Nursing & Midwifery Board of Ireland
27th September 2016

Symposium for Registered Nurses &
students in intellectual disability

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Aims of the presentation

- Overview of the evidence of the everyday health needs experienced by people with Intellectual disabilities
- General health services experiences and people with intellectual disabilities
- Models of additional support in general health services and liaison nursing
Physical Health

- A different pattern of physical health than the general population
- Causes of death different from the general population
- Assessment and diagnosis a problem
- Unmet health needs
- As a result of health needs, high users of everyday health services, including general hospitals
The Evidence . . .

Cardiovascular Disease and associated conditions

- Second most common cause of death
- Congenital heart disease common - assessment, screening & on-going review important
- Ischaemia common - ? Increase as the population ages
- Obesity a major issue with associated impact on mental and physical health
- Increasing prevalence of diabetes, hypertension, stroke, metabolic syndrome
- No single cause of nutritional issues
- ? Increase in Cardiovascular disease and associated complications in ageing population
- Increase access to everyday health services
Respiratory disease

- *Commonest* cause of death
- Pneumonia and gastric aspiration – dysphagia, GORD, Down syndrome
- Swallowing assessments and prevention to minimise chest infections
- Postural care to minimise chest infections and pneumonia
- Management of chest infections, dyspnoea, asthma, COPD
- Lower level of respiratory cancer
- Oral care important to prevent chest infections
The Evidence...

Gastrointestinal disorders

- Gastric Oesophageal Reflux Disorder - ‘GORD’
- Helicobacter Pylori
- Gastric & Oesophageal cancers
- Constipation
- Choking
- Dysphagia issues
- Dehydration
- Malnutrition
The Evidence . . .

Neurological disorders

- Epilepsy 1-2% in general population
- Increases with the severity of intellectual disability, 60% + in PMLD population
- Prevalent, complex and multiple seizure types
- Seizure management
- Assessment, diagnosis, treatment and review
- Injury & accidents – fractures, head injuries, subluxation and dislocation due to seizures
- SUDEP
The Evidence . . .

Musculoskeletal

- Cerebral palsy common with associated mobility, balance, coordination, posture
- Link with accidents
  - Fractures,
  - Dislocations
  - Subluxation
- Poor foot care
- Association with increased mortality
Metabolic Syndrome: A global concern

- The metabolic syndrome is a cluster of the most dangerous cardiac risk factors:
  1. Diabetes
  2. Prediabetes,
  3. Abdominal obesity
  4. High cholesterol
  5. Hypertension
- Up to 80% of the 200 million people with diabetes globally will die of cardiovascular disease

- A quarter of the world’s adults have metabolic syndrome
- Have a five-fold greater risk of developing type 2 diabetes
- Metabolic Syndrome and diabetes contribute significantly to morbidity and mortality yet is not as well recognised
- Are twice as likely to die from, and three times as likely to have a heart attack or stroke
Communication

- Communication issues is the most common issue experienced by people with intellectual disabilities communication
- Contributes to issues relating to Assessment, diagnosis & treatment
- Contributes to ability to communicate needs, such as pain, discomfort, distress
- Assessment of individual communication needs & hearing and vision required
- Role of training programmes for carers and practitioners to improve skills
- Evidence supporting Intensive interactions, Individualised Sensory Approaches, Symbols, Signing, Objects of reference
Co-existing health conditions that result in complexity

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

Additional care needs due to multi-morbidities

- Communication disorders +
- Challenging behaviours +
- Autism Spectrum Disorder +
- Mental illness +
- Foetal Alcohol Spectrum Disorder +
- ADHD +
- Dementia +
Access to every day health services

• Access to appropriate assessment, treatment, diagnosis & interventions
• Access to person-centred and compassionate care
• Access to safe care
• Access to health screening
• Access to health promotion
• Access to accessible health education
• Access to well men and well women services
• Enabling equality of access to primary care services and general hospitals
• Necessitates collaborative working across primary care, general hospitals colleagues & specialist ID services
Complexity, quality & Care

Death by indifference
Following up the Treat me right report

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)
Final report
Death by Indifference

- Significant failures in safeguarding
- Serious service and system failures
- Avoidable deaths
- Poor practice & care
- Failure to adhere to legislation
- In short, *indifference*
- Recommend the appointment of Learning Disability Liaison Nurses in general hospitals
- **74 deaths and counting**
Confidential Inquiry

- Reviewed events leading to deaths of 233 adults and 14 children with intellectual disabilities
- People with intellectual disabilities die 16 years sooner than the non-disabled
- Three times as many people with learning disabilities had deaths that could have been avoided through the provision of good quality healthcare
- Heslop et al. (2013) recommended systems to identify people with learning disabilities within general health services be developed;
  1. The making reasonable adjustments to ensure person-centred care;
  2. The sharing of best practice; the implementation of clinical guidelines to take account of multi-morbidities;
  3. The allocation of a named healthcare coordinator for people with learning disabilities with complex needs with two or more long-term health conditions;
  4. The introduction of patient-held records for those with multiple health conditions;
  5. Equal access to investigations and treatments to achieve the same outcomes as for the non-learning disabled;
  6. Proactive referral to specialist learning disability services; access and adherence to capacity legislation with regular, mandatory updates for practitioners in health and social care;
  7. A review of the Do not attempt cardiopulmonary resuscitation guidelines
Backer et al. (2009) identified and reviewed 13 research studies and identified evidence-based recommendations aimed at improving the care and support of people with intellectual disabilities in the general hospital environment:

1. The development of liaison nursing models
2. Developing and enhancing care systems within health services to better meet the needs of people with intellectual disabilities
3. Developing education that improves practitioner knowledge and confidence about the needs of people with intellectual disabilities and
4. Improving systems to share information, communication and providing support for families and carers.

Systematic Review

Bradbury-Jones et al., (2013) reviewed eight research studies and identified six factors found to influence care in general hospitals:

1. Communication systems within the general hospital environment
2. Safety and welfare in the general hospital setting
3. Adjustments to the care environment to enable reasonable adjustments to be made
4. Staff attitudes and values regarding people with intellectual disabilities
5. Staff knowledge about care and support needs
6. Recognising and harnessing the role of families and contributions of families and carers in providing supporter and advice

Iacono et al. (2014) identified and reviewed 16 research studies related to the experiences of people with intellectual disabilities and their carers in general hospitals and identified:

- Fear of hospital encounters
- The role of carers in supporting their family member with intellectual disabilities
- Care delivery in the general hospital environment and failure to meet care needs
- Knowledge & skills of practitioners in general hospitals about intellectual disabilities
- Policies and procedures that take account of and reflect the needs of people with intellectual disabilities when attending general hospitals
- Attitudes of practitioners when meeting the needs of people with intellectual disabilities in general hospitals
- Models of additional support and establishing liaison nursing roles

Recurring themes and issues

• Ensuring care needs are met. The ‘basics’ - food, fluid, toileting, medication
• Supporting and respecting the role of carers, their contributions to care delivery and their knowledge of the person with intellectual disabilities
• Improving communication and information before, during and after general hospital attendance
• Education to address knowledge, skills and attitudinal issues
• Policies and procedures that include and reflect the needs of people with intellectual disabilities
• Safety and adjustments to care systems and direct care delivery
• Models of additional support and the establishment of Intellectual Disability Liaison Nursing roles in general hospitals
Working with complexity:
The role of the Liaison Nurse
What is Intellectual Disability Liaison Nursing?

Intellectual Disability Liaison Nursing is:

The application of the knowledge, skills and expertise of the Registered Nurse in Intellectual Disabilities of the distinct needs of people with intellectual disabilities at the point of pre-attendance, attendance and discharge within the general hospital environment to enable and facilitate safe and effective, compassionate, person-centred care

(Brown, 2016)
Liaison Nursing: The Journey…

- Work started in Edinburgh 1997 to review the care and support of people with intellectual disabilities in the general hospital setting
- Collaboration established Nurse Directors from Acute and Primary Care – Mrs Alex Harvey & Dr Linda Pollock
- Practice and Service Development Project undertaken by Juliet MacArthur and Michael Brown
- The first liaison nursing post for people with intellectual disabilities established in 1999 at the Western General Hospital, Edinburgh
- Audits, evaluations, business cases, service developments and research undertaken
- On-going Lothian-wide liaison nursing post established at the Royal Infirmary of Edinburgh, St John’s Hospital and Royal Hospital for Sick Children
The seven key elements of the intellectual disability liaison nursing role

| 1. Advocating | • Acting as a credible ambassador for people with a learning disability.  
| | • Fostering equal care through recommending reasonable adjustments and, where needed, representing the views of patients and carers to general hospital practitioners.  
| | • Ensuring recognition of and adherence to specific legislation such as capacity to consent to treatment, Disability Equality Duty and sensitive policies such as ‘do not resuscitate’ orders. |
| 2. Collaborating | • Acting as an expert link between clinical areas, services, sectors, patients and carers. |
| 3. Communicating | • Ensuring information flow across health boundaries, professional groups and between health staff and carers.  
| | • Advising general hospital practitioners on specific communication issues and methods to enhance and ensure understanding, including advising on augmented communication and the provision of specialist resources. |
| 4. Educating | • Formally through induction, updates, CPD programmes and skill development.  
| | • Targeting different professional groups, notably the need for medical staff training.  
| | • Informal – particularly opportunistic learning opportunities and through role modelling |
| 6. Mediating | • Building bridges between services, across agencies and health services.  
| | • ‘Speaking the same language’ as both learning disability and general hospital professionals.  
| | • Removing barriers that prevent equal access to care and treatment |
| 7. Facilitating | • Reasonable and achievable adjustments.  
| | • Access to care through arrangement and adjustment of appointments, pre-hospital preparation, accessible information.  
| | • Negotiating an appropriate environments of care. |
### Practice-based activities undertaken by the Liaison Nurses

<table>
<thead>
<tr>
<th>Percentage of patient-related activity</th>
<th>Percentage of patient-related activity</th>
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<tbody>
<tr>
<td>1. Information Sharing</td>
<td>67%</td>
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<tr>
<td>2. Capacity &amp; consent issues</td>
<td>41%</td>
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<td>3. Discharge Planning</td>
<td>40%</td>
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<td>4. Risk Management</td>
<td>39%</td>
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<tr>
<td>5. Behaviour Management</td>
<td>36%</td>
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<tr>
<td>6. Communication Advice</td>
<td>30%</td>
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<tr>
<td>7. Client Support - Psychological</td>
<td>27%</td>
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<tr>
<td>8. Carer Support - Education</td>
<td>27%</td>
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<tr>
<td>9. Carer Support - Psychological</td>
<td>27%</td>
</tr>
<tr>
<td>10. Bed Management</td>
<td>24%</td>
</tr>
<tr>
<td>11. Client Support - Education</td>
<td>23%</td>
</tr>
<tr>
<td>12. Client Support - Physical</td>
<td>20%</td>
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<tr>
<td>13. Baseline Assessment</td>
<td>19%</td>
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<tr>
<td>14. Rearrangement of Appointments</td>
<td>19%</td>
</tr>
<tr>
<td>15. Protection of Vulnerable Adults</td>
<td>16%</td>
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<tr>
<td>16. Eating, Drinking &amp; Swallowing</td>
<td>13%</td>
</tr>
<tr>
<td>17. Support during diagnostic tests</td>
<td>10%</td>
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<tr>
<td>18. Ward Visit</td>
<td>4%</td>
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A model of Learning Disability Liaison Nursing Practice

1. Sets out the supporting infrastructure required for an effective Intellectual Disability Liaison Nursing Services – a clear hospital base and presence, access to patient information systems, networks of support, reporting systems

2. Draws on the knowledge, skills and expertise of the liaison nurses about the health and support needs of people with Intellectual disabilities

3. Identifies the complex interface and relationship between the 7 elements of Intellectual disability liaison nursing role

4. The combined elements of the role – clinical practice, education and strategy development, results in outcomes for people with intellectual disability and their carers

5. Enables improved patient outcomes that are safe and person-centred and compassionate

Person-centred outcomes achieved by liaison nurses: Stakeholder perspectives

• Vulnerability & Presence
Patients with intellectual disabilities can have significant difficulties with understanding, retaining and processing health information regarding their treatment and care

• Personal & ‘The Human Interface
The importance of a professional relationship, which is personal, with the liaison nurse who can be consistent, provide safety and security

• Information Balance
Patients with intellectual disabilities can have significant difficulties with understanding, retaining and processing health information regarding their treatment and care

• Critical Points & Broken Trust
Miscommunication, limited resources, and unclear care pathways resulted in care which was not compassionate or person centred and therefore

• Roles & Responsibilities
Multiple professionals are involved in the care in the acute care environment and the roles and responsibilities of each needs to be explained to patients, their family and paid carers

• Flagging up’ & Communication
Managing multiple transitions within the acute care environment

The wider outcomes achieved by liaison nurses

- Person-centred and compassionate care enabled within general hospitals
- Pre-attendance planning, attendance support and discharge coordination
- Improved equality of access to general hospital assessment, treatment and interventions and safe care
- Access to additional support and expertise from knowledgeable and skilled Intellectual Disability Liaison Nurses
- The delivery of education and practice development to practitioners in general hospitals related to the care needs of people with intellectual disabilities
- Strategic, organisational response to the distinct health needs of people with intellectual disabilities
- Compliance with legislation, such as Disability Equality and capacity - *Treating people with intellectual disabilities more favourably if necessary to get a safe and person-centred outcome*

Conclusions

• The intellectual disability population is ageing, living longer and with complex health multi-morbidities which present organisational risk and challenges

• Liaison nurses as an innovative mechanism of supporting and facilitating the delivery of safe, compassionate, person centred care in general hospital environments

• Liaison nurses can minimise the numerous barriers faced by people with intellectual disabilities and their families which make their journey through the healthcare system that makes it challenging and stressful

• Liaison nurses can help address challenges through compassionate, person centred care, minimising risks to patient safety by contributing to managing the care journey effectively and sensitively

• Liaison nurses are a key mechanism in operationalising compassionate, person centred care for people with intellectual disabilities in the acute care environment

• Liaison nursing roles need to be fully developed and adopt across the general hospital environment if policy aspirations are to be realised

• Liaison nurses can help improve the patient care experience to achieve quality, efficiency and safety of care

• Liaison Nurses are part of the solution to improving the health outcomes for people with intellectual disabilities in the general hospital environment, they are not THE solution
What next: The Transitions Study

The number of young people with intellectual disabilities is increasing, with many presenting with complex care needs, so…

- A three year study to investigate nurse-led care to enable transition from child to adult services for people with intellectual disabilities and their learning, development and support needs.

1. To investigate and understand the experience of transition between child and adult health services, the challenges involved and the barriers
2. To develop best practice strategies in providing person centred care during transitions
3. To develop and pilot an education resource for nurses in practice on how best to manage transition between child and adult health services for people with learning disabilities and their families and carers
Some bed time reading

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The Research Team

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THANKS FOR LISTENING
KEEP CLAPPING
BUT
STAY CALM