Intellectual disability

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INTELLECTUAL DISABILITY
EMPOWERMENT IN ACTION

What's your thoughts?

- A key component of disability is some form of deviation from the norm?
- Are you disabled if you cant climb stairs?
- Is an Olympic runner who uses Cheetah blades disabled?
- Was Stephen Hawking disabled?
- Language is important
- Intellectual disability?

Intellectual Disability

- An IQ of 70 or less
- Significant deficits in adaptive functioning in areas such as communication, self care, home management and social skills
- Becomes apparent before age 18
- Can be syndrome specific
- Unknown cause

The Past

1949	•A group of parents got together to advocate for better educational and vocational opportunities for their children, challenging institutional options – led to formation of IHC Parents Association
1950/1960	•Internationally and in NZ the term "normalisation" was emerging – mostly advocating for access to education
1980's	•International shift to deinstitutionalised approaches gathered pace, specifically in Canada, the UK, Australia and NZ
1985	•NZ Government adopted a deinstitutionalisation policy
1992	•PPPR act enacted by some Area Health Boards
2003	•"To have an ordinary life" report reviewed by the NZ Health Committee – community inclusion formally endorsed
2006	•Last group of people moved from Kimberly facility to new homes in the community •The community marched to Parliament to celebrate. •United Nations Convention on the Rights of Persons with Disabilities was signed in December 06 – 82 signatories

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OUR MISSION

IHC will advocate for the rights, inclusion and welfare of all people with intellectual disabilities and support them to live satisfying lives in the community

OUR VALUES

- INCLUSION
- RESPONSIVENESS
- SUPPORT
- EMPOWERMENT

WE BELIEVE IN PEOPLE

Being treated with respect and dignity; Having a say in their lives; Living, learning, working and enjoying life as part of a community; Having support to meet their goals and aspirations; Being part of a family

THE WAY WE WORK - OUR BEHAVIOUR

Listen and respond

- Be person-centred
- Respect and value the whole person
- Support change and growth

Create the right environment

- Be professional
- Support development of skills and knowledge
- Build the right connections
- Use resources efficiently

Work together

- Seek strength from partnerships
- Encourage inclusion in communities
- Take chances and opportunities together
- Learn from each other

Try new ways

- Reflect on what we do
- Be open to feedback
- Be open to new ideas
- Celebrate success
- Become more capable

Make it safer

- Be well informed
- Balance rights and risks
- Follow our policy and procedure
- Talk about safety-be aware, plan and act

Demographics

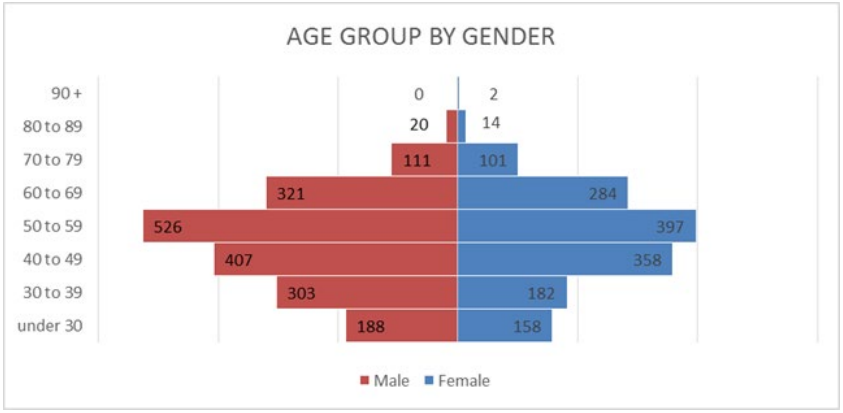
We support over 3,300 people in 600 homes across New Zealand.

3,500+
frontline workers on daily surveillance testing

3,726+
people we support

5,450+
supported living visits every week to 860+ people

601
residential houses staffed 24/7



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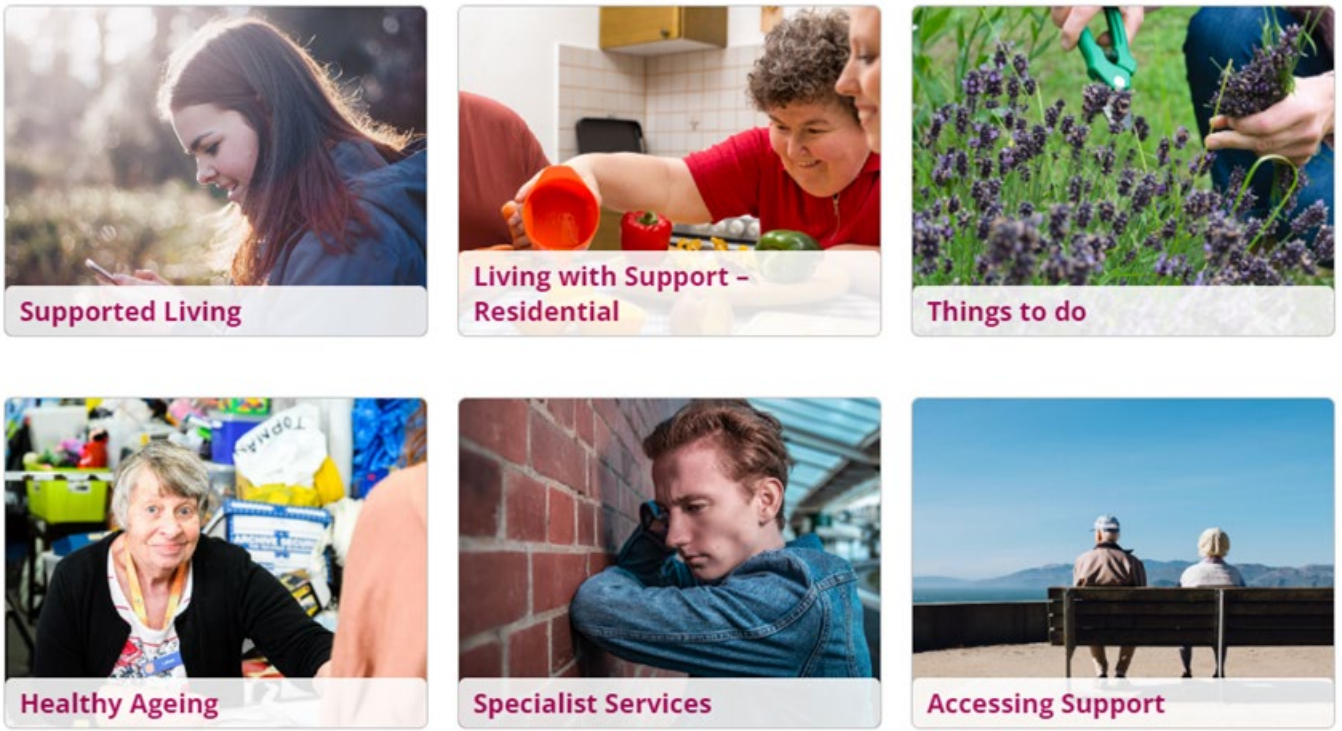
Our Services



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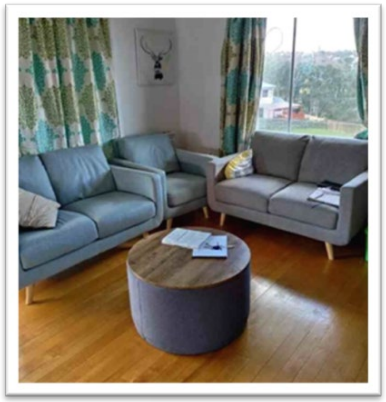
Our homes



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That big red poster on the wall?

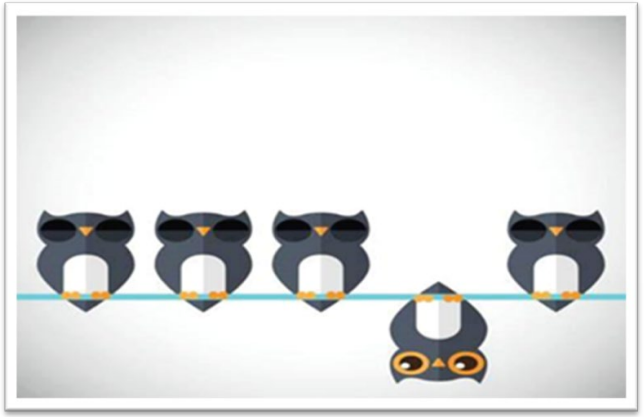
- The 10 Code rights are there to regulate quality of care and it applies to <u>all</u> providers of health and disability services.
- The Code of Rights is about QUALITY of care.
- It is there to ensure safety and <u>quality improvement</u>
- The Commission focuses on <u>systems</u> and <u>quality improvement</u> –"… rather than only seeking to identify individual scapegoats when things go wrong." (Merry&Seddon NZMJ21/7/06)

Legal, Ethical & Psychosocial

- Social not medical model of support
- EPOA and Welfare Guardianship - are unique
- Be aware of unconscious bias
- Informed consent & paternal decision making
- Advanced Care Planning – literacy & communication styles
- Modern medicine & expectations

Medical complexity

- Health inequalities – delayed diagnosis
- Incidental diagnosis vs screening & active investigation
- Diagnostic overshadowing
- Lack of ID Specialists and the relationship between ID and mental health
- Syndrome specific considerations
- Communication styles



The Fatal Four

- Aspiration
- Dehydration
- Constipation
- Seizures

Outcomes

- Look at the four health conditions commonly linked to preventable deaths among people with intellectual disability
- Why there are challenges for clinicians?
- Recognition and management strategies
- Improving the experience for everyone through making reasonable adjustments
- Improving health outcomes

Aspiration

- People with intellectual disability have an increased risk of dysphagia. (Perez,2015)
- Swallowing disorders put people at risk of choking and aspiration.
- Prevalence rates for dysphagia vary from 25% of all people with developmental disorders to 85% for people with cerebral palsy (Hemsley et al 2015)
- People more at risk?
  - Neurological conditions
  - Some syndromes
  - Cerebral palsy and other physical disabilities
  - Risky behaviours
  - Those with communication challenges
  - Medication/ Poly pharmacy
  - With dementia/ageing
  - With epilepsy

Aspiration: Barriers to diagnosis

- Support Workers require training to recognise the signs and symptoms of both eating and drinking issues and aspiration
- Lack of access to medical instrumental investigations
- Up to 90% of people with intellectual disability will have some communication delay

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Aspiration: Why potentially life-threatening?

- Progression to aspirative pneumonia
- Silent aspiration that is not recognised or suspected
- If oral health is compromised then bacteria in the mouth will increase risk of pneumonia
- Choking incidents minimised or dismissed as behavioural
- Untreated reflux leading to other complications

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Health care opportunities

Reducing aspiration pneumonias by:

1. Efficient response to complications after a choking incident
2. Health checks should include questions about respiratory infections and eating, drinking and swallowing
3. Advising on first steps in managing eating and drinking with strategies
4. Highlighting that oral cares are important in reducing aspiration pneumonia
5. Using a multi-disciplinary approach: referral to SLT and referral to other therapies physiotherapy, occupational therapy and dietitian
6. Successful management plans for reflux, epilepsy and sedating medications can lower risk significantly

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Dehydration

- More prone to experiencing loss of appetite, nausea and vomiting
- Poor oral health
- Insufficient mechanical means to chew food
- Medication interactions
- Inability to express thirst
- Always consider delirium

Dehydration: Why potentially life threatening?

Common presenting symptoms:

- Hypotension, dry mouth, tachycardia
- Decreased skin turgor, delayed capillary refill
- Seizures

Signs of circulatory or cardiovascular collapse:

- Low blood pressure, shallow breathing, weak pulse
- Clammy skin, cyanosis
- Low urine output
- Unconsciousness

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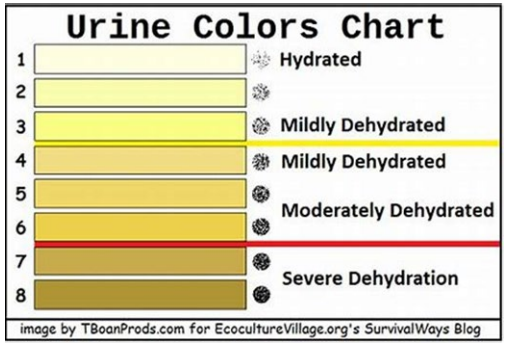
Dehydration: Diagnostics

- CBC
- Chemistry profile
- Urinalysis
- Serum creatinine level
- BUN – blood, urea nitrogen
- Eliminate delirium as a contributing factor
- Infection as a cause of dehydration

Dehydration: Treatment & Prevention

- Fluid and electrolyte replacement, Intravenous fluids for severe dehydration
- Hospitalization for symptoms of circulatory collapse
- Consider dietary consultation to assist with prevention plan that addresses fluid and nutritional needs
- Remember, adequate fluid intake in those with alternate feeding routes such as a gastronomy tube
- **Be aware of increased incidence for dehydration during the following:**
  - Fever
  - Diarrhoea
  - Elevated blood glucose
  - Vomiting



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Health Care Opportunities

1. Getting a comprehensive history
2. Medication reviews – interactions, polypharmacy
3. SLT reviews
4. Recommend fluid balance charts
5. Refer to Explore Behaviour support

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Constipation

- People with intellectual disability are more likely to suffer from constipation than people without intellectual disability.

- There are 3 categories of constipation:
  - Primary – lifestyle factors and environment
  - Secondary – associated physiological conditions
  - Latrogenic – medication side effects

Constipation: Barriers to diagnosis

- Understand the baseline functioning of the individual
- Communication impairment of the individual
- Atypical presentations
- Assumption that constipation is more likely in older people
- Difficulty performing diagnostic procedures

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Constipation: Difficulties reporting symptoms

- Problems that would normally present as a specific complaint or symptom might instead present as an undifferentiated change in behaviour
- Some undifferentiated presentations might be atypical in their morphology
- A single behavioural morphology might be the only expression of distress available to the individual with IDD and might be the result of unrelated, temporally overlapping processes

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Constipation: why potentially life threatening?

- Faecal incontinence
- Haemorrhoids and anal fissure
- Pelvic organ prolapse
- Faecal impaction
- Mega colon
- Bowel obstruction
- Bowel perforation
- Death

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Constipation: Assessment?

Table 1. Rome III diagnostic criteria* for chronic constipation
1. Must include two or more of the following: • Straining during at least 25% of defecations • Lumpy or hard stools in at least 25% of defecations • Sensation of incomplete evacuation for at least 25% of defecations • Sensation of anorectal obstruction/ blockage for at least 25% of defecations • Manual manoeuvres to facilitate at least 25% of defecations (e.g. digital evacuation, support of the pelvic floor) • Fewer than three defecations per week
2. Loose stools are rarely present without the use of laxatives
3. Insufficient criteria for irritable bowel syndrome

**Criteria fulfilled for the last 3 months with symptom onset at least 6 months before diagnosis. Rome 111 Diagnostic Criteria for Functional Gastrointestinal Disorders (Rome Foundation, 2006)*

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Health Care Opportunities

- The importance of the caregiver as voice and advocate
- Relationship between GP, Support Workers and people we support
- Low threshold for returning for reassessment
- Beware of diagnostic overshadowing
- Consider chronic constipation as a diagnosis in itself
- Medical review

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Seizures

- Approximately 1% of the general population in NZ has epilepsy
- However the incidence is much higher at 20-25% of people who have an intellectual disability. Often a person will have multiple types of seizure and poly therapy
- Recognition of subtle changes and worsening of seizures can be “disguised”
- Assumed to be behaviours that challenge or physical effects of cerebral palsy
- Self reporting can be unreliable
- Compliance to optimal lifestyle factors
- Access to Specialist Review is often difficult

Seizures – Why potentially life threatening?

- Commonly known fatal seizures or SUDEP
- Less commonly attributed – related to injury from Tonic Clonic, Tonic or Atonic seizures – falls, choking, aspiration, drowning
- Status epilepticus
- First time seizures in adolescence or seizures associated with the onset of dementia
- Accumulated effects of seizures over a lifetime
- Accumulated effects of anticonvulsant treatments over a lifetime

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Seizures: Diagnostics

- New onset – Commonly refer to Neurology & Epilepsy Support Organisation
- Age related – Earlier for some syndrome related trajectories
- BGL related when polypharmacy – Clinical Pharmacy review or Dual Disability Teams
- Related to constipation?
- Related to dehydration?
- Related to underlying infection?

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Health Care Opportunities

- Communication and seeking feedback
- Timely and creative ways to check anticonvulsant levels according to best practice guidelines
- Consider if changes in behaviour presentation may be a complication of epilepsy
- Prescribing prn interventions
- Seek early engagement with Secondary and Tertiary review to accommodate inequity of access

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Cancer

- Atypical presentations
- Difficulty performing diagnostic procedures and physical examination
- Increased risk of undiagnosed cancer
- Lower rates of screening
- Some syndromes have higher cancer risk
- GORD and Barrett’s oesophagus, H. Pylori – ID link
- Treatment & support groups

What can you do differently?

- Aspiration
- Dehydration
- Constipation
- Seizures

Take home messages

- Time and place for everything
- Easy read information
- Contribute to and use the HDC NZ hospital passport
- Always find out how the person communicates
- Use of Key Word Sign can help conversations
- Early engagement
- Reasonable adjustments or accommodations
- Preventable “non fatal” 4

Doctor

More information

A Picture of health – Reasonable adjustments

http://www.apictureofhealth.southwest.nhs.uk/

Treat me well

https://www.mencap.org.uk/get-involved/campaign-mencap/treat-me-well

People First

https://www.peoplefirst.org.nz/

Acknowledgements and references

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Any questions?

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