



# The ADHB Dementia Network

# Origins of the Process

- ▶ Requirement for a “Dementia Pathway”
- ▶ Northern Region Dementia Services Guide
- ▶ National Framework for Dementia Services
- ▶ Desire for whole of system approach and enduring governance for dementia services in ADHB
- ▶ Funder request for “Codesign” Approach

# Some resources on Service Design and Codesign

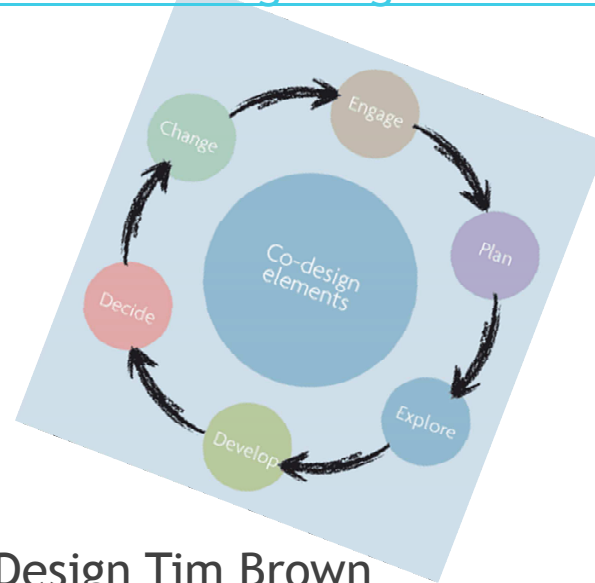
- ▶ Better Services By Design UK.
  - ▶ <http://www.bsbd.org.uk>
- ▶ Design for Care: Innovating Healthcare experience by Peter H Jones Rosenfeld Media 2013 New York
- ▶ Designing and Delivering Dementia Services. De Waal H, Lyketsos C, Ames D, O'Brien J 2013 John Wiley and Sons



# Resources on Service Design

- ▶ Codesign Handbook Boyd, McKernan, Old

<http://www.healthcodesign.org.nz/about.html>

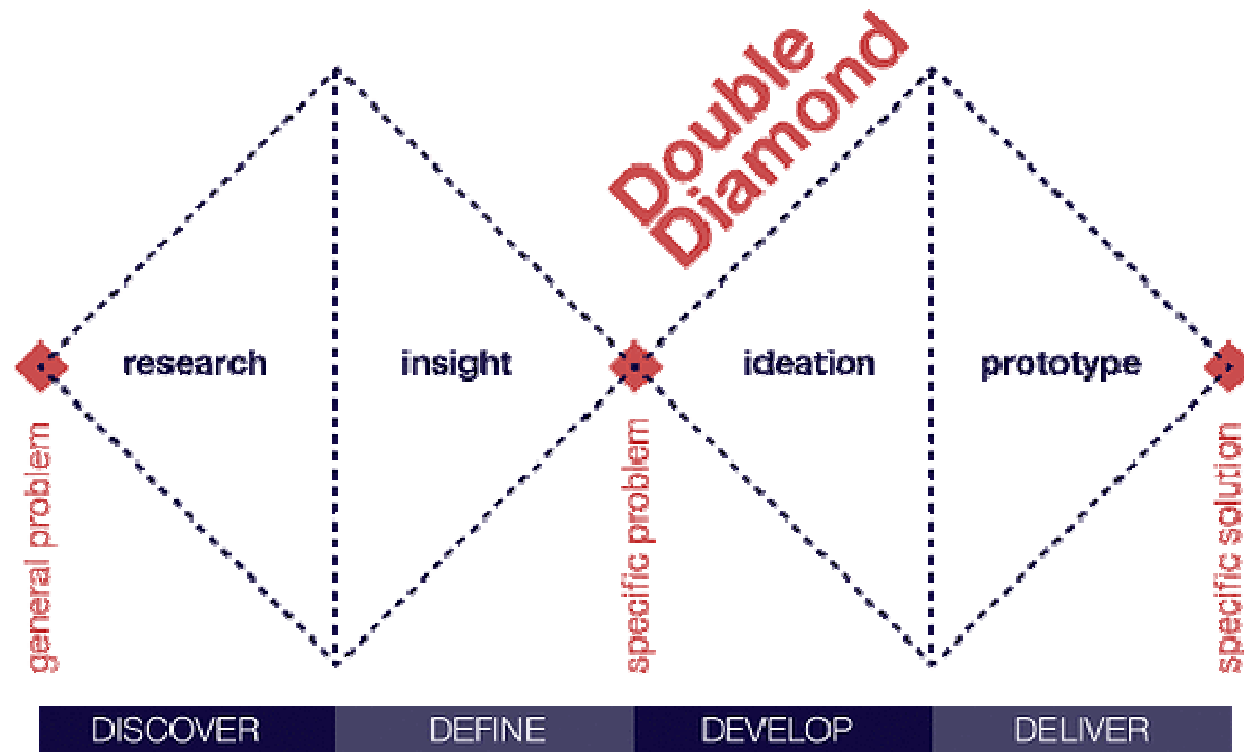


- ▶ Better By Design Tim Brown

# Getting Started

- ▶ Governance Group: Engagement with Key Stakeholders: Caregiver; Funding and Planning, Senior Management, OPH, MHSOP, Neurology, Alzheimer's Auckland, ARC, Home Support Services
- ▶ Initial Project Team: Project Manager Cathy Taylor; Codesign Consultant Stephen McKernan; Richard Worrall Psychogeriatrician

# Approach



# Discover

- ▶ Stocktake / Literature Review
- ▶ Linkage with National Framework Focus Group
- ▶ Carers Workshop
- ▶ “Journey Map” Interviews with people with dementia
- ▶ Staff workshop 1
  - ▶ System workshop: Service and Process Mapping

# ADHB Codesign: Involving people with dementia and Carers

- ▶ Carer on the governance group
- ▶ Workshops (funder included):
  - Hearing stories
  - Journey /Emotion mapping
- ▶ Interviews with people with dementia and caregivers

Following the journey, areas covered included:

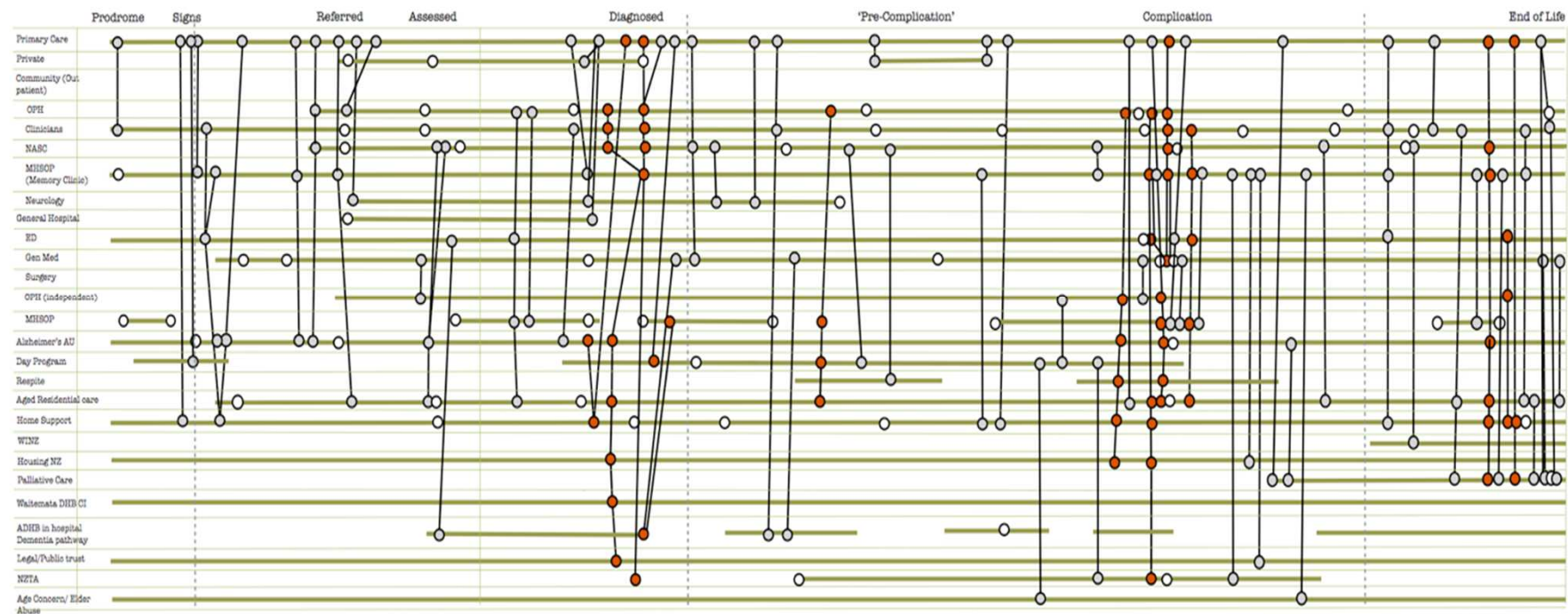
- Diagnosis
- Information
- Support
- Knowing who to call
- What is important for a good life



# Codesign: Bringing services together



# Dementia Pathway Profiling: staff map of pathway connections and interactions



# What you're saying about living with dementia

"I go to (*day care*) once a week which I love because everybody has the same problem -we makes things, do activities and its social - it really helps the loneliness"

"Before I had the dog, people would avoid me, now I talk to people along the way and they are mostly friendly and they don't seem to mind if I forget from day to day, probably because we have something in common".

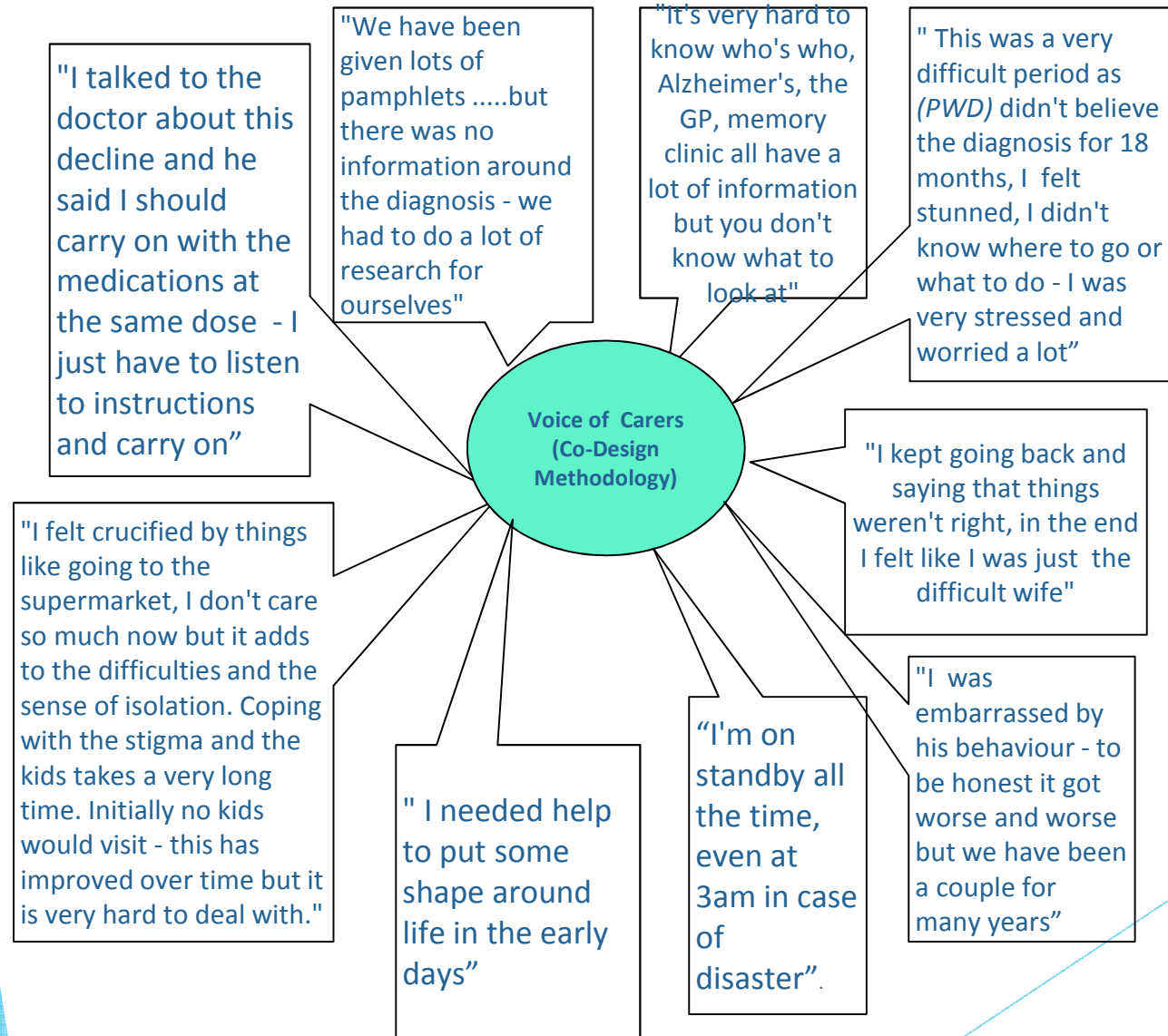
Voice of Patients  
(Co-Design  
Methodology)

"I went to a walking group once but won't go back as they were all very old"

" I have no anxiety to live".

"It was a terrible shock, I wanted to die"

# Voice of the Carer



# What is it like for People with Dementia and Carers?

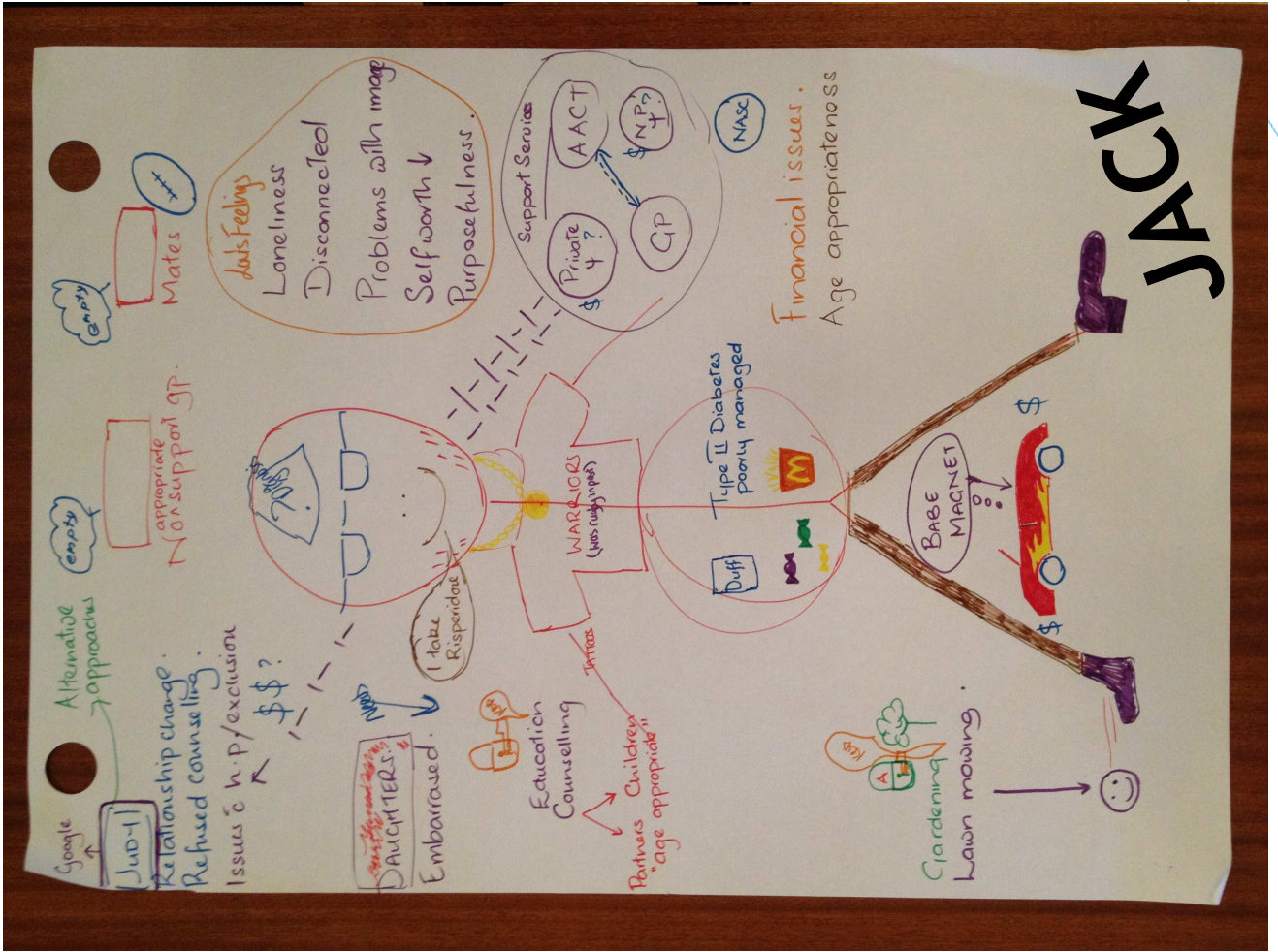
- ▶ People with dementia and their carers want to be able to keep doing the simple things that they enjoy.
- ▶ People with dementia often feel like a burden and struggle to find ways to give their life meaning.
- ▶ Carers usually want to provide care but recognise that they need a break from time to time.
- ▶ Carers often have very high levels of stress and people with dementia often feel locked in to a world that they dislike

# Define

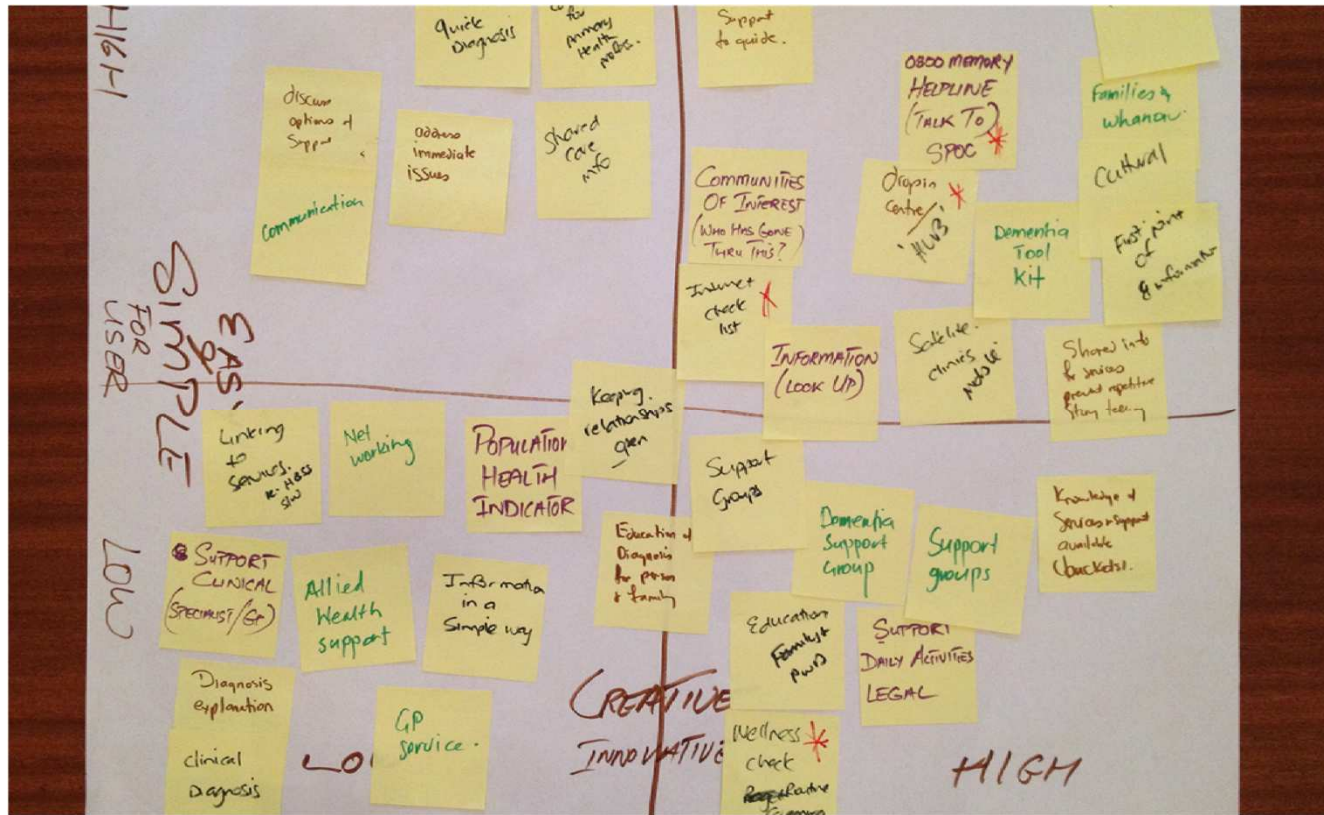
- ▶ Suggestions from people with dementia and carers
- ▶ Workshop 2
  - Persona Development
  - Service Propositions
- ▶ Data Analysis, Definition of Principles
- ▶ Workshop 3
  - Presentation of Principles
  - Planned Workstreams/ Projects

# Feedback and Suggestions from People with Dementia and Carers

- ▶ Its not easy to get help
- ▶ We often get asked the same questions repeatedly
- ▶ We don't get information when we need it
- ▶ The system is complex and hard for everyone to navigate
- ▶ The available supports don't meet everyone's needs
- ▶ We don't know who to call when there's a problem



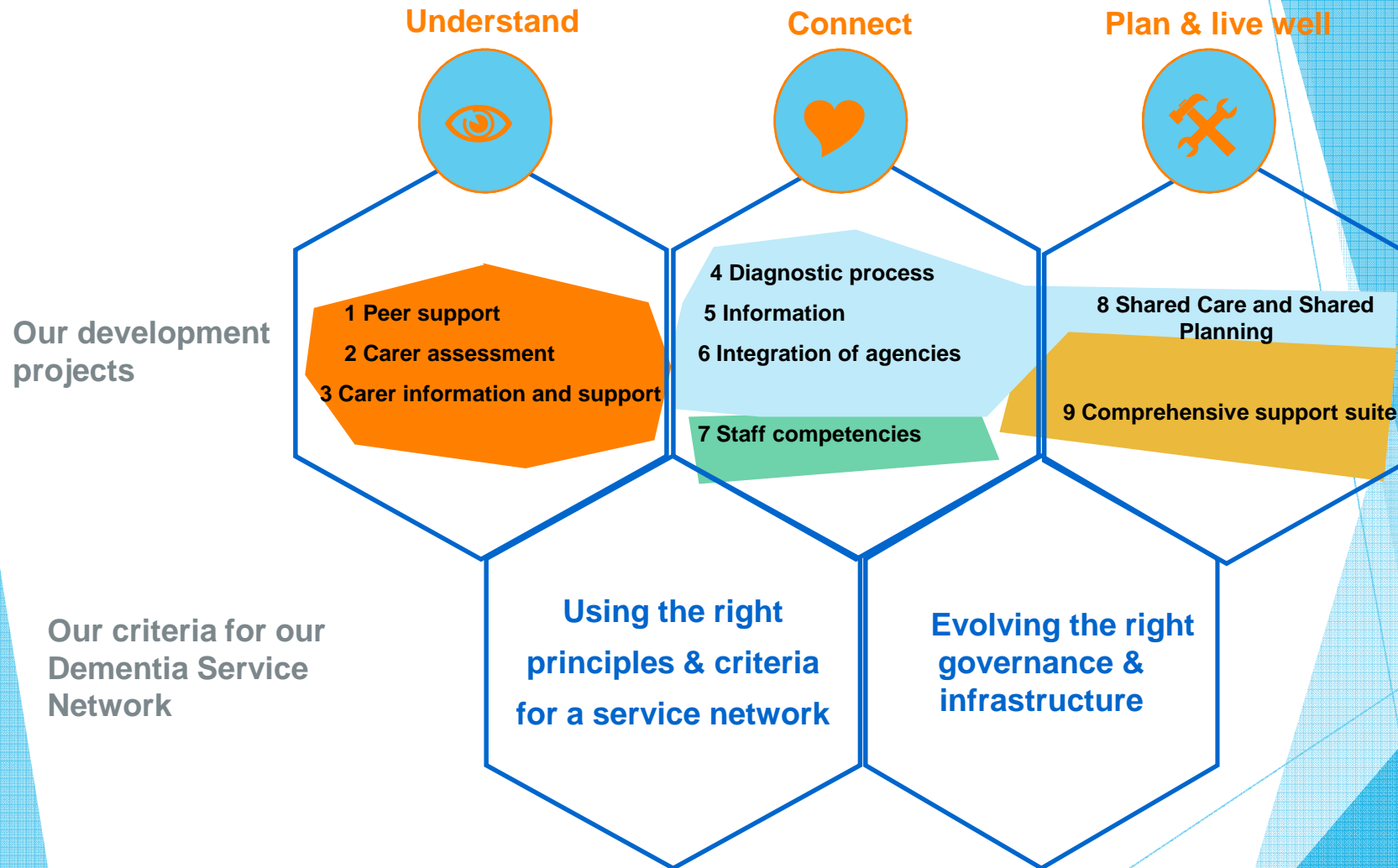




## Service suggestions

Inspired by personas

# This is what will get us there



# Key Success Factors

- ▶ Identifying key stakeholders
- ▶ Putting faces to names
- ▶ Using experiences of people with dementia and caregivers as the driver for change
- ▶ Developing relationships and respect for roles and services
- ▶ Sharing leadership
- ▶ Workstreams owning problems and solutions
- ▶ Not reinventing the wheel

# Challenges

- ▶ Carers have busy stressful lives
- ▶ Organisational upheaval
- ▶ Maintaining original intent despite structural changes
- ▶ Change through relationships rather than hierarchy
- ▶ Linking with and learning from other initiatives in development
  - ▶ Other regional initiatives
  - ▶ Regional Dementia Pathway
  - ▶ National information project
  - ▶ Seniorline

# Develop: Integration Workstream

People with dementia and their carers find the delays to diagnosis very distressing and disorientating, and see an early diagnosis as vital. People with dementia and their carers constantly struggle with the lack of coordination and integration between and within services, they want to know that there is a plan in place and that everybody involved is on the same page.

## ▶ Problems

- ▶ Unclear diagnostic process
- ▶ Lack of capacity / knowledge outside of specialist services
- ▶ Inability to share clinical information
- ▶ Limited patient information resources

## ▶ Solutions

- ▶ Regional cognitive impairment pathway
- ▶ Shared care record
- ▶ National information project

# Develop: Carer Workstream

Carers want to look after people with dementia at home for as long as possible. They need support and information to enable them to do this.

## ▶ Problems

- ▶ Navigating through the complex health system
- ▶ Understanding information and services
- ▶ Planning for the future
- ▶ Managing day to day

## ▶ Solutions

- ▶ Carer Assessment leading to Action
- ▶ Education information and support incl peer support
- ▶ Opt off rather than opt on referral to Alzheimer's

# Develop: Support Suite Workstream

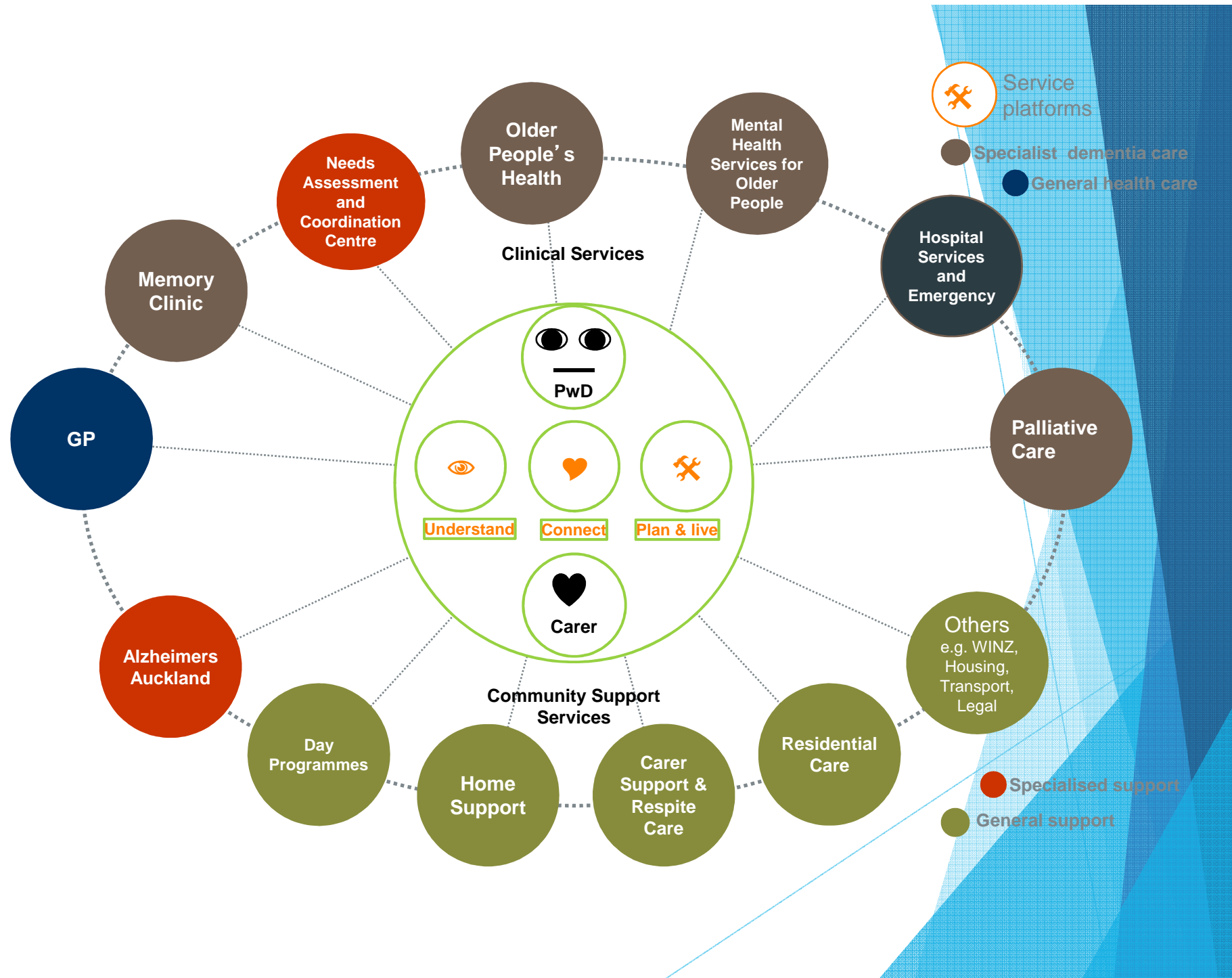
People with dementia and carers need information about dementia and support services. Support services need to be flexible to meet the needs of people with dementia and carers.

## ▶ Problems:

- ▶ Available services and supports don't always enable people to live normally in their own community
- ▶ PWD and carers don't know what services are available or how to access them
- ▶ Services are not always sufficiently flexible

## ▶ Solutions:

- ▶ Recommendations re support services respite, day programmes end of life care, alternatives to hospital care, HBSS, ARRC, supported living, transport.
- ▶ Service directory providing information about the dementia network services involved in dementia care





# Develop: Foundation Workstream

People with dementia, carers and staff want to understand the role of everybody in the network so that they can work in partnership.

- ▶ Problems:

- ▶ Lack of clarity about service responsibility and accountabilities leading to duplication and inefficiencies and confusion for PWD and Carers

- ▶ Solutions:

- ▶ Service responsibilities and accountabilities defined
- ▶ Services Summary
- ▶ Competencies Framework (linked to unit standards)
- ▶ Recommended training plus comprehensive list of available training

# Deliver:

## Have we made a difference?

- ▶ Too early to tell we are at the beginning of deliver!
- ▶ Groundwork has been done
- ▶ Embedding and sustaining change across the network
  - ▶ Shared care plan and information sharing
  - ▶ Carer assessment
  - ▶ Staff and Carers and PWD navigating the network
  - ▶ Referral to Alzheimers
  - ▶ Education and Training
- ▶ Organisational Commitment to Co-design
  - ▶ Ongoing governance with multi-agency and carer involvement
  - ▶ Support suite

### Next steps

- ▶ Support regional pathway and links with primary care
- ▶ ? Restarting hospital dementia pathway using tools developed