



Younger Onset Dementia: International Literature Review and Needs and Feasibility Assessment of Services

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Younger Onset Dementia project

- Australian Government funded, July 2012 – Feb 2013
- Two elements:
 - International literature review; and
 - Consultations concerning a needs analysis and feasibility assessment of services for people with younger onset dementia
- Examined the service and care needs of people with younger onset dementia
- Identified guiding principles for service design and development, and examples of good practice

Needs and Feasibility Study

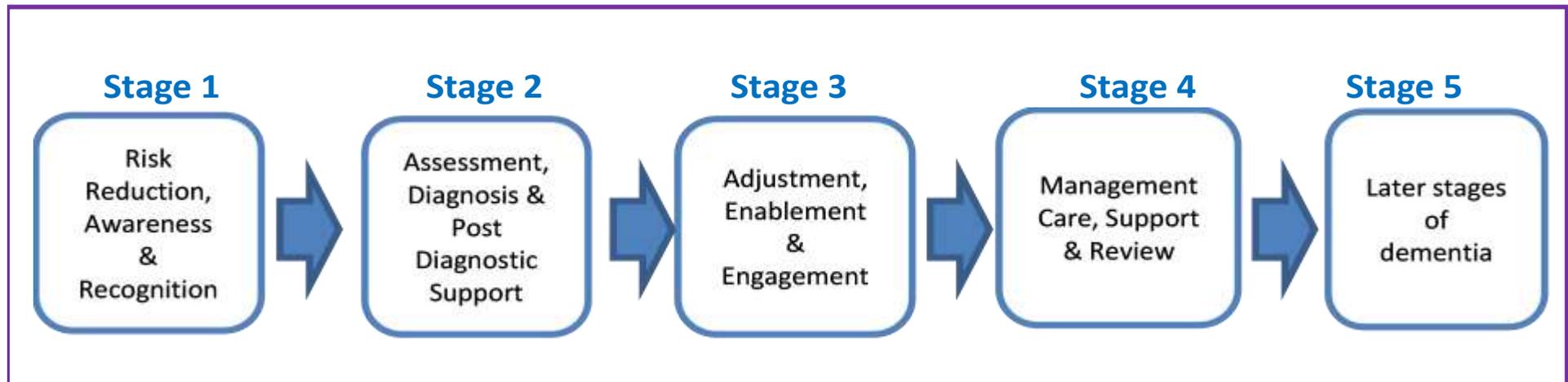
Methodology

- National consultations and online surveys
- Working closely with Alzheimer's Australia
- Broad definition of younger onset dementia
 - primary condition – Alzheimer's Disease, Fronto-Temporal Dementia
 - secondary condition – HIV/AIDS, Parkinson's, Huntington's, drug and alcohol
- Broad definition of needs
 - Living arrangements, social, economic and environmental factors that enable and support people with younger onset dementia

Re-framing 'dementia'

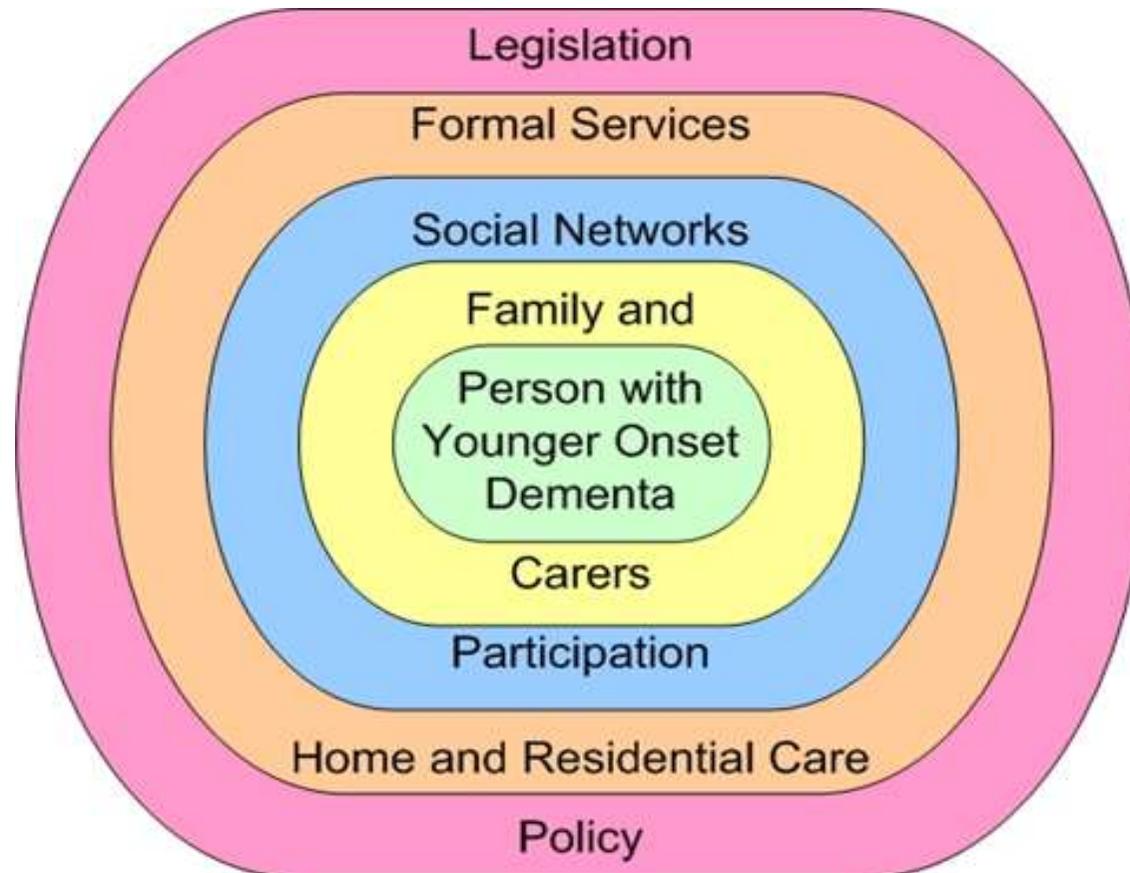
- Meeting with Alzheimer's Australia National Dementia Consumer Advisory Committee Sept 2012
- Highlighted gaps in usual 'dementia journey' frameworks
- Two dimensions: longitudinally as well as systemically

Five Stages of Dementia



Re-framing our approach *cont'd*

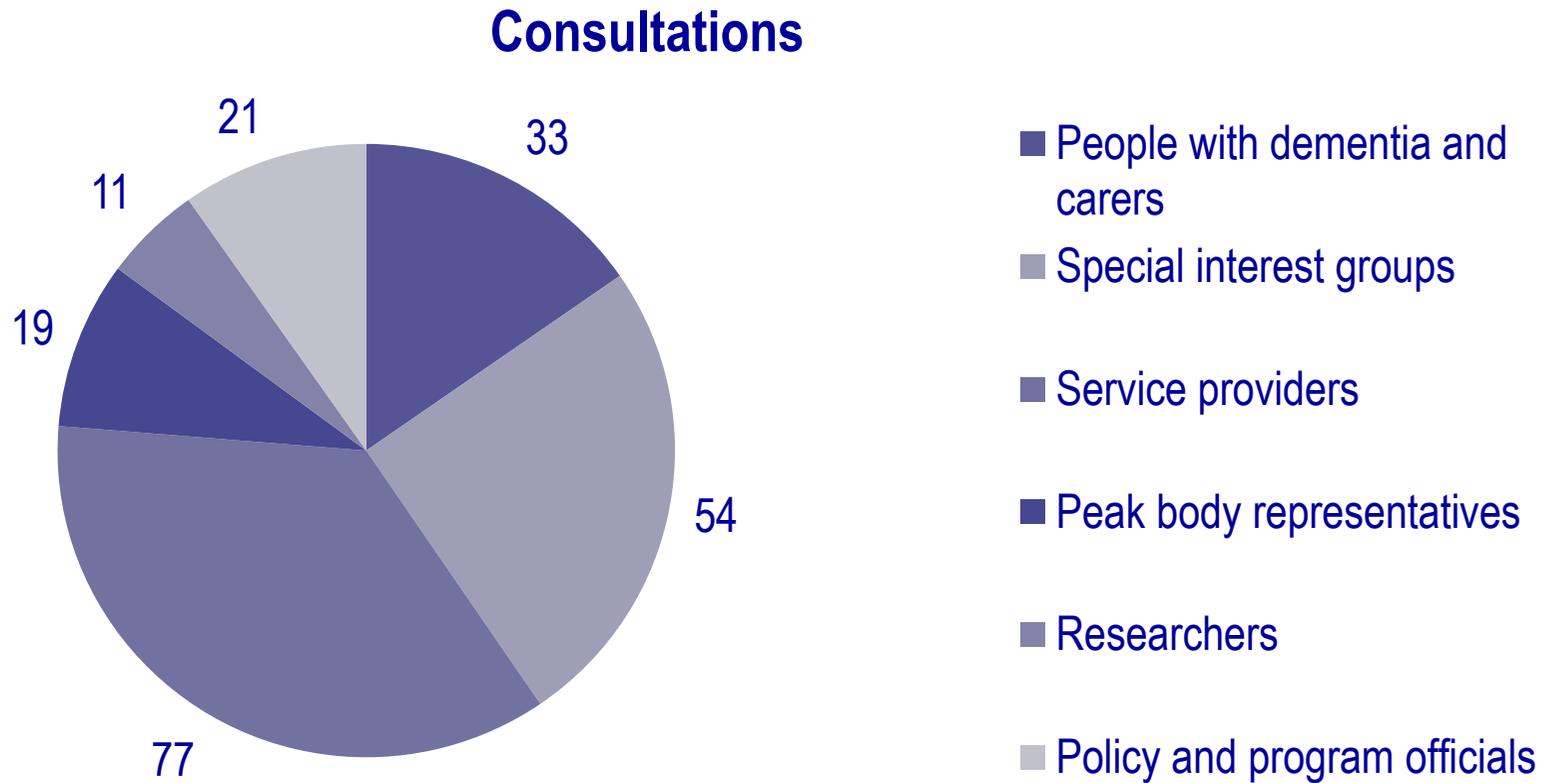
Circles of impact of younger onset dementia



Results

- 215 people interviewed nationally
 - All States and Territories (except Tasmania)
 - Metro, rural and remote
 - Special interest groups :
 - Aboriginal and Torres Strait Islander
 - Cultural and Linguistically diverse
 - Homeless
 - Care leavers – unavailable at that time
- 97 survey responses; 29 complete

Consultations

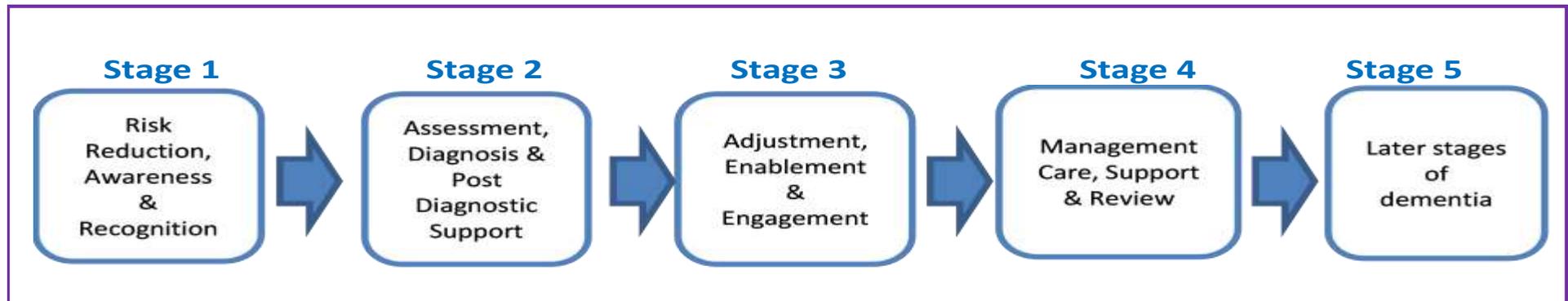


Service delivery: best practice

- **Key Service Attributes**
 - **Individualised model of service** (listening, person-centred, whole of family, ongoing needs assessment, recognise diversity)
 - **Staff attributes** (skilled; holistic, enabling, & consumer centred approaches; effective communication, flexibility, capacity building)
 - **Organisational attributes** (facilitate access to relevant services, integrated and coordinated interagency partnerships & pathways, dementia friendly & timely service provision, respect & consideration, cultural safety, address needs of people in rural & remote areas, manage risk effectively, capacity for organisational change)

Service delivery: best practice *cont'd*

- Address all elements of the ‘circles of impact’,
 - starting with a focus on the person with younger onset dementia and working outwards to facilitate the enablers within the surrounding spheres of influence.
- Requires different emphases of effort across the five stages of dementia support.



What we found

- Unsurprisingly ... relatively few services nationally
- Most in aged care sector – extension of existing models to meet the different needs of younger clients:
 - Risk factors - clients more active and physically strong
 - Client interests - vocational, purposeful, meaningful activities
 - Relationship factors – partners/spouses and children
- Some arising from within disability service sector
 - More ‘enabling’ philosophy, community engagement

What we found *cont'd*

- Many used a mix of aged care and disability program funding applied 'flexibly'
 - E.g., combining transport and respite funding for outings
- Partnerships with generic community services
 - Health and fitness, 'gym clubs', swimming, walking groups
 - Vocational – gardening services, Men's Sheds, art groups
 - Health pathways – links with health and aged care services, localised agreements re priority referrals, cross-sector education and training

Examples

- **Gardening on the Tram Tracks: (Adelaide SA)**
 - Men with younger onset dementia are supported and supervised by a council worker and a volunteer to beautify the nearby Black Forest Tram Stop gardens.
 - Also provides an opportunity for them to speak to commuters about the issues relating to younger onset dementia.
- **BANCPASS:** (Melbourne, Vic)
 - Collaboration between health and aged care service
 - Clients remain 'on books' even after entry to residential care
 - Priority referral pathway, in return for ongoing education of aged care staff

Implications for service delivery

- Timely and accurate diagnosis - health professionals and community awareness
- Focus on the individual – tailored to interests, needs, context
- Integrated – capacity building approach, flexible, networked with specialist services
- Continuity – case manager/co-ordinator who works with the client and their family for tailored support across ‘journey’
- Respite services – meaningful, vocational activities; offered in ‘blocks’ of sufficient time to enable carers continue family, personal and employment activities.

Organisational implications

- Most innovative service models driven by commitment of *individuals* – risks re sustainability
- Organisational support needs to be explicit – philosophy/mission, resources, staff skills and support, policies and processes.
- Underpinned by philosophy of partnership - Inclusion of clients and their families in development, design and delivery
- Commitment to quality e.g., evidence based assessment and care
- Capacity for advocacy

Policy implications

- Promote Independence
 - No 'prescribed disengagement' - i.e., arbitrary cessation of particular activities upon diagnosis;
 - Focusses on assessment of attributes and capacity rather than loss and disability.
- Facilitate Interdependence
 - Program eligibility and funding to include interdependence of people with dementia and their carers. E.g., NDIS
 - Cross-sector and inter-jurisdictional approaches to supporting people with dual diagnoses and complex health, care and accommodation needs.

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Want to know more?

Reports are available on University of Wollongong website:

<http://ahsri.uow.edu.au/chsd/projects/yod/index.html>

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