England, it has been possible to start to address them. One example he gave was the health check programme in England. Sally-Ann Cooper, Professor of Learning Disabilities, then drew upon some local experiences in the West of Scotland to show how NHS services could be developed to respond better to the needs of people with learning disabilities.

The two main highlights of the morning then followed. Catherine Heaney shared many of the challenges, obstacles and stressful situations she had had to overcome over the years to ensure her son was able to get the health care he needed. There are clearly still lessons for health professionals to learn. Catherine also talked highly of PAMIS and of several health professionals, saying how much she and her son needed and appreciated their support. Glasgow People First made everyone think very deeply. Iden Lewis and Pamela Niven opened up about their own experiences, and Edward Stanton showed a highly educational DVD about some really bad things that had happened to him during a recent hospital stay. Edward had successfully complained about this, and his complaint had been taken very seriously indeed by the hospital, who realised that they had to try to put things right, so that Edward and other people wouldn't be treated so badly in the future. So in the end this turned out to be a definite success story. Sandra Graham asked Edward questions so he could explain the problems in hospital, before everyone watched the DVD.

After lunch, there were four workshops. The workshops had four questions to consider, and within these considerations, delegates were asked to think what policies there should be to try to improve health.

The questions were:

1. What are the challenges to improving the physical health of people with learning disabilities?
2. How can we better address the multiple co-occurring health conditions that some people with learning disabilities have?
3. How can health and social care services improve and be better organised, delivered, and supported to address health improvement?
4. What are the key health indicators of Scotland's health improvement priorities?

**A lot of interesting ideas were generated, including:**

- People with learning disabilities have higher rates of many health needs, including respiratory disease and aspiration/choking, being born with heart disease (especially people with Down syndrome), reflux disorder, constipation, obesity, epilepsy, sensory impairments, incontinence, movement disorders, and mental health needs.
- They are less likely to seek medical advice for some types of problems,
- The challenges include:
  - Needing properly funded support – good support staff, with access to supervision and training. This includes staff being supported and directed in what is needed from them regarding health,
  - A role for monitoring health support requirements in the reviews of contracts that are placed with support providers,
  - Provision of more information from childhood, to educate people about health,
  - Better information on how to afford activities and good quality food, especially if there is no local supermarket,
  - The need for more accessible medical information,
  - The need for support to attend appointments and to understand the issues they raise,
  - How to change people's attitudes,
  - The multiple co-occurring health conditions that people experience.
- Some solutions may include
  - Strategy to inform local implementation plans, for example, around education, passports, certain types of diagnoses,
  - A stronger focus on equity. This is relevant to a number of issues, including, for example, access to screening (bowel screening being a good example), liaison nursing, and issues at transition,
  - Better scrutiny, to ensure that standards are being met, and best practice shared,
  - Support for a Scottish observatory. What people want from the observatory are:
    - To be able to identify the different health profiles of people with learning disabilities compared with the general population,
    - To find ways to measure indicators of health for people with learning disabilities,

- To reduce inequalities in health between the people with learning disabilities and the general population,
  - To be able to identify local health needs,
  - To identify unmet needs e.g. related to geography, or domain-specific,
  - Information to help with needs assessment and planning,
  - Empowering the learning disabilities population and carers,
  - A provision of general education, to train and tackle inaccurate beliefs,
  - Information to support advocacy and funding,
  - Qualitative information as well as quantitative,
  - A website that also includes links to other learning disabilities information,
  - A website that includes accessible information,
  - To be clear about definitions of learning disabilities e.g. using Local Authority services/funding, versus GP registers, and ideally a comparison of the two,
  - To be clear about definitions of health e.g. a model that considers social and environmental determinants of health, versus a simplistic "disease" model.
- There are already examples of good practice in Scotland, including:
    - Health checks – there are different models around Scotland, but all are positive, as are health screening clinics (such as those for people with Down syndrome)
    - Sensory assessment services – these are too small in number, but positive; also Bridge to Vision work,
    - Special needs dentistry, and increased engagement with special dentists following health checks,
    - Learning disabilities champions,
    - Learning disabilities nurses,
    - Learning disabilities liaison services in acute settings,
    - Hospital information booklets,
    - Health passports,
    - Carers' support,
    - Autism alert care,
    - Training DVDs for others, such as the police and GPs,
    - NES supported training,
    - Provision of less busy environments, with staff who have time to spend and gain knowledge about the person with learning disabilities,
    - Staff with good attitudes, values, and with enough time,
    - Communication aids for GPs,
    - Joint working with palliative care,
    - Easy read materials, such as on health promotion, information leaflets, and letters; sharing health improvement information, as well as information on health services (such as NHS24, admission to ward)
    - Healthy living courses,
    - Exercise programmes,
    - National screening programmes made accessible,

- PR in schools to create positive images,
  - Websites showing specific care pathways,
  - Service user training groups,
  - Good practice at the point of employment, including measuring values and attitudes, and previous experience,
  - Scottish Government health inequalities network.
- Policy priorities and actions could include:
    - National standards – equity across the country,
    - Rolling out best practice nationally,
    - Use of HEAT targets,
    - Links to other strategies, such as transition coordinator, OPAC, dementia, quality strategy,
    - Requiring local health improvements strategies specifically addressing the needs of people with learning disabilities,
    - Requiring all NHS Boards to specifically consider the potential impact on people with learning disabilities of any/all changes they introduce across their whole service provision,
    - Introduction nationally of health screening and health passports,
    - Investing to support transitional periods – and across the lifespan,
    - Legislation/strategy specifically on people with learning disabilities,
    - Better clarification of the term “reasonable adjustments”,
    - Moving away from services that are too big, and that are reactive rather than proactive,
    - Education and personal development for all staff, to be able to provide coordinated care,
    - Mandatory training for all health and social work staff,
    - Being clearer about what the needs actually are!
    - Having the different agencies working to one strategy,
    - Providing liaison nursing services in acute care settings,
    - Better detailing in support provider contracts of the requirements to support health, and better monitoring of their delivery of this,
    - Programmes for people with learning disabilities to speak to children in schools,
    - Initiatives to reduce bullying in schools,
    - Developing learning disabilities physicians for adults,
    - Ensuring closer working between public health and learning disabilities,
    - Supporting a learning disabilities observatory in Scotland,
    - Explicit policy requiring national monitoring of the health of the population with learning disabilities,
    - Development of health indicators for the population with learning disabilities,
    - Including the consideration of the population with learning disabilities in all other public health initiatives.

The conference was attended by 111 people from a range of backgrounds; people with learning disabilities, family carers, paid carers, learning disabilities health and social work professionals, public health professionals, primary care health professionals, secondary care health professionals, service managers,

third sector workers, academics, and representatives from the Scottish Government.