

# Make it Better: Executive Summary

## Investigation into hospital/patient experiences among people with a learning disability on Merseyside

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- The aim of this investigation was to evaluate the in-patient experiences of people with a learning disability at NHS hospitals on Merseyside since the release of Royal Mencap's 'Death by Indifference' publication in March 2007.
- The investigators hoped to gain a better understanding of matters of importance for learning disabled hospital patients on Merseyside, and ways in which they believe their future hospital experiences could be improved. There appears **not** to have been an independent investigation of this type conducted on Merseyside previously.
- Participants came via Mencap Liverpool's existing membership, day-care centres in the Merseyside area, and other local learning disability charities. In cases where the person with a learning disability lacked capacity to participate in an interview their carers acted as a proxy. Twelve interviews were conducted in all: two involved people with a learning disability individually, three involved people with a learning disability alongside their carers, seven involved carers speaking on behalf of people with a learning disability in their care. All matters of consent and best interests were recorded in accordance with the Mental Capacity Act 2005.
- The findings are to be presented as discussions of a number of emergent themes rather than as case studies of each interviewee. These themes include:
  - *communication with nursing staff,*
  - *experiences of admittance to A&E,*
  - *involvement of family in the planning and provision of hospital care,*
  - *perceived attitudes of nursing staff towards learning disabled patients.*
- The report contains recommendations (overleaf) for the integration of the investigations' findings into general hospital practise.

## Recommendations:

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- i. Mencap Liverpool recommends that hospitals should make efforts to promote awareness of Learning Disability Liaison Nurses, their role, and the ways in which they can be contacted by patients. Mencap Liverpool hopes that this report will contribute to the evidence base supporting the appointment of Learning Disability Liaison Nurses, and their value in improving the hospital experiences of patients with a learning disability and their carers.
- ii. Mencap Liverpool recommends that hospitals and general practitioners engage in proactive collaboration to raise awareness about where and how annual health checks can be accessed so as to maximise their uptake on Merseyside.
- iii. Mencap Liverpool recommends that patients with a learning disability be afforded input into choices made about their placement within hospital whenever circumstances allow.
- iv. Mencap Liverpool recommends that hospital staff direct proactive verbal enquiries towards the families and carers of patients with a learning disability, so as to access the unique understanding, knowledge and evidence those people possess about the patient's disability and utilise it when making decisions about the patient's pathway to care as a matter of routine.
- v. Mencap Liverpool recommends that hospitals establish protocols for providing the families and carers of hospital patients with a learning disability with advice on how to effectively communicate their understanding, knowledge and evidence of the patient's learning disability to healthcare professionals, so as to optimise the usefulness of this information.
- vi. Mencap Liverpool recommends that all patients with a learning disability and/or their carers be provided with clear information about their responsibilities upon leaving hospital; ways in which they must maintain any ongoing treatments; signs of deterioration of their condition; appropriate ways in which they should recommence contact with the hospital; and the circumstances under which this contact should be made.
- vii. Mencap Liverpool recommends that nursing staff make reasonable adjustments to minimise disruption to the usual daily medication routines of patients with a learning disability during hospital stays.
- viii. Mencap Liverpool recommends that hospitals ensure that accessible written information about medical conditions, treatment options and relevant legislation is available to all hospital patients with a learning disability on request.

- ix. Mencap Liverpool recommends that hospitals make patients with a learning disability aware of the availability of Patient Passports, provide them with their own Patient Passport where requested, offer guidance to patients with a learning disability on optimizing their use, and solicit for Patient Passports as a matter of routine when patients with a learning disability are admitted.
- x. Mencap Liverpool recommends that nursing staff adopt a flexible approach to the hospital care of people with a learning disability and that hospitals make all staff aware of their duty to provide reasonable adjustments to the care of patients with a learning disability as legislated for by the Disability Equality Duty of the Disability Discrimination Act 2005.
- xi. Mencap Liverpool recommends that all hospital staff be provided with ongoing learning disability awareness training which emphasises the important of empathic staff attitudes to the hospital experiences of people with a learning disability.