

Intellectual Disability, Dementia, and Health

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Covering

- Context – demographic changes
- Features of dementia and health status
- Challenges related to assessment of older people with lifelong disabilities
- Foundation principles for support to people with dementia
- What we can do

Demographics with a face

- Double whammy – baby boomers + increased life expectancy
- A skewed cross-generational framework
 - – children outliving their parents
 - - adults not bearing children
- Dementia rates high for people with Down Syndrome

- *“Life’s a long time, eh!”*
- *“I never dreamed I’d go before her – who will watch out for her?”*
- *“My boys will see me right - I have to hope they’ll do the same for their brother”*
- *“Its just not fair! She’s just moved into her own unit, she’s got a job, cat, even her ife - its all ahead of her”*

People with Down Syndrome and Dementia

	People with Down Syndrome	General population
Up to 49 years	10-25%	
50-59	20-50%	
60+	30-75%	6.1%

Prevalence doubles every 5 years over 50 for developing Alzheimer's disease

Dementia differences

- Younger onset
- Different presentation (epilepsy)
- Identified later (mid and advanced stage)
- Faster disease trajectory

Health differences

- Polypharmacy
- Lifestyle – inactivity, diet
- Poverty
- Health access – personal and mental
- Communication – low participation in health awareness and management

Have hope... the stars are aligning

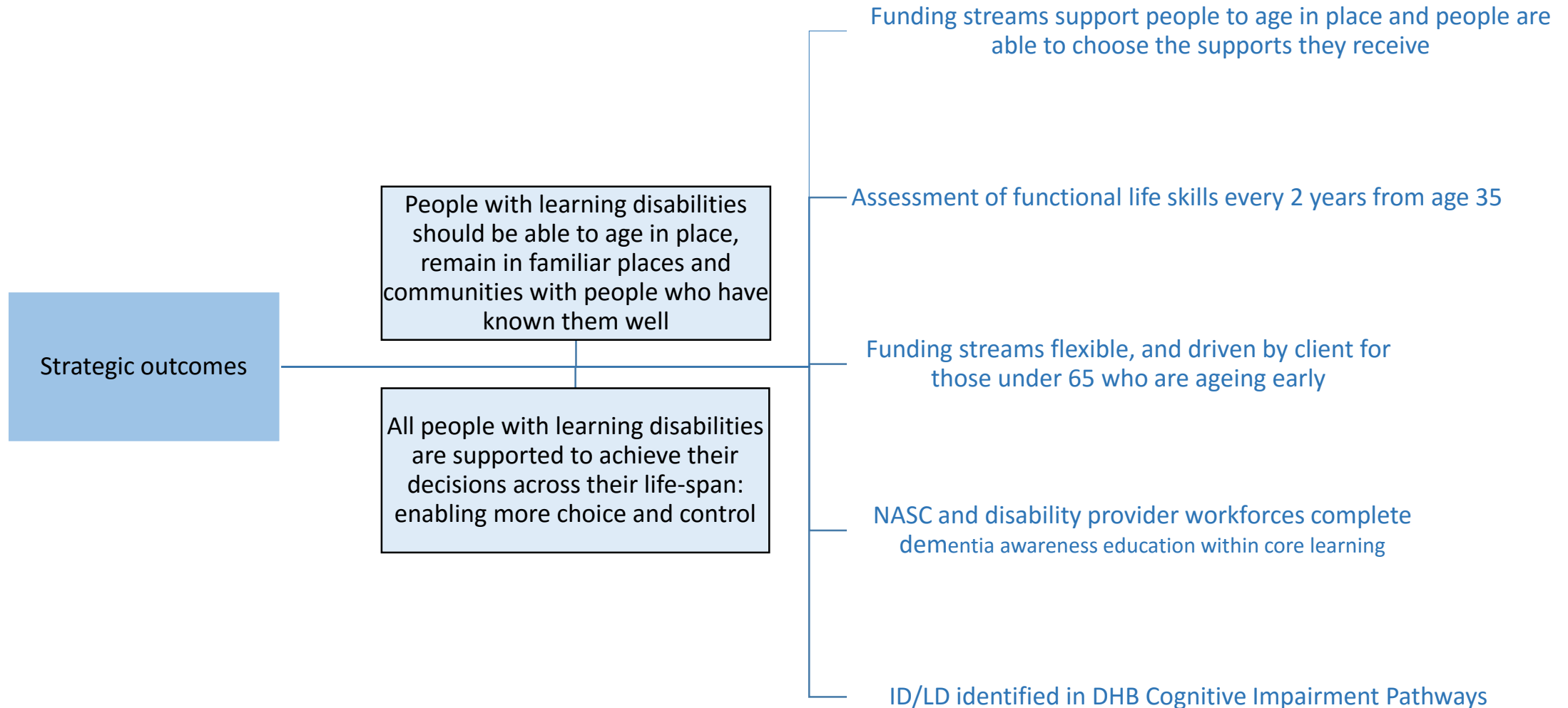


- NZ Framework for Dementia Care
- NZ Health Strategy revision
- NZ Health Outcomes Report
- UN Convention of Rights of Persons with Disabilities

NZ Framework on Dementia Care (2013)

1. Awareness and risk reduction
2. Assessment, diagnosis, early intervention and ongoing support
3. Living well
4. Meeting challenges to maximise wellbeing
5. End of life

Health outcomes for people with intellectual disability – recommendations for Minister



So what triggers an assessment request to you?

- Health changes
- Parental/caregiver status change
- Inability of existing provider to sustain support needed
- ?
- ?

So when an assessment is triggered....

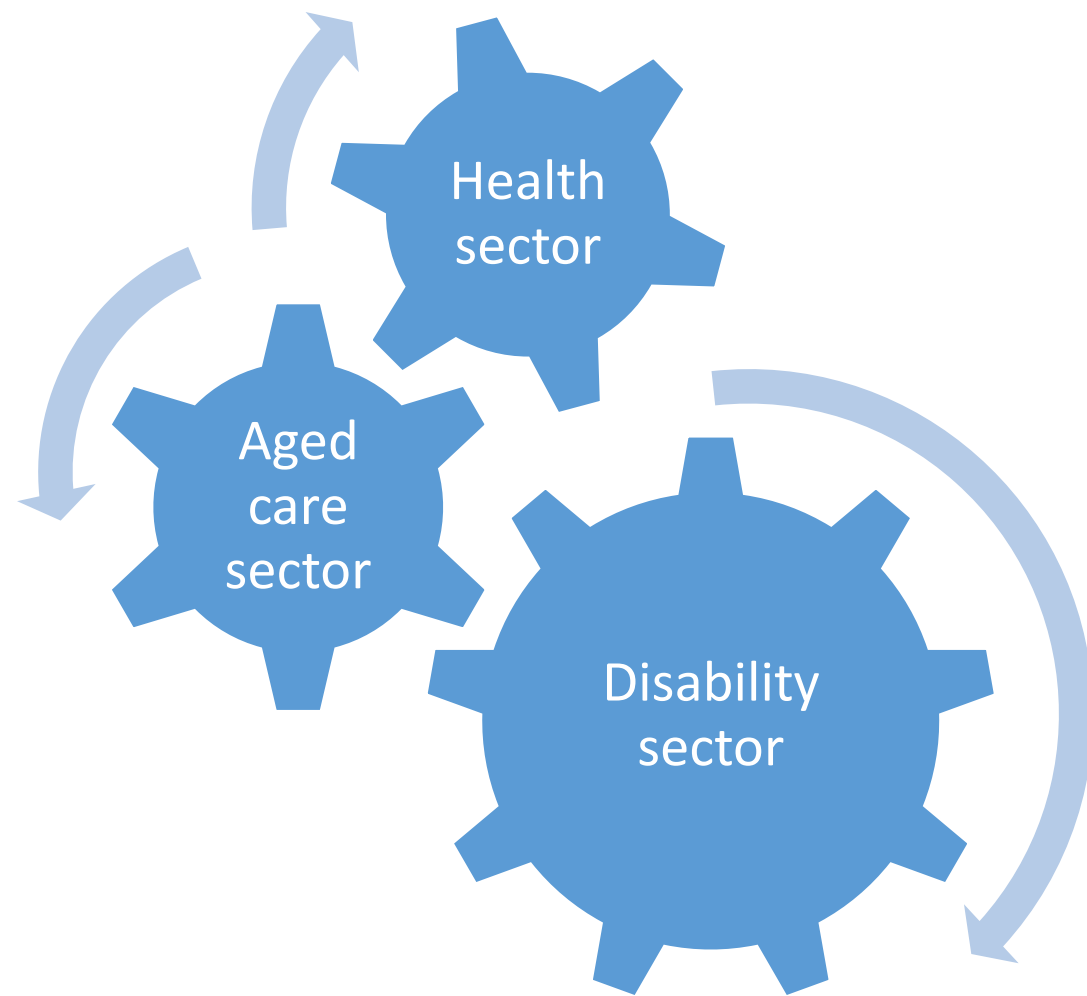
- **Tools used** – what is the best tool to capture the picture and maximise the response best suited to person
- **Sources** - who has the information, and who is willing to share
- **Interpretation** – what sense to make of the assessment, how will it be applied

Who then responds?

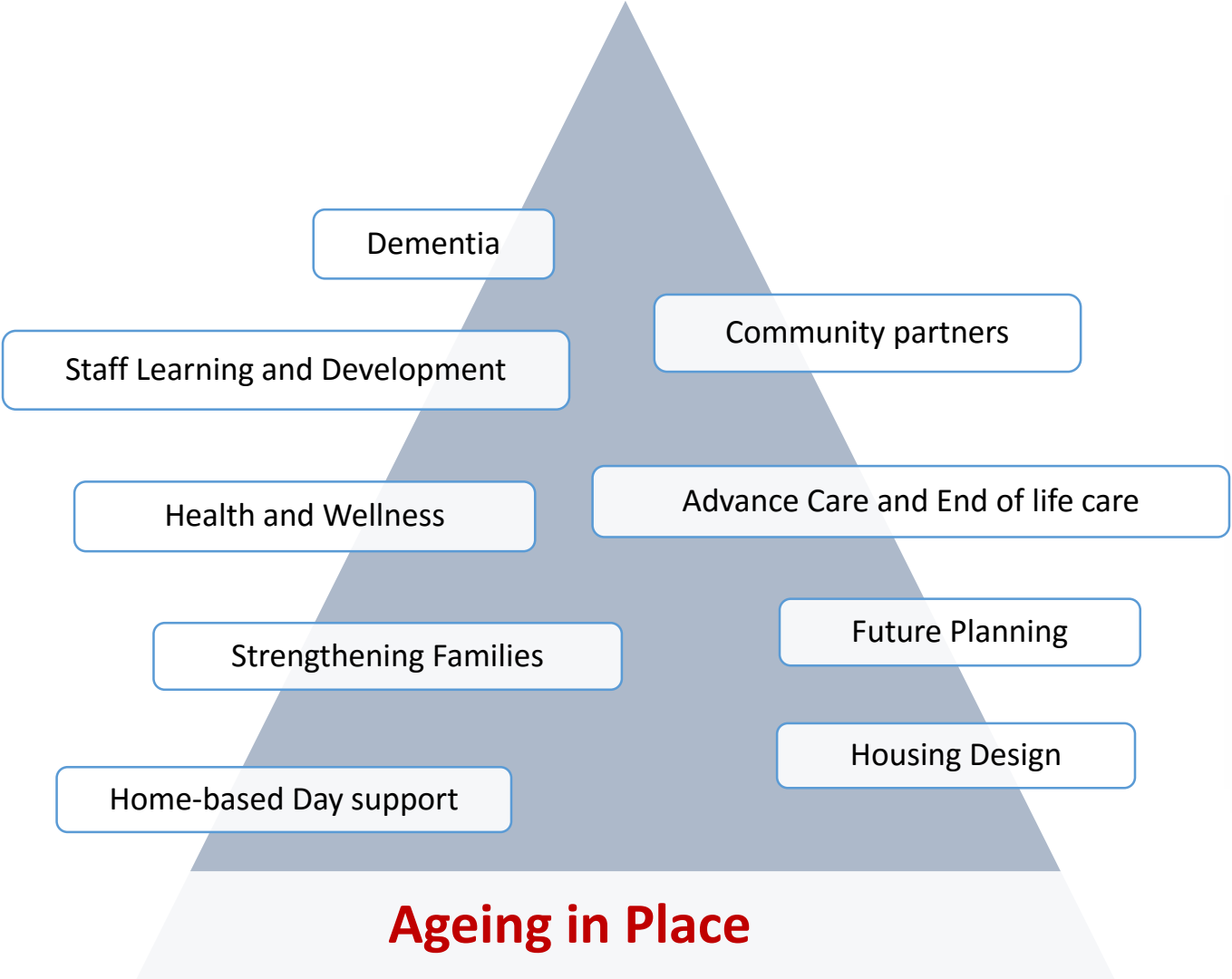
Who then responds?



International research suggests **ALL OF US**



Disability Strategies to support Ageing in Place



Lots can be done

Aged/Health sector

- Person-centred education for support staff
- Use of memory/life story resources to retain identity
- Partnering with disability services to retain familiar people and place
- Respect and draw from family and social networks
- Flexible contracting to sustain fluctuating support needs
- Be vigilant to risks of social and activity exclusion

Disability sector

- Person-centred education for support staff
- Develop life story/preference banks resources to retain identity
- Partnering with aged care services to retain familiar people and place
- Build alternative and robust family and social networks
- Make accommodations to fluctuating support need levels – they will pass

Thanks

Resources

- <http://ndc.hiirc.org.nz/section/27383/intellectual-disability-and-dementia/>
- www.ihc.org.nz/library

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