Towards better care for people with intellectual developmental disorders and mental disorders

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I will address

- What we know

-Mental and physical health

-Services

- What we can do

-Practice

-Research

-Policy

Intellectual Disability (DSM-V)

http://www.dsm5.org/documents/intellectual%20disability%20fact%20sheet.pdf

Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas.

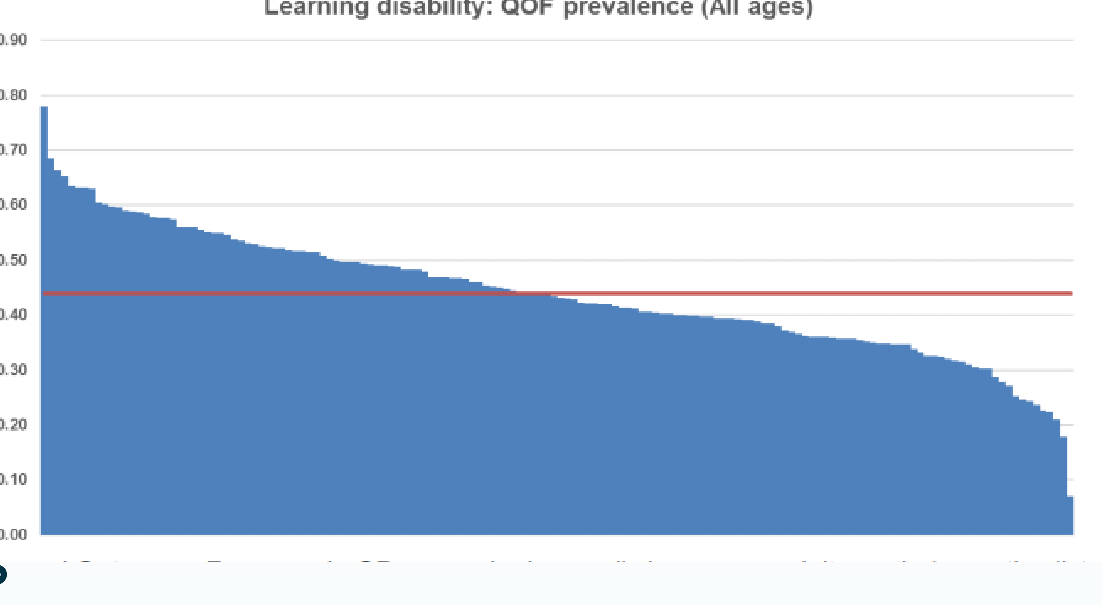
- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental period

Chronicity and comorbidity

Who has an ID?

- UK: 1-2% of the population meet criteria for intellectual disability
- In England, about 25% of adults with ID are known to services (900,000)

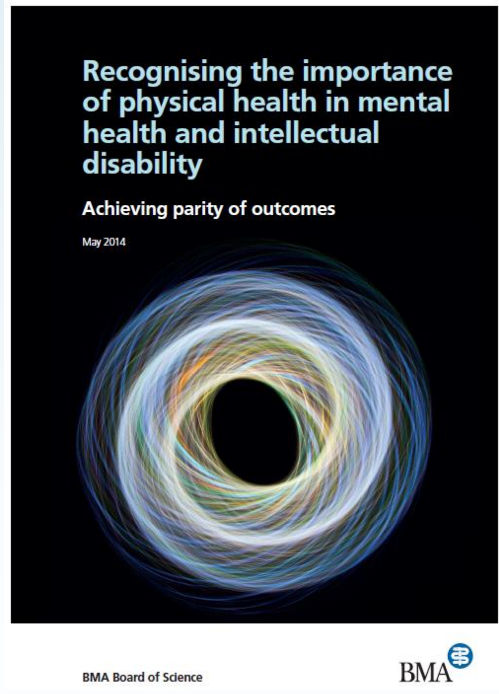


Physical health

- Multimorbidity (http://bmjopen.bmj.com/content/8/2/e018292)
- 98.7% of participants were multimorbid (2/3 responded n=1023)
- Mean 11 conditions per participant
- visual impairment, obesity, epilepsy, constipation and ataxic/gait disorders

Diagnostic overshadowing

Occurs when a presentation is attributed to intellectual disability rather than a potentially treatable cause



Why does this matter?

- Confidential inquiry into premature deaths of people with intellectual disabilities (CIPOLD)[1]:
  - Men with LD die 13 years younger than men without ID
  - Women with LD die 20 years younger than women without ID
  - 37% deaths investigated were deemed “avoidable” i.e. preventable by the provision of good quality healthcare (cf. 13% general population deaths)
  - Barriers and delays in treatment are a problem
  - Lower uptake of screening and preventative medicine
  - Communication between professionals needs to be improved
  - Staff knowledge of ID and services should be better

The economics of ID

Burden on carers and lifelong disability and health problems

- UK 2010: 3.5bn euros (https://www.ncbi.nlm.nih.gov/pubmed/22175760)

National Audit Office (England)

- £8bn estimated annual spend by government to support adults with ID (2015-16)

£4.6bn Social care

£1bn NHS

£2.5bn benefits

Mental ill-health (adults)

- Schizophrenia 3% (cf. 1% people without ID; Morgan et al, 2008)
- Four to six fold more likely to suffer from affective disorders (Richards et al, 2001; Maughan, 1999).
- Apprx 40% have a mental disorder (Cooper et al, 2007)
- Dementia is twice as common in people with ID as they age
  - Down syndrome is associated with early-onset Alzheimer's disease
- 11% of mental disorders may be due to rare deletions or duplications (chromosomal copy number variations; Wolfe et al, 2017)
- Scottish census data show 7 fold increase in self/proxy report of mental illhealth

Mental illhealth (children)

Children and young people

- 30-50% vs 8-18% in peers without
- 41% (no control)
- RR: 2.8–4.5

https://www.ncbi.nlm.nih.gov/pubmed/21609299/

Or

1:7 children with a mental disorder has an IDD

Incidence of new records of mental illness & challenging behaviour

Mental illness	Number of events	Incidence per 10,000 PYs	95% confidence interval
Any mental illness	3,998	262	254 to 271
SMI	617	32	29 to 34
Depression	3,054	171	165 to 177
Anxiety	2,512	139	134 to 145

	Number of events	Incidence per 10,000 PYs	95% confidence interval
Challenging behaviour	3,615	239	231 to 247

Sheehan et al 2016, BMJ 2015

Benchmarking Report-Learning Disabilities 2018

Bed based service	% of participants who provide the service
High secure forensic beds	0%
Medium secure forensic beds	18%
Low secure forensic beds	37%
Acute admission beds within specialist LD units	74%
Acute admissions beds within generic mental health settings	24%
Forensic rehabilitation beds	9%
Complex continuing care & rehabilitations beds	29%
Other beds including those for specialist neuropsychiatric conditions	9%
Step up/ step down beds	12%
Crisis beds	0%
Inpatient short breaks/ respite schemes	29%

Benchmarking Report 2018

Bed Type	Mean beds per 100,000 population 2016/17	Mean beds per 100,000 population 2015/16	Mean beds per 100,000 population 2013/14
Secure/ Forensic (Low, Medium, High)	1.7	1.7	2.3
Acute admission (specialist LD units)	1.3	1.5	1.8
Acute admission (generic MH setting)	3.1	1.1	2.4
Forensic rehabilitation	0.2	0.1	0.9
Complex continuing care and rehabilitation	1.3	1.3	2.0
Other beds	0.4	0.5	1.2
Average total beds	6.0	4.8	7.5

Benchmarking Report 2018

Bed Type	Average length of stay (discharges, 2016/17)	Average length of stay (discharges, 2015/16)
Secure / Forensic (Low)	806	1,139 ↓
Secure / Forensic (Medium)	534	446 ↑
Acute Admission (specialist LD units)	230	244 ↓
Acute admission (generic MH setting)	5	20 ↓
Forensic rehabilitation	336	614 ↓
Complex continuing care and rehab	1,036	1,217 ↓
Other beds	49	96 ↓

Our inpatient service

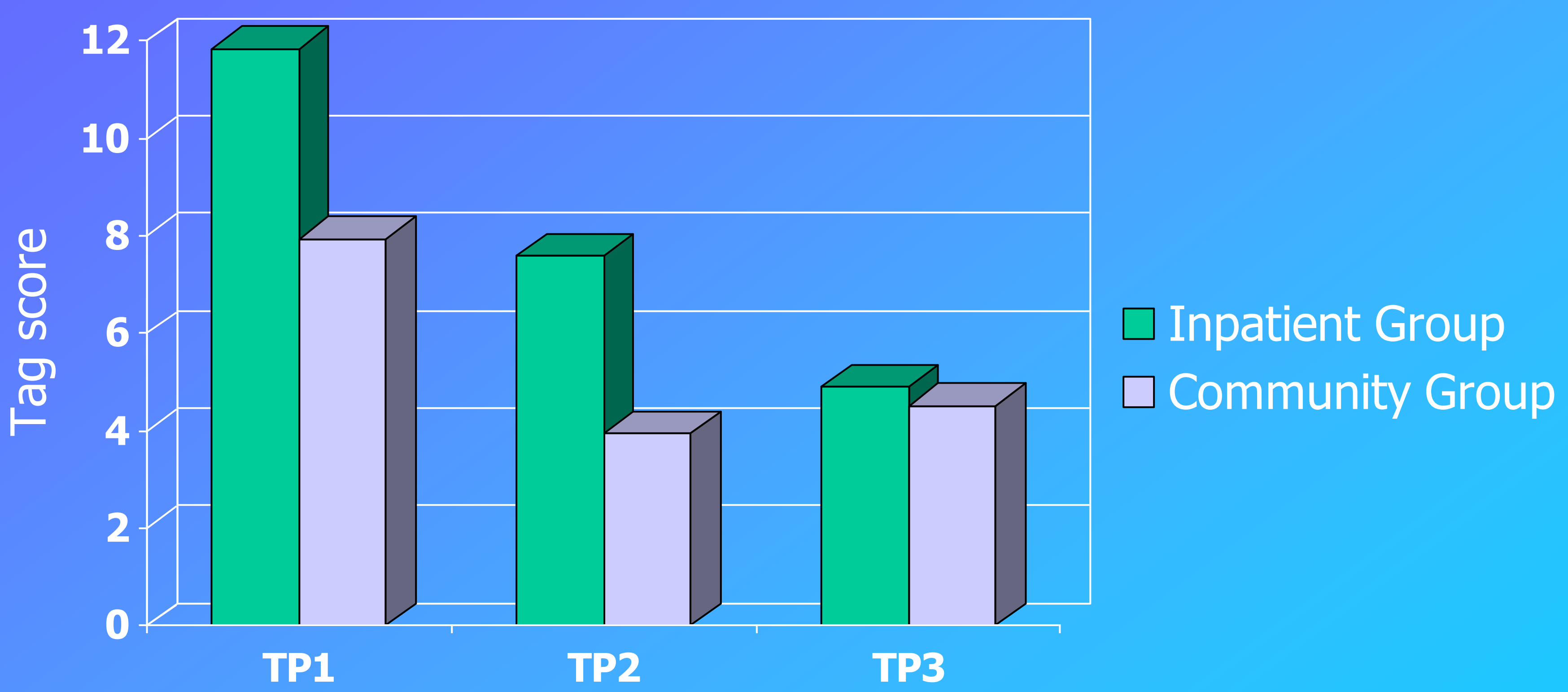
- General adult ward – 12 beds
- 4 beds allocated for people with LD

J Intellect Disabil Res. 2006 Aug;50(Pt 8):598-607.

Working across boundaries: clinical outcomes for an integrated mental health service for people with intellectual disabilities.

Hall I[1], Parkes C, Samuels S, Hassiotis A.

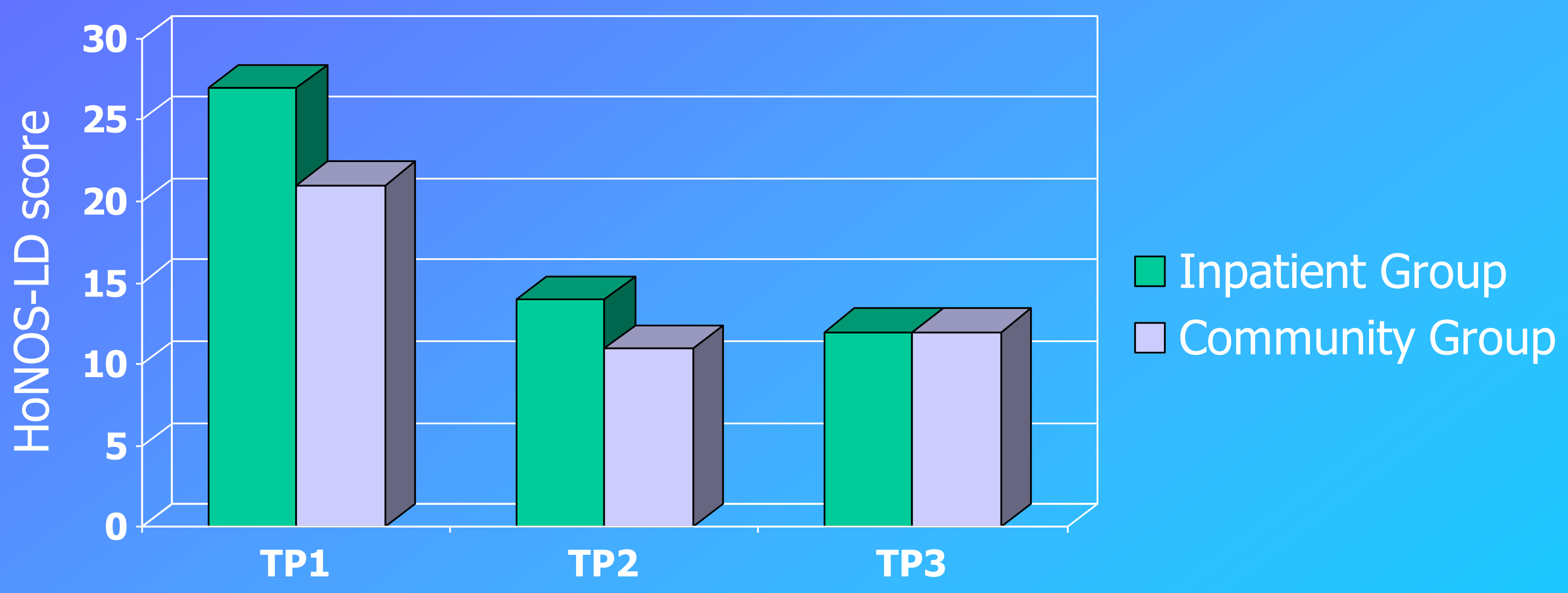
Risk over time (TAG)



Overall difference between mean TAG scores

(Inpatient Group $F= 41.9$, $p<0.001$; Community Group $F=12.7$, $p<0.001$)

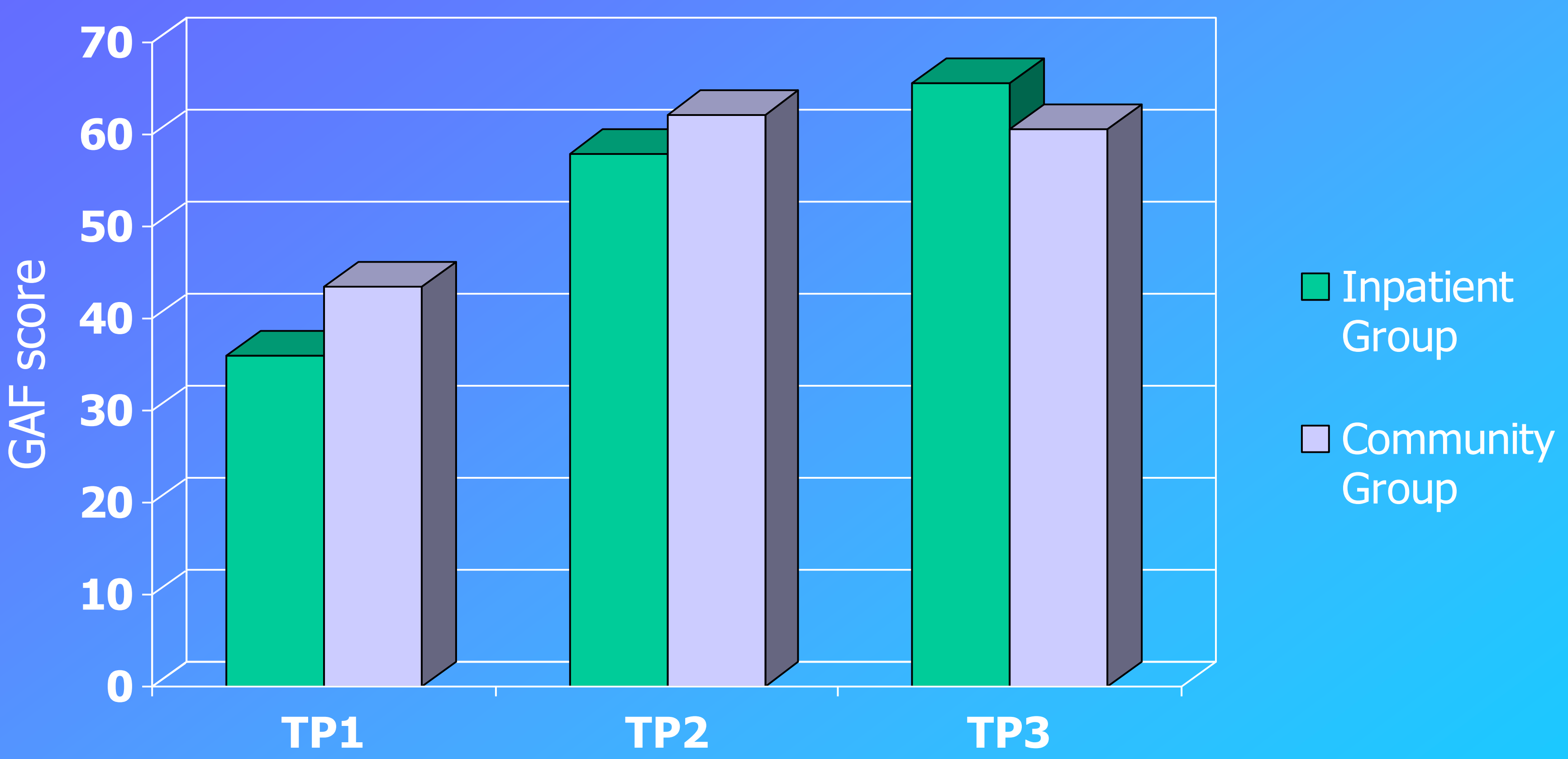
Outcome over time (HoNOS-LD)



Overall difference between mean HoNOS-LD scores

Inpatient Group $F=26.7$, $p<0.001$; Community Group $F=17.3$, $p<0.001$)

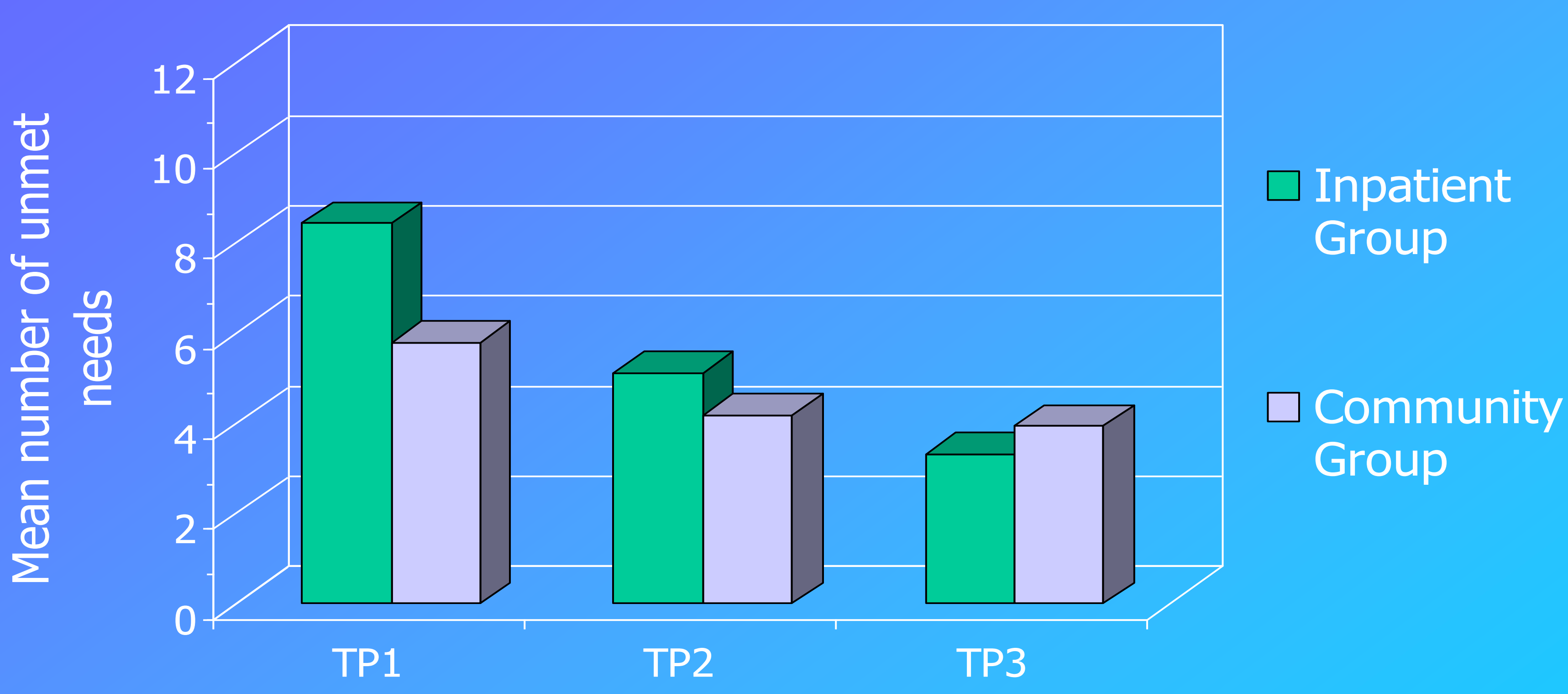
Global functioning over time (GAF)



Overall difference between mean GAF scores

Inpatient Group $F=27.2$, $p<0.001$; Community Group $F=13.9$, $p<0.001$)

Unmet needs over time (CANDID)



Overall difference between mean CANDID-LD scores for Unmet needs

(Inpatient Group $F=12.5$, $p<0.001$; Community Group $F=8.2$, $p=0.003$)

They should like accept that people with learning difficulty and mental health and with people with just mental health, they should mix, mix people in together. So that people with the mental health can understand people with learning difficulties.
They can make friends and understand each other and their problems and all that you know.
They shouldn't be really separated from people like us you know, people like with a learning difficulty and with a mental health problem shouldn't really like be separated, they should really all be mixed in together."

How to provide good care?

Contextual aspects

- Historical context
- Stigma and prejudice (https://www.amazon.co.uk/Intellectual-Disability-Stigma-Stepping-Margins/dp/1137524987)
- Population heterogeneity (mild ID vs severe ID)
- The right of people with ID to live their lives as individuals and citizens (http://www.tandfonline.com/doi/full/10.1080/23297018.2017.1312505?src=recsys&)

Practice

Challenges to good care: Hemmings et al 2014 http://www.mdpi.com/1660-4601/11/9/8624

- Interface/mainstreaming
- Diagnosis at entry point
- Lack of evaluation of care models
- Difficulty in accessing crisis care
- Case for “shared care” rather than dualistic thinking

NICE guidelines

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

NICE guideline [NG11] Published date: May 2015 Uptake of this guidance

Mental health problems in people with learning disabilities: prevention, assessment and management

NICE guideline [NG54] Published date: September 2016

Learning disabilities and behaviour that challenges: service design and delivery

NICE guideline [NG93] Published date: March 2018 Register as a stakeholder

Care and support of people growing older with learning disabilities

NICE guideline [NG96] Published date: April 2018

NICE Guideline #54

https://www.nice.org.uk/guidance/ng54

Recommendations

This guideline includes recommendations on:

- organising and delivering care
- involving people in their care
- prevention, including social, physical environment and occupational interventions
- annual GP health checks
- assessment
- psychological interventions, and how to adapt these for people with learning disabilities
- prescribing, monitoring and reviewing pharmacological interventions

Regulation-Care Quality Commission

- Fundamental standards (person centred care, consent, dignity & respect, safety, safeguarding from abuse, premises & equipment, good governance, staffing, duty of candour)
- Safety, effectiveness, caring, responsive, well-led

Community mental health services for people with learning disabilities or autism Good

Public (mental) health approach

Research

Gaps-size of the problem

- Population: by IQ or adaptive functioning?
- Cross-sectional, period and lifetime comorbidity
- Pathogenic, diagnostic and prognostic comorbidity

- Use of large data

Primary care

Secondary care

Across countries

Population surveys

- Public Health Observatories, e.g. England/Scotland

Children and adults excluded from epidemiological studies
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4814928/

Gaps- we need to better understand the problem

- Challenging behaviour

Distinct from mental disorders

Possible demonstration of a mental disorder

ELSEVIER

Research in Developmental Disabilities

Volume 55, August 2016, Pages 1-13

Problem behaviours and symptom dimensions of psychiatric disorders in adults with intellectual disabilities: An exploratory and confirmatory factor analysis

Craig A. Melville [a], Paul C.D. Johnson [b], Elita Smiley [c], Neill Simpson [c], David Purves [d], Alex McConnachie [a, 1], Sally-Ann Cooper [a]

Original Articles

Associations Between Mental Health Problems and Challenging Behavior in Adults With Intellectual Disabilities: A Test of the Behavioral Equivalents Hypothesis

Jon Painter, Richard Hastings, Barry Ingham, Liam Trevithick & Ashok Roy

Pages 157-172 | Published online: 07 Feb 2018

Download citation

https://doi.org/10.1080/19315864.2018.1431747

Check for updates

Gaps-Interventions and effectiveness

- Pharmacological

Psychotropics

Antidementia treatments

Other

- Psychosocial

Pos Beh Supp/ABA

Early Intervention/parenting programmes

Older people/dementia

Adapted treatments

Mild to moderate vs Severe/profound IDD

Gaps-costs (last but not least)

- Modelling
- ?other drivers
- Competing priorities
- Cost tools in guidelines
- Health economic evaluations added to clinical trials

Policy

Transforming Care
https://www.england.nhs.uk/learning-disabilities/care/

- Homes not hospitals by March 2019
- Care & Treatment Reviews (in 403/552 CTRs the decision was NOT to admit; 2016/17 data)
- Assuring Transformation Data (NHS Digital)
- Children and Young People

National Plan: Building the Right Support

Anti-psychotic medication prescribing

- Ensure GP monitors physical health and bloods as recommended by NICE
- Physical check before starting including ECG where indicated
- Do not prescribe solely to sedate
- Ensure and monitor compliance
- Ask about side effects

https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

England

Advice for patients, families and carers

On 14 July 2015, reports came out which showed that strong medicines called 'antipsychotics' and other medicines to treat mental illness were being used to treat people with learning disabilities when they should not have been.

The Learning Disabilities Mortality Review Annual Report 2017

https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2017/#.WvlEEoAvxpg

From 1st July 2016 to 30th November 2017, 1,311 deaths were notified to the LeDeR programme. The most frequent role of those notifying a death was Learning Disability Nurse (25%), most commonly working in a Community Learning Disabilities Team.

Key information about the people with learning disabilities whose deaths were notified to the LeDeR programme includes:

- Just over half (57%) of the deaths were of males
- Most people (96%) were single
- Most people (93%) were of White ethnic background
- Just over a quarter (27%) had mild learning disabilities; 33% had moderate learning disabilities; 29% severe learning disabilities; and 11% profound or multiple learning disabilities.
- Approximately one in ten (9%) usually lived alone
- Approximately one in ten (9%) had been in an out-of-area placement

Thank you