Palliative and End of Life care for people with intellectual disability

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2. Overview

• Intellectual Disability (ID) - About Us
• The past
• The present
• The UN Convention, legal & ethical rights
• Medical complexity
• Our workforce & service
• Our experiences of end of life care
• The future
### 3. The Past

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1949</td>
<td>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</td>
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<tr>
<td>1950/1960</td>
<td>Internationally and in NZ the term “normalisation” was emerging – mostly advocating for access to education</td>
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<tr>
<td>1980's</td>
<td>International shift to deinstitutionalised approaches gathered pace, specifically in Canada, the UK, Australia and NZ</td>
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<td>1985</td>
<td>NZ Government adopted a deinstitutionalisation policy</td>
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<td>1992</td>
<td>PPPR act enacted by some Area Health Boards</td>
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<td>2003</td>
<td>“To have an ordinary life” report reviewed by the NZ Health Committee – community inclusion formally endorsed</td>
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<td>2006</td>
<td>Last group of people moved from Kimberly facility to new homes in the community</td>
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<td></td>
<td>The community marched to Parliament to celebrate</td>
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<tr>
<td></td>
<td>United Nations Convention on the Rights of Persons with Disabilities was signed in December 06 – 82 signatories</td>
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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
5. Demographics

<table>
<thead>
<tr>
<th>TOTAL SERVICE USER NUMBERS</th>
<th>TOTAL NUMBER OF RESIDENTIAL HOMES</th>
<th>AVERAGE AGE</th>
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<tbody>
<tr>
<td>3,372</td>
<td>625</td>
<td>50</td>
</tr>
</tbody>
</table>

Age Group by Gender:

- **90+:**
  - Male: 14
  - Female: 2

- **80 to 89:**
  - Male: 20
  - Female: 111

- **70 to 79:**
  - Male: 321
  - Female: 101

- **60 to 69:**
  - Male: 407
  - Female: 284

- **50 to 59:**
  - Male: 303
  - Female: 397

- **40 to 49:**
  - Male: 188
  - Female: 358

- **30 to 39:**
  - Male: 158

- **under 30:**
  - Male: 111
  - Female: 284

Ethnicity:

- NZ Specified Pakeha: 625
- Maori: 17%
- Pacific Island: 2%
- Asian: 1%
- Not Specified: 1%
- Other: 2%
6. The UN Convention on the Rights of Persons with Disabilities

The principles of the present Convention shall be:

• Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
• Non-discrimination;
• Full and effective participation and inclusion in society;
• Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
• Equality of opportunity;
• Accessibility;
• Equality between men and women;
• Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
7. 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
8. 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
9. Workforce scope of practice

- Predominately Support Workers
- Service Managers & Clinical Governance team
- Health literacy
- Direction & delegation
- PRN meds and syringe drivers
10. Our experiences of End of Life Care

<table>
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<tr>
<th>Positive</th>
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<tr>
<td>Dignified and respectful end of life experiences</td>
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<td>Early engagement with external partners</td>
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<td>Ability to home visit</td>
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<tr>
<td>Excellent communication &amp; documentation</td>
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<tr>
<td>In-house training &amp; coaching</td>
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<tr>
<td>After hours support</td>
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<tr>
<td>Assimilate to our environment &amp; accepting our limitations</td>
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<tr>
<td>Expert pain management &amp; advice</td>
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<td>Post bereavement support</td>
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## 11. Our experiences of End of Life Care

<table>
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<tr>
<th>Challenges</th>
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<tr>
<td>Delayed recognition of need by primary care</td>
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<td>Services in silos – including funding</td>
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<tr>
<td>Delayed Hospice referral</td>
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<tr>
<td>Our documentation – not familiar to external services</td>
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<tr>
<td>Delays to post mortem support</td>
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<tr>
<td>Expected vs unexpected event pathways</td>
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<tr>
<td>Lack of consistent access to education modules</td>
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<td>DHB variation</td>
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12. The Future - Internal

- Currently reviewing our residential homes that support older people
- Review & alignment of our policies & guidelines to the latest best practice in collaboration with external stakeholders
- Increase our ability to support “services closer to home “ type initiatives
- Hospice education modules and lecture series
13. The Future - External

- Increased access to Hospice Day services & short inpatient stays to stabilise symptoms
- Opportunity to co-design service user information in an easy read format
- Improving the national consistency of local Hospice relationships
- Supporting the HQSC Advanced Care Planning Programme
14. Summary

• We have learned from the past
• We are planning for our future
• Responding to our ageing population
• Collaborating with services to improve people health and wellbeing

*Many thanks for your time*

We look forward to working with you to support people with intellectual disabilities

Questions?
We would like to thank the following people for their input and expertise

- Janine Stewart – General Manager – IHC Programmes
- Lynne Sijbrant – Health & Disability Specialist Legal Counsel
- Communications Team – IHC

References

- IHC. (2007). What we believe. Wellington, New Zealand: Author