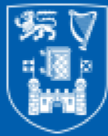


Martin C Henman
The School of Pharmacy and Pharmaceutical Sciences

Matching Pharmacy Care for people with Learning Disabilities

Belfast, 2018

Intellectual Disability (ID)

Terms

Intellectual disability
Learning disabilities/difficulties
Developmental difficulties

Causes

Chromosomal disorders - Down Syndrome
Pregnancy - Foetal Alcohol Syndrome
Post-natal - Head injury, Meningitis
Unknown (~50%)

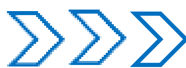
DSM-IV TR - an IQ of 75-70 or below

Mild 50-70

Moderate 35-49

Severe 20-34

Profound ≤20



Health
Communication
Social or interpersonal skills
Self-care

Problems: actual & potential

Capacity & consent
Strangers
Describing symptoms
Atypical disease presentation
Multimorbidity
Accepting 'invasive' tests
Response to medications
Reporting side effects
Challenging behaviours
Excessive polypharmacy
Prescribing cascade
Poor Health Status
Avoidable Early Mortality

Practicalities

An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing

Living arrangements

- Independent – alone, with partner, with family; self sufficient for most/many daily activities
- Community Group Home/Sheltered accommodation – with a small group; self sufficient for many daily activities but with daily support from Social services
- Residential – Nursing home – supervised care 24/7

Health Care provision

- Independent – General Practitioner & Community Pharmacist
- Community Group Home - General Practitioner & Community Pharmacist
- Residential – Health care assistant +/- Nurses +/- On call or daily Medical

Experiences

An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing

Some people with an intellectual disability face a situation of 'double jeopardy' where they are at risk of receiving second rate services from both the disability and health service because they are seen to be the primary responsibility of neither.

Bland, R., Hutchinson, N., Oakes, P. & Yates, C. 2003. Double Jeopardy? Journal of Learning Disabilities,

Some people with intellectual disabilities have reported that they had very helpful pharmacists who helped them understand their medication.

Too often the picture was of prescribed tablets given with limited information.

NPSA, 2004. Listening to people with learning difficulties and family carers talk about patient safety

REVIEW ARTICLE

Pharmacists' medicines-related interventions for people with intellectual disabilities: a narrative review

Máire O'Dwyer · Arijana Meštrović · Martin Henman

Case 1 – 40 year old male

Mild Intellectual Disability; High Functioning; At home with parents

- Down's syndrome
- Visits GP for check up once a year; Annual Diabetes clinic visit
- Medical history
  - Hypothyroidism
  - GORD
  - Diabetes – type 1
- Medications
  - Levothyroxine – 100mcg daily
  - Esomeprazole 20mg – once daily, as needed
  - Insuman comb 25/100
  - Perindopril 5mg daily
  - Paracetamol – 1-2 tabs, three times daily, as needed

Working method - Clinical

Acute or Chronic problem? Stable or Unstable?

Potential Clinical benefit of control

Potential risks & harm from lack of control

Medication – Check indication & dose – High risk? - Easy to use? - Recognition of problems?

Prioritisation

- Uncontrolled conditions - Medications needed – Simplification
- Medication-related problems - ADRs - Formulations

Setting – Primary Care

- Prescribers? - Information?

Medical procedures and tests for Health screening in people with Down's syndrome

Procedure or test;	Total (n=144) n (%)	Independent/family (n=27) n (%)	Community Group Home (n=63) n (%)	Residential care (n=54) n (%)
Eye test (n=137)				
Within last year	83 (60.6)	14 (53.8)	39 (63.9)	30 (60.0)
Hearing test (n=122)				
Within last year	29 (23.8)	2 (7.7)	18 (35.3)	9 (20.0)
Dentist/hygienist visit (n=142)				
Within last year	98 (69.0)	18 (69.2)	47 (74.6)	33 (62.3)
Bone density test (n=76)				
Within last year	7 (9.2)	1 (4.5)	4 (11.8)	2 (10.0)
Thyroid function test (n=133)				
Within last 2 years	116 (87.2)	15 (60.0)	51 (92.7)	50 (94.3)
Influenza vaccination (N=139)				
Within 2 years	131 (94.2)	21 (80.8)	60 (98.4)	50 (96.2)
Dementia assessment (n=82)				
Within last 2 years	27 (32.9)	4 (18.2)	14 (36.8)	9 (40.9)
Blood pressure (n=136)				
Within last 2 years	128 (94.1)	20 (80.0)	58 (96.7)	50 (98.0)
Blood glucose (n=128)				
Within last 2 years	105 (82.0)	10 (45.5)	52 (89.7)	43 (89.6)
Blood cholesterol (n=137)				
Within last 2 years	116 (84.7)	12 (52.2)	56 (90.3)	48 (92.3)

Belton et al. Medication Use and Health Screening in an Ageing Adult Population With Down Syndrome in Ireland: Journal of Policy and Practice in Intellectual Disabilities 2018; 15(2): 145–154.

Working Method - Clinical

Diabetes

- Insulin use - Dose selection - Dose administration - Management of use
- Monitoring of Blood glucose; Monitoring of BP
- HbA_{1c} ? - need for additional medication?
- Lipids? - need for lipid lowering medication?

Pain

- Severity & frequency - paracetamol use - other actions

GIT

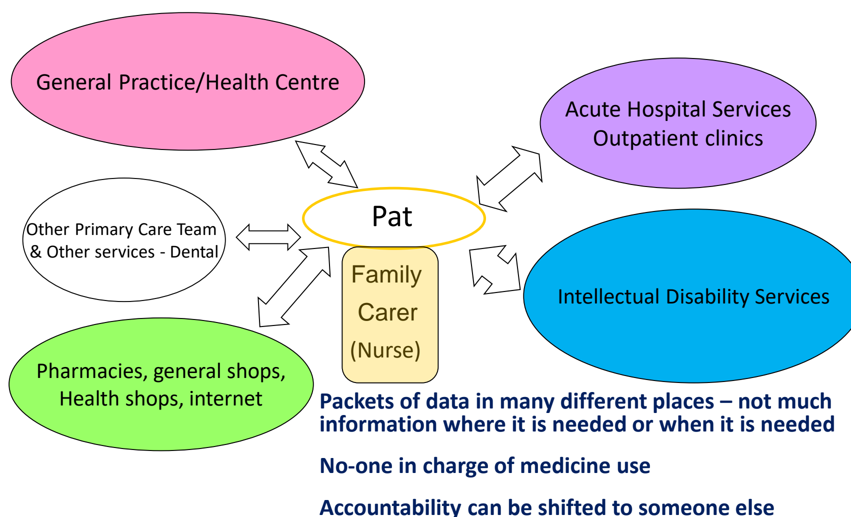
- Symptoms - why PPI? - use of PPI

The healthcare and social environment in which people with learning disabilities receive care and are prescribed medication is increasingly complex.

It has not been common practice to evaluate health care status or outcomes from the perspective of the direct care worker, or the person with the intellectual disability

Lessons from the Labrynth. Lennox & Edwards, 2001

Care with medicines is multi-setting, multi-prescriber & multi-carer



Packets of data in many different places – not much information where it is needed or when it is needed

No-one in charge of medicine use

Accountability can be shifted to someone else

Pat & his medicines:

He says he hates diabetes, but does not want to die

Does not take his medicines

Monitored Dose System provided by Pharmacy 1

Esomeprazole + Perindopril 5mg, Levothyroxine in each compartment – random compartments empty

Original packs dispensed by Pharmacy 2

– Esomeprazole – different brand

Non-prescription medicines

– Loperamide 2mg tabs x 2 different brands
– Paracetamol, codeine, caffeine analgesic tablets

Insulin pen

– 13 Lantus pens & 4 Novorapid pens – none in original containers – kept beside bed

Glucagon

– 3 GlucaGen Hypokits – one out of date

Glucose test strips/lancets/needles

Glucose diary – 2, very few entries

Flood B & Henman MC (2015) Br J Learn Disab; 43 (3): 234-242.

Flood B & Henman MC (2016) Int J Dev Disab; 62 (1): 24-40

Provision of information does *not guarantee* that an individual has understood & accepted it

The National Patient Safety Agency in England has highlighted the lack of information about *medication* that people with intellectual disabilities have been prescribed as an area of concern .

NPSA, 2004. Listening to people with learning difficulties and family carers talk about patient safety

However, people with limited literacy, such as people with learning disabilities, are less likely to;

- ask questions during a health care consultation
- seek health information from print resources
- understand medical/healthcare terminology & jargon

AHRQ, 2010 Health Literacy Universal Precautions Toolkit

A qualitative study of 21 people with intellectual disabilities/& prescribers in England, found that few of the people with intellectual disabilities were fully informed about their treatment.
Carers said that they knew how to administer the medication, but they knew little about why the person was taking it and what the implications might be.

Heslop, P., Folkes, L. & Rodgers, J. 2005. The Knowledge People with Learning Disabilities and their Carers have about Psychotropic Medication. Tizard learning Disability review, 10.

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Coláiste na Tríonóide, Baile Átha Cliath
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People with disabilities are excluded from decisions about their healthcare

The people who exclude them are;

Health Care Professionals

'There's a course called DAFNE and which is a really intensive one-week course that people do to learn how to use insulin appropriately. No, there's no way in a million years that somebody with a learning disability could do that course; it's just not possible at all.' (Diabetes Physician 1)

Brown et al. Improving diabetes care for people with intellectual disabilities: a qualitative study exploring the perceptions and experiences of professionals in diabetes and intellectual disability services. Journal of Intellectual Disability Research 2017; 61 (5): 435–449

Family

Family behaviours that are non-supportive can sabotage the person's efforts to perform self care behaviours.

- Inform family members about diabetes
- Enhance their motivation and behavioural skills around not interfering with the person's diabetes 'self-care' efforts

Health Service

A Diabetes UK survey of Primary Care Trusts found that only 38% provided psychological support for adults with diabetes.

Lewis C. 2009. Interventions to reduce emergency hospital admissions for diabetes. Liverpool Public Health Observatory.

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Facilitating CPD

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

Advice and support ongoing - disability can, where good support is provided, enable people with mild to moderate intellectual develop sufficient knowledge and understanding to play a key role in their own health **self-management**.

Strategies to self-manage their diabetes - a **nominated buddy** to encourage their exercise, and having to provide advice and reminders.

New Zealand - people with mild to moderate intellectual disability were able to develop knowledge and different levels of understanding about diabetes management.

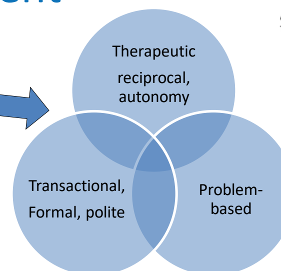
Hale et al 2011

Working method - Patient

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

Relationship

- Supplier or Carer?
- Open to change
- Personal
- Autonomy



Purpose

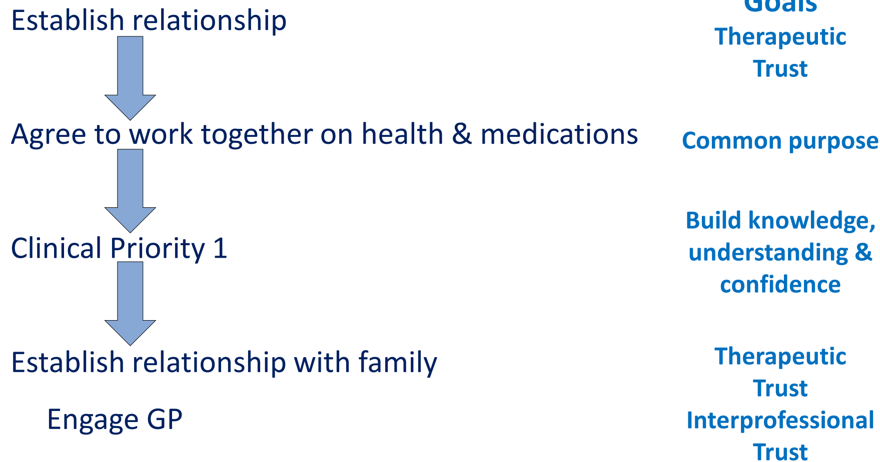
- Acknowledgement & recognition
- Offer of help & purpose
- Encourage exchange of information

Assessment

- Previous experience & attitudes
  - To conditions - to medications - to health service
- Capacity
  - Understanding & adherence for each clinical priority
  - Manage medications during maintenance
  - Recognise problems & act appropriately

Case 1 – Path to Priorities

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing



Establish relationship

Agree to work together on health & medications

Clinical Priority 1

Establish relationship with family

Engage GP

Goals

Therapeutic Trust

Common purpose

Build knowledge, understanding & confidence

Therapeutic Trust
Interprofessional Trust

Case 2 – 54 year old lady

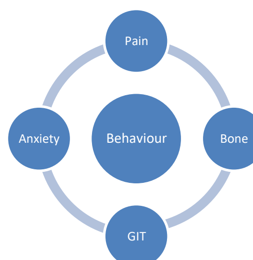
An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

Moderate Intellectual Disability; Moved to CGH in April from Nursing Home; requires assistance but takes part in social activities in community with friends & family (cousin) when she is able

– ID cause unknown
– Medical history
  - Hypothyroidism
  - Mild depression
  - Anxiety & emotional problems
  - Challenging Behaviour
  - Sleep problems
– Medications
  - Levothyroxine 50 mcg daily
  - Escitalopram 20mg daily
  - Risperidone 1mg twice daily
  - Zopiclone 7.5mg at night
  - Haloperidol 5mg/ml IM, as needed
  - Lansoprazole 20mg, twice daily
  - Lactulose, 15ml before bed
  - Paracetamol 1-2 tabs, four times daily
  - Ergocalciferol & Calcium, one daily
  - Salbutamol inhaler 2 puffs as needed

Working Method - Clinical

Prioritisation



Pain
- Cause
- Effectiveness of medication

GIT
- Symptoms
- Use of medication

Problem/Challenging Behaviour
- Verbal aggression; Physical aggression; Destruction; Self-injury; Other
- Effectiveness of medication – frequency of use of Haloperidol

Mood, Anxiety
- History
- Effectiveness of Medication

Respiratory
- Indication for salbutamol & use

Bone Health
- Assessment

Judgements about analgesics & antipsychotics

Medication	Pain	Behaviour
Efficacy vs Safety	Y?	?
Benefit vs Risk	Y?	+/-
Individual vs Society	Y	Y/N

People with intellectual disabilities should be included in decisions about their own healthcare of which medication use is a major component.
Exercising autonomy in the medication use process can be difficult and may not ensure the highest healthcare quality for people with intellectual disabilities - who usually are dependent on others for many aspects their care and access to care.

Pain

Only 8% of the nurses working with people with intellectual disability had undertaken education for pain management. Kankkunen et al. (2010)

64% of nurses were aware of the WHO ladder, but only 49% used it. Cringles (2002)

'…participants' understanding of pain was synonymous with their understanding of challenging behaviour... As a result, poor recognition of pain may occur with resulting inappropriate treatment practices, such as the administration of antipsychotics and sedatives instead of analgesics.'
'Other issues …include communication difficulties and varied knowledge among staff and medical practitioners regarding painful conditions associated with ageing and persistent beliefs that people with intellectual disability have high pain thresholds.'
Cleary & Doody. Professional carers' experiences of caring for individuals with intellectual disability and dementia: A review of the literature. J Intellect Disab 2017; 21(1): 68–86

Given the complexity of pain management, there is a need for a comprehensive assessment and empathic support of the individual. This complexity is reinforced by family/carer knowledge, understanding, assessment and ability to understand the individual's verbal/non-verbal communication.
Doody & Bailey. Interventions in pain management for persons with an intellectual disability. Journal of Intellectual Disabilities 2017; 1–13

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Working method - Situation

Assessment
- Support for daily living; support for health & social services
- History – stable, predictable or at risk

Information available - adequate
- to make a determination or, to indicate potential problem

Access to additional information

Communication
- Why? - inform of need/problem & inform of action taken or options for action
- With whom?
- How?
- What do you want? - for patient, for you, for them

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Situation - Community Group Homes

Organisation & staffing – according to medical need…but also available resources

- On site - Daily visit by Service Provider – Nurse or Social Worker
- On call - General Practitioner +/- specialist e.g. Psychiatrist/Psychiatric Nurse

Provision of medications

- Visits Community Pharmacy
- Management of medications in the Home
  - Responsibilities & support of Nurse/Social Worker
- Medication Review procedure
  - part of annual check up at GP surgery
  - Liaison with Service Provider

At risk, even though they live in a 'safe' place.

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Situation - Community Group Homes

Relationship

- Patient – sometimes visits Pharmacy on days out
- With others living in the Home, who are friends/may influence
- Family, if they live nearby
- GP
- Disability Service Provider

Monitoring

'Black hole'

Mood

Mobility

Social interactions

Eating & personal care

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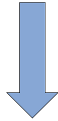
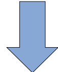
Case 2 – Path to Priorities

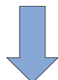
Establish relationship with Service Provider



Agree to exchange information, offer advice



Establish relationship with patient & friends



Clinical Priority 1

Engage GP

Goals

Therapeutic
Trust
Common purpose

Build knowledge, understanding & confidence

Therapeutic
Trust

Interprofessional
Trust

Nursing Homes & Pharmacy services

Denmark

Mygind, et al. Community
2017; 25: 282–291.

Mygind, et al. Developme
facilities. International Jo

IJPP
International Journal of Pharmacy Practice

Research Paper

Community pharmacists as educators in Danish residential facilities: a qualitative study

Anna Mygind, Mira El-Souri, Kirsten Pultz, Charlotte Rossing and Linda A. Thomsen

Pharmakon, Danish College for Pharmacy Practice, Hillerød, Denmark

IJPP
Pharmacy Practice

Research Paper

Development and perceived effects of an educational programme on quality and safety in medication handling in residential facilities

Anna Mygind, Mira El-Souri, Charlotte Rossing and Linda Aagaard Thomsen

Case 3 - 63 year old lady

Moderate Intellectual Disability; Nursing home; highly dependent, no family

- ID cause unknown
- Medical history
  - Hypothyroidism — Diabetes — Hypertension
  - Epilepsy — Sleep problems
  - Challenging Behaviours — Osteoporosis
- Medications
  - Levothyroxine 50 mcg daily - Lansoprazole 30mg, daily
  - Humulin M3 daily - Cyanocobalamin 50mcg, x2
  - Valproic acid 500mg x2 - Lamotrigine 100mg x2 Buccal midazolam as needed
  - Sertraline 200mg daily - Lactulose, 15ml before bed
  - Haloperidol 2mg x2 - Bisacodyl, 10mg, as needed
  - Aripiprazole 30mg daily - Nitrazepam 10mg at night - Biperiden 2mg, x3
  - Timolol & bendroflumethiazide 2x2 daily - Aspirin 75mg daily
  - Pregabalin 150mg x3 - Paracetamol 500mg Codeine 30mg 1-2 tabs, x3
  - Ferrograd C, one daily - Ergocalciferol with Ca, one daily

Working method - Clinical

Acute or Chronic problem? Stable or Unstable?
Potential Clinical benefit of control
Potential risks & harm from lack of control
Medication – High risk? - Easy to use? - Recognition of problems?

Prioritisation

Epilepsy

Kiani et al., 2013 Robertson et al., 2015

- 'Drug resistant'– partial control - impact of treatment on cognitive capacity
- Sudden death – other drugs with epileptogenic potential

Challenging behaviours

- Antipsychotics & mood stabilisers & sedatives
- Anticholinergic - Laxatives

Diabetes & CVD

- Progressive? - Lipids? Assess & control?

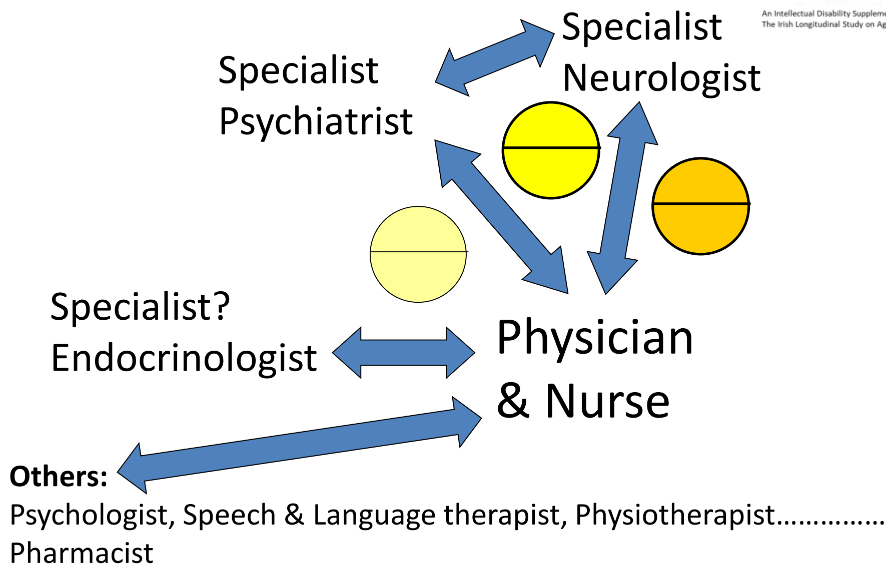
Barthel Index Activities of Daily Living

- Ordinal Scale
- Scores from 0 – 20
- Lower score indicates poorer function
- Age, gender, level of ID

- Mobility
- Using stairs
- Dressing
- Bathing
- Grooming
- Feeding
- Transfer
- Toileting
- Bladder continence
- Bowel continence

Barthel Index Score
Complete Independence - 100
Mild Dependence – 91-99
Moderate Dependence – 60-90
Severe Dependence – 21-60
Total Dependence – 0-20

Review by Multidisciplinary team



Others:
Psychologist, Speech & Language therapist, Physiotherapist…………..
Pharmacist

Patient Assessment

Multidisciplinary
- Specialists may be deferred to
- New problems will be attended to
- Carer's – Nurse's or Care Assistant's concerns & opinions
- Patient's voice?

Medication
- Several decision makers acting almost independently
- Inertia is a major force

Implementation – feasibility, convenience
- Final deciding factor

Working method – Carer's perspective

Prioritisation – Burden & Control

Epilepsy
- Ineffective drugs – multiple drugs to administer
- Sudden death

Challenging behaviours
- Tranquilisers – multiple drugs to administer

Gastro-intestinal
- Swallowing & medication administration
- GORD & acute discomfort
- Constipation

Diabetes
- Injection to administer

Nursing Homes & Pharmacy services

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

'Medical supervision'

Organisation & staffing – according to medical need…but also available resources

- On site - Nurse(s) or Care Assistant
- On call - General Practitioner +/- specialist –Psych, Neuro
- External service provider - Community Pharmacy
- Management of medications in the Home
  - Responsibilities & support of Nurse(s)
  - Capability of Care Assistants
- Medication Review procedure

Nursing Homes & Pharmacy services

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

Compliance Assessment – Supply of Medicines to Patients in Residential Care Settings

Having completed the review, please consider the statements listed below and select the level of compliance that you think best represents your pharmacy

Compliant: ☐

- ☐ The preparation, dispensing and supply of prescription medicines is always carried out under the personal supervision of a pharmacist.
- ☐ A pharmacist reviews each prescription for its validity, the pharmaceutical and therapeutic appropriateness of the medicine for the patient, and screens the prescription for any potential problems. Each patient and/or their carer(s) is offered counselling on their medicines.
- ☐ There is a clear, documented procedure for the supply of prescription medicines to patients in residential care settings, which reflects practices in place in the pharmacy.
- ☐ The supply of medicines to patients in residential care settings fully meets the requirements of PSI guidance.

Re-structuring the Care process

In countries with an early level of deinstitutionalisation, measures need to be taken to prevent people living in unstaffed living arrangements from being excluded from primary health care services during and after the deinstitutionalisation process, and to improve the health care offered in their staffed residences.

Martínez-Leal et al. The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe. J Intellect Disabil Res. 2011; 55(9): 858–872.

The relatively high ratio of unmet to met needs found with respect to minor and major mental health problems, however, reveals a systematic deficit in meeting mental health needs. This is probably owing to the fact that mental health care for adults with ID is, in Germany as in many other countries, provided by a system that is separated from ID services, so that the needs of adults with ID cross traditional lines of professional responsibility.

Schützwohl et al. Mental illness, problem behaviour, needs and service use in adults with intellectual disability. Soc Psychiatry Psychiatr Epidemiol (2016) 51:767–776

Personalised Care

Genomics

Phenotype

Vulnerable 'invisible'

Therapeutic relationship

Carers Communication

Specialist care

Generalists

Ask Don't assume

Maintenance

Medications

WHO 3rd Global Patient Safety Challenge – Medication without harm

A different perspective…
Video – Going to the doctor

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

Intellectual Disability Supplement -TILDA

https://www.youtube.com/watch?v=ZI_bHH3VC5k&feature=youtu.be

Observational cohort

- Inclusion criteria; Registered with National ID Database, > 40 years
- Wave 1 – 2010, now Wave 3 data cleaned

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Acknowledgements

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

- Participants: People with an intellectual disability
- Service Providers
- Advocacy Groups
- Collaborators & PIs

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