Improving general hospital care for people with learning disabilities in Scotland

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Aims

- Evidence of general hospital issues and the needs of people with learning disabilities
- Developments in general hospital care in Scotland
- Research initiates in Scotland
- Opportunities and challenges for the future
The Scottish Context

- Scottish population 5,000,000
- Significant health inequalities exist
- Clear policy direction in Scotland
- Estimates 120,000 children and adults with intellectual disabilities in Scotland
- Learning Disability population increasing
- Health needs poorly historically addressed

1. Ageing learning disability subpopulation
2. Increasing number of people with complex learning disabilities
3. Limited data on needs across the life course to inform planning and commissioning
4. Focus on general hospital care
The Same as You?

29 key recommendations including -
• Close long-stay hospitals by 2005
• Appropriate health services to avoid in-patient episodes
• Support for people with Challenging Behaviours
• Local Area Co-ordination
• Scottish Consortium for Learning Disabilities
• Network for people with Autism
• Public awareness programmes
• Training for professionals in early detection of dementia
• Life long plans
• Partnership in Practice Agreements
Promoting Health, Supporting Inclusion: Scotland’s National Nursing Review

- 24 recommendations to enable and support nurses and midwives to contribute to:
  - *Promote Health* to address health inequalities and improve health and well-being
  - *Supporting Inclusion* to enable ordinary lives
  - Enable the contribution of all nurses and midwives across the lifespan
  - Mediate across generalist and specialist health care
  - Develop the research and practice development capacity for the future
  - Develop education and practice development opportunities for nurses and midwives
  - 2008 Government review of progress
General hospital Issues

“People with learning disability may be more at risk of things going wrong than the general population, leading to varying degrees of harm being caused whilst in general hospitals”

(National Patient Safety Agency, 2004 p.11)

- Evidence of high health needs and increased admissions yet shorter admission periods
- Diagnosis a problem
- Issues relating to challenging behaviours and communication
- Challenges of detecting pain and distress in people with ID
- Limited education and experience on the needs of people with ID for general health professionals
- Consent to treatment can be a significant issue
General health service failures

- The Experiences of Jimmy Mauchland
- Failing to protect Human Rights
- People with ID as equal citizens
- Challenging institutional discrimination
- Duty of Care of all health practitioners
- Equality and diversity
NHS Quality Improvement Scotland

- Integration of the outcomes of the Nursing Review within the National QIS Learning Disability Inspection Programme
- National specialist health services inspection programme established 2004
- Inspection review report and action plans published 2006
- Service failures in general health services
- National *general health services* inspection programme commencing Autumn 2008
Education & practice development

- Nursing year-one Common Foundation Programmes
- Learning Disability content review in all branches
- Scottish Framework for Learning Disability Nurse Education
- Post registration education developments and database
Physical Health

- A different pattern of physical health than the general population
- Mortality profile different from the general population
- Diagnosis a problem
- High levels of unmet health needs
Mental health

- A different pattern of mental ill health from the general population
- Early dementia more prevalent
- Schizophrenia common
- Depression & anxiety disorder common
- Lower levels of suicide
- High levels of unmet need
Common health needs &
general hospital care

- Gastrointestinal disorders
- Respiratory disease
- Cardiovascular disease
- Epilepsy
- Cancers
- Haematological disorders
- Ophthalmic disorders
- Musculoskeletal disorders
- Accidents and trauma

Additional care needs due to:
- Autism Spectrum Disorder
- Communication disorders
- Challenging behaviours
- Mental illness
A different pattern of health need from the general population
Higher level of health needs
Overwhelming evidence to support significant levels of need are often unrecognised and untreated
High users of ALL aspects of healthcare systems, including general hospitals
Liaison nursing in Scotland

- Focus on general hospital care for 10 years in Edinburgh and increasing focus across the UK
- Scotland-wide Liaison Nurses Network established
- Initial development day – February 2007
- NHS Lothian, Borders, Fife, Lanarkshire, Tayside and now others from across Scotland
- Support from South East Scotland Learning Disability Managed Care Network
- Standardised data collection format
- Information and sharing of practice
Objectives of the group

- Detailed analysis of Liaison Service
- Identification of core elements
- Development of service standards
- Audit programme to measure effectiveness of services
- Dissemination of findings to improve care and outcomes
The Data Set

- Known to learning disability service
- Liaison with whom
- Specific activities undertaken
- Outcomes
- Length of involvement
- Letter to GP and timescale

- By NHS Board - age and gender
- Reason for admission
- Admission type – elective, emergency, day case
- General hospital directorates involved
- Details of referrer
- Response time and method
Initial findings

Analysis based on 3 months of referrals from four NHS Board areas n = 57 new cases

Age range: 11 to 86 years old, mean of n = 47

Gender: 63% male, 37% female

People with learning disabilities move in and around general hospitals on a daily basis...
Who are the main referrers?

- Acute staff: 30
- CLDT staff: 26
- Paid carer: 18
- Social work: 12
- Self / family: 9
- Other: 5
Some Initial Findings

• 78% admitted to a medical ward
• 16% admitted to a surgical ward
• 2% admitted to an assessment ward
• 4% not admitted and discharged
Initial Findings

Diverse range of reasons for admission:

Dysphagia, aspiration, pneumonia, burns, colonoscopy, brain imaging, hip fractures, cardiac arrest, bowel obstruction, attempted suicide, cellulitis, haematemesis, barium swallow, MRI, unstable diabetes and many others....
## Liaison and referrals

<table>
<thead>
<tr>
<th>Liaison with</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Ward staff</td>
<td>61%</td>
</tr>
<tr>
<td>Support staff</td>
<td>47%</td>
</tr>
<tr>
<td>The patient</td>
<td>39%</td>
</tr>
<tr>
<td>CLDT</td>
<td>28%</td>
</tr>
<tr>
<td>Families</td>
<td>11%</td>
</tr>
<tr>
<td>Social work</td>
<td>9%</td>
</tr>
</tbody>
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### Referral responses

- 72% by phone
- 24% direct contact
- 4% by email
- 84% response within 4 hours
Specific activities undertaken

- Information sharing 95%
- Risk management 85%
- Capacity issues 80%
- Discharge planning 65%
- Carer support – educational 65%
- Behavioural advice 60%
- Client support – psychological 55%
- Bed management 50%
- Client support – educational 50%
- Pre morbid baseline 45%
- Rearrangement of appointments 40%
- Communication needs 35%
- Eating and drinking guidelines 30%
- Diagnostic advice 25%
- Client support – physical 25%
- Carer support – psychological 25%
- Vulnerable adult issues 20%
- Arranging visit to ward 5%
Some outcomes

Patient outcomes

- 94% care episodes complete
- 4% deaths
- 2% palliative care
- 93% GP notified within 2 working days

Contacts

- Length of involvement ranged from 1 to 38 days with mean of 14 days
- Number of contacts ranged from 2 to 26 with mean of 8
And the future...
The DisDAT research study

- The aim of the study was to evaluate the use of the DisDAT (Disability Distress Assessment Toll) as a clinical tool to assess distress in people with intellectual disabilities attending for general hospital care.
- To assess whether general hospital professionals find the tool straightforward to use and beneficial to the delivery of care.
- To identify if the use of DisDAT has any demonstrable links to the management of the patient's care, including pain management.
- To determine the perceptions of families and carers on the impact of DisDAT.
DisDAT Assesses ...

- Communication levels
- Facial signs
- Skin appearance
- Vocal signs
- Habits and mannerisms
- Body posture
- Body observations

- DisDAT involves the main carers with intimate knowledge of communication methods and needs of the patient
- DisDAT acts as a means to capture the carers’ knowledge about the individual’s expression of distress
- The assessment evidence can support general healthcare professionals to plan and deliver care
The subjects

- **Group one** subjects were people with profound intellectual disability unable to effectively communicate their possible distress (n=10)
  - n=5 planned admissions
  - n=5 emergency admissions
- **Group two** were general hospital professionals prepared on the use of DisDAT (n=8-10)
- **Group three** were families and carers involved in the care of the person with profound learning disabilities (n=10-20)
Participant identification

Healthcare databases of people with PLMD who previously attended for general hospital care

- n=168 potential patient participants
- n=31 potential PMID patient participants
- n=10 patients participants identified
- n=3 finally participated
The outcomes

• The small scale study exploring the issue of distress in people with PMLD was not completed
• Study design required to be reviewed and modified to enable involvement of people with PMLD
• Limit the opportunity for patients with PMLD to participate in research that may be of benefit
Research in Scotland

‘Impact of the Learning Disability Liaison Services on health experiences and outcomes on people with learning disabilities attending for general hospital care’
Liaison nursing research project

- 18 month government funded project
- Detailed data set analysis of Liaison Services in 4 NHS Board areas
- Obtaining views & experiences of stakeholders
- Formulation of nursing outcome measures
- Publication and dissemination of findings
So what next?

Opportunities

- Involving users and carers as consumers of healthcare
- Building on the interest and focus on general hospital care
- Improving education and practice development
- Increasing the evidence-base on achieving health outcomes
- Developing and evaluating service models to improve care and outcomes

Challenges

- Involving users and carers as consumers of healthcare
- Maintaining the policy momentum
- Gaining and keeping the interest of general hospital professionals
- Changing the education curricula
- Evolving the research evidence-base
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The South East Scotland Managed Care Network

Scottish Liaison Nurses Network
Thanks for taking the time to listen and now, please reflect on the nursing contribution where you are...

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