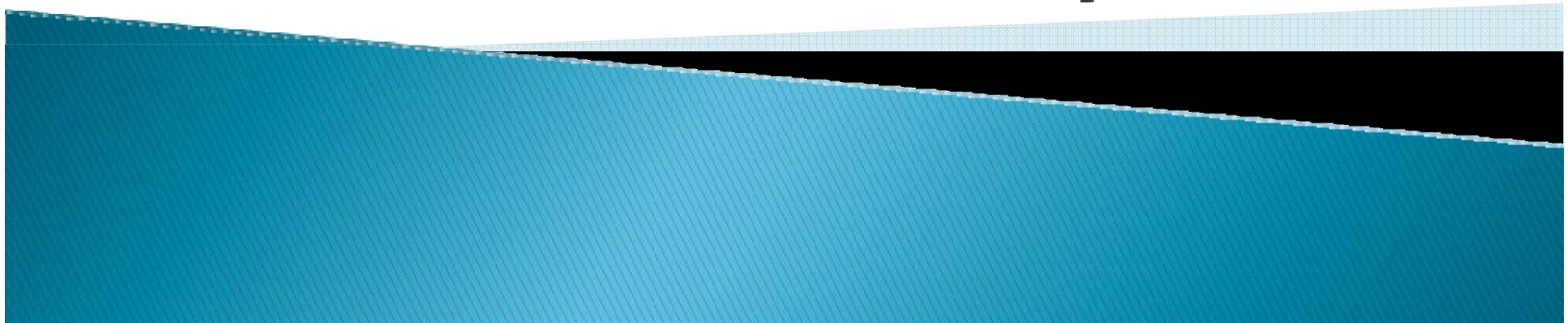




Adam Dinsmore, Researcher
Sarah Jones, Chief Executive

Provisional Recommendations for Enhancing Patient Experience Amongst People with Learning Disabilities on Merseyside



The Vodafone Foundation: World of Difference UK 2010



- ▶ 1000+ applicants
- ▶ 500 'Winners' from around the UK
- ▶ Paid work with your favourite charity



Overview

- ▶ People with Learning Disabilities who have attended NHS hospitals since March 2007
- ▶ Semi-structured Interview
- ▶ Patient Experience Questionnaire (Pettersen et al, 2004)
- ▶ Adaptation of Fox and Wilson's (1999) investigation in the Nottingham area

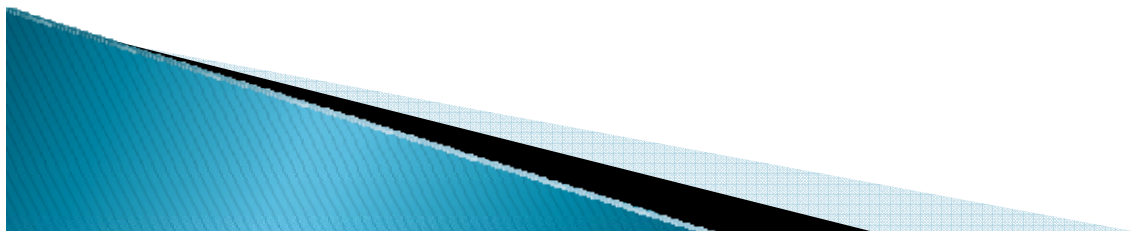


Overview

- ▶ Recommendations for enhancement of care drawn from our first 8 interviews
 - 5 Parents/Carers only
 - 2 Person with Learning Disability + Parent side-by-side
 - 1 Person with Learning Disability individually
- ▶ Final report to be released during this year's Learning Disability Week (week commencing 21/6/10)



- ▶ Equal healthcare, reasonable adjustments



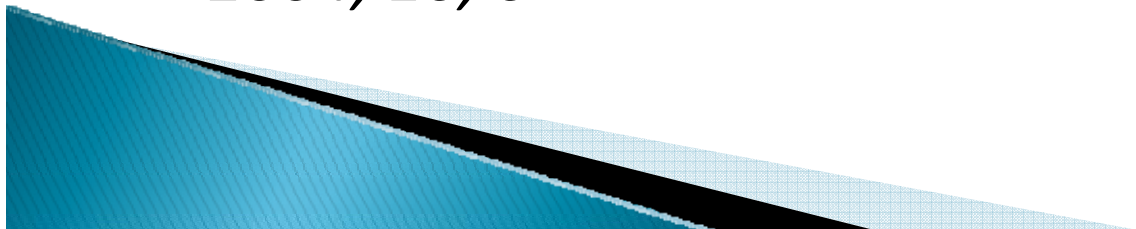


Methodology: PEQ

'a self-report instrument covering the most important subjects of interest to hospital patients. Results are presented as 10 scales with good validity and reliability. It emphasizes practicability and comprehensibility while at the same time providing sufficient information about domains applicable to most patients admitted to medical and surgical wards.'



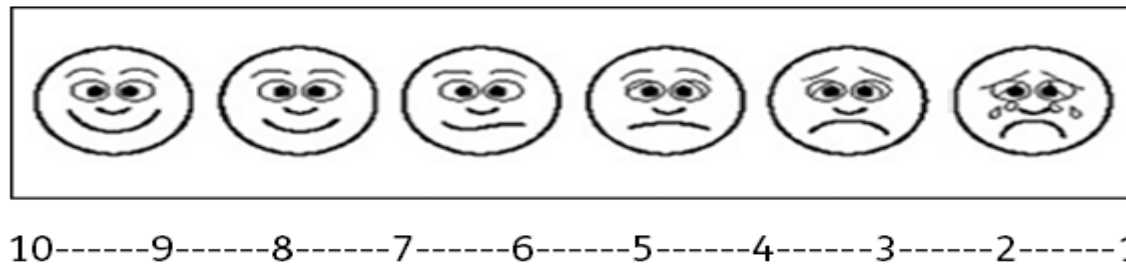
*-International Journal for Quality in Health Care,
2004, 16, 6*



Methodology: PEQ

- ▶ Easy-to-read Adaptation

10) I was generally satisfied with everything that happened at the hospital.

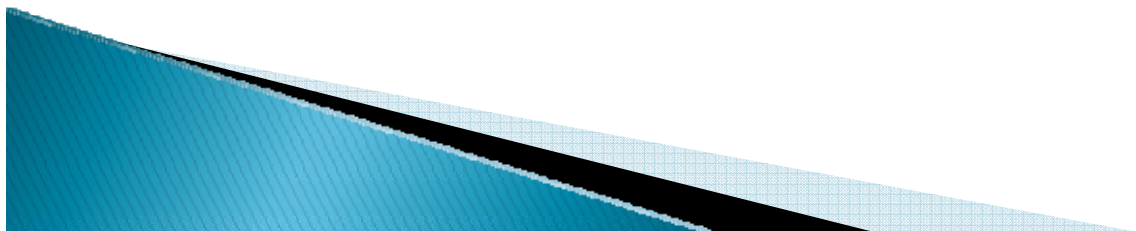


- ▶ Usability assessed during pilot interview



Methodology: Semi-Structured Interview

- ▶ Literature Review
- ▶ Emergent themes and recommendations collated
- ▶ Nine 'Key Areas of Enquiry'
- ▶ One hour pilot interview



Methodology:

Semi-Structured Interview

Publications Reviewed:

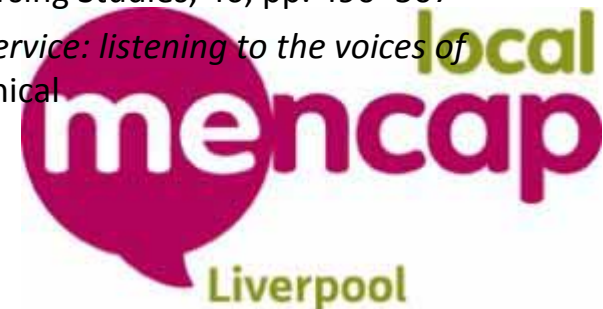
- ▶ Royal Mencap (2007), *Death By Indifference*. London: Mencap
- ▶ Royal Mencap (2004), *Treat Me Right!* London: Mencap
- ▶ Disability Rights Commission (2006), *Equal Treatment: Closing the Gap*. London: Disability Rights Commission
- ▶ Department of Health (2009), *Valuing People Now: A new three-year strategy for people with learning disabilities*. London: Department of Health
- ▶ Department of Health (2008), *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*. London: Department of Health
- ▶ The Joint Committee of Human Rights (2008), *A Life Like Any Other? Human rights of Adults with Learning Disabilities*. London: Joint Committee of Human Rights.
- ▶ Royal Mencap (2009), *Annual Health Checks Announced*. In Press
- ▶ Department of Health (2009), *Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance*. London: Department of Health
- ▶ Royal Liverpool and Broad Green University Hospital Trust: Single Equality and Human Rights Guide (2009-2012)
- ▶ Boland, M., Daly, L., Staines, A., (2008), *Methodological Issues in Inclusive Intellectual Disability Research: A Health Promotion Needs Assessment of People Attending Irish Disability Services*. Journal of Applied Research in Intellectual Disabilities, 21, pp. 199-209



Methodology:

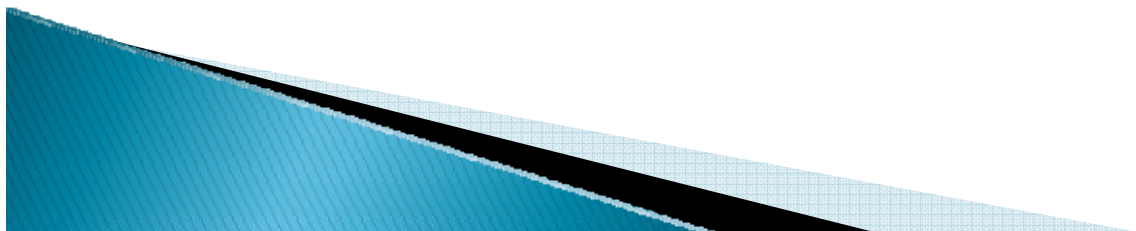
Semi-Structured Interview

- ▶ Fox, D., Wilson, D., (1999). *Parents' experiences of general hospital admission for adults with learning disabilities*. *Journal of Clinical Nursing*, 8, pp. 610-614
- ▶ UK Learning Disability Consultant Nurse Network (2006), *Shaping the Future: A Vision for Learning Disability Nursing*. London: UK Learning Disability Consultant Nurse Network
- ▶ Marsham, M. (2009). *Raising awareness of learning disability needs in acute sector care: A reflective account of a workshop from the guest facilitator perspective*. *Nurse Education Today*. 29, pp. 770-774
- ▶ Hart, S.L. (1998). *Learning disabled people's experience of general hospitals*. *British Journal of Nursing*. 7,8.
- ▶ Department of Health (2001). *Seeking consent: working with people with learning disabilities*. London: Department of health
- ▶ Hannon, L. (2004). *Better preadmission assessment improves learning disability care*. *Nursing Times*. 100, 25, pp. 44
- ▶ Aintree University Hospital Trust: Disability Equality Scheme (2006-2009)
- ▶ Griffiths, P., Bennett, J., Smith, E., (2009). *The size, extent and nature of the learning disability nursing research base: A systematic scoping review*. *International Journal of Nursing Studies*, 46, pp. 490-507
- ▶ Koch, T., Marks, J., Tooke, E., (2001). *Evaluating a community nursing service: listening to the voices of clients with an intellectual disability and/or their proxies*. *Journal of Clinical Nursing*, 10, pp. 352-363
- ▶ Royal Liverpool and Broad Green University Hospital Trust: Corporate Report (April - September 2009)



Recommendations

- ▶ Individual Recommendations of each of the first 8 participants
- ▶ Summary



Individual Recommendations

- I. Listen to the person with learning disabilities rather than automatically speaking to the carer – using simple yes/no questions if necessary
- II. Greater empathy on the part of nursing staff, greater value given to input of client and carer
- III. ‘Someone who understands’ in the hospital, someone to whom a LD carer can be referred to for support
- IV. Generally satisfied – credited their satisfaction to opportunity to become familiar with hospital staff



Individual Recommendations

- v. More credence given to anecdotal evidence presented by family members, healthcare staff could be trained to ask 'intelligent, proactive, probing' questions; Introduction of a 'greeter' independent of admissions staff, *not* specific to people with learning disabilities but trained to deal with them, could enquire about Patient Passports/Health Action Plans

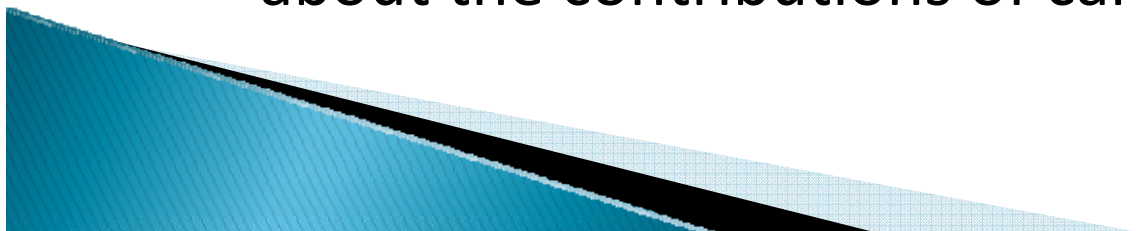
- vi. A member of healthcare staff responsible for informing the relevant parties of the rights and needs of each person with learning disabilities admitted to inpatient care



Individual Recommendations

- vii. Greater effort made to facilitate communication between healthcare staff and patients with learning disabilities – visual aids ‘would be a massive help’; waiting can cause great distress both to the learning disabled patient and others in the room, possible risk of violence – could some arrangement be made in advance to minimise/eliminate waiting

- viii. Better liaising between staff; ‘Listen to mum and dad’ - Healthcare staff mustn’t generalise about the contributions of carers



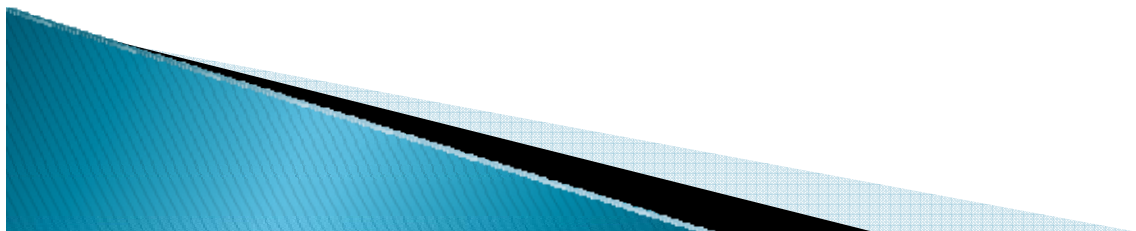
Recommendations: Summary

- ▶ Greater awareness of appropriate communicative strategies between healthcare staff and people with learning disabilities
- ▶ Greater credence given to input of parents/carers, particularly concerning idiosyncrasies of individuals with complex needs
- ▶ Introduction/modification of staff roles to improve support for patients with learning disabilities
- ▶ Participants often qualified their recommendations by warning against stigmatization or segregation



Moving Forward

- ▶ We're here today primarily to seek advice about:
 - Effective dissemination of our report
 - Maximisation of the impact and visibility of the report's recommendations
 - Pragmatic ways in which our recommendations could be incorporated into working practise



Thank You For Listening

- ▶ Any Questions?
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