

Palliative and End of Life care for people with intellectual disability

Prudence Lennox DoN

Kim Fuller Programme Lead RN

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

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



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

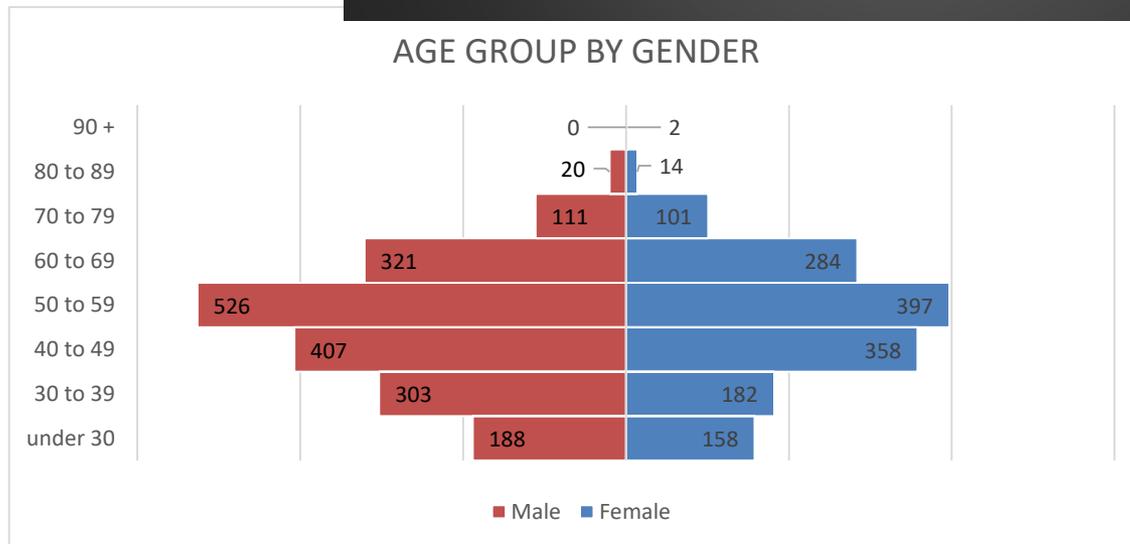
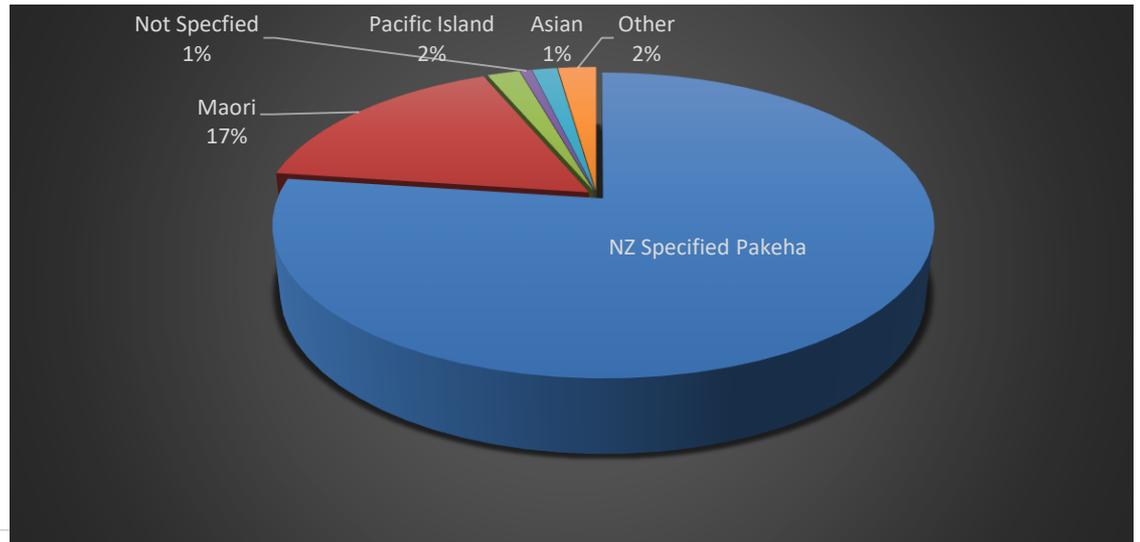
Make it safer

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



5. Demographics

TOTAL SERVICE USER NUMBERS	TOTAL NUMBER OF RESIDENTIAL HOMES	AVERAGE AGE
3,372	625	50



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

Positive

Dignified and respectful end of life experiences

Early engagement with external partners

Ability to home visit

Excellent communication & documentation

In-house training & coaching

After hours support

Assimilate to our environment & accepting our limitations

Expert pain management & advice

Post bereavement support

11. Our experiences of End of Life Care

Challenges

Delayed recognition of need by primary care

Services in silos – including funding

Delayed Hospice referral

Our documentation – not familiar to external services

Delays to post mortem support

Expected vs unexpected event pathways

Lack of consistent access to education modules

DHB variation

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?

15. References and Acknowledgements

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

- Emerson, E., & Hatton, C., (2014). Health Inequalities and People with Intellectual Disabilities. New York: Cambridge University Press.
- IHC. (2007). What we believe. Wellington, New Zealand: Author
- Ministry of Health (2009) Government response to the Social Services Committee Inquiry into the Quality of Care and Services Provision for People with Disabilities <http://www.odi.govt.nz/what-we-do/improving-disability-supports/government-response/index.html>
- Ministry of Health. 2011. Health Indicators for New Zealanders with Intellectual Disability. Wellington: Ministry of Health.
- National Health Committee (2003). To Have an Ordinary Life: Kia Whai Oranga 'Noa': Community membership for adults with an intellectual disability. Wellington, New Zealand: Author
- United Nations (2006) Convention on the Rights of Persons with Disabilities. New York