

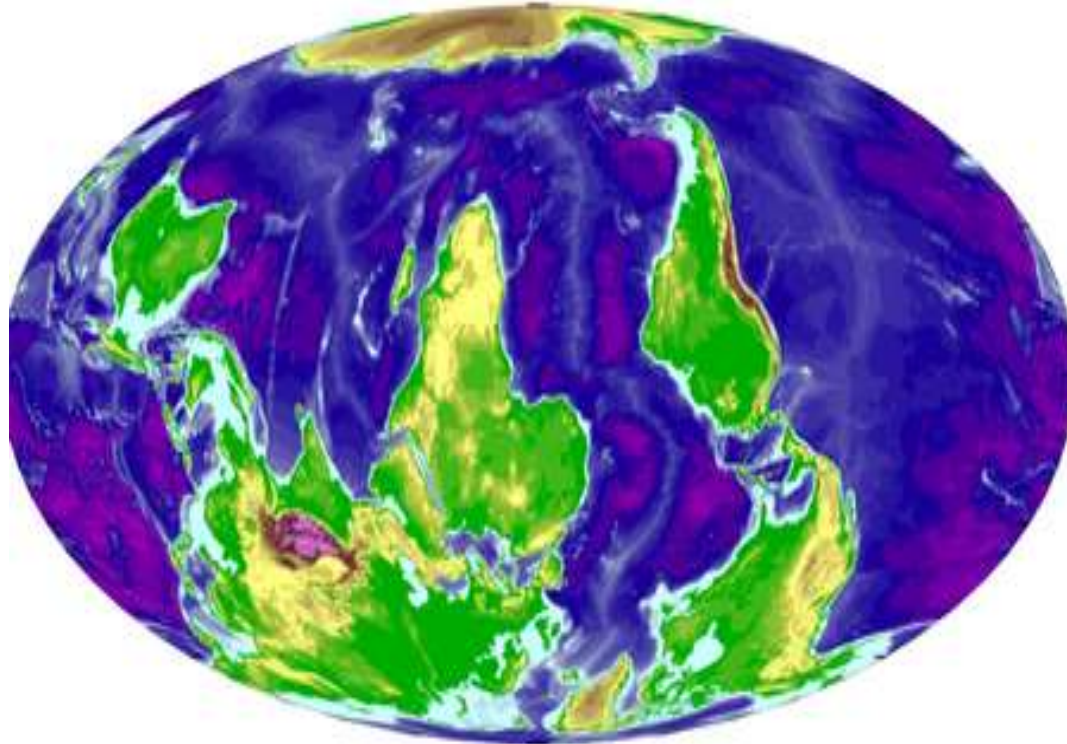
# Young people collaborating for social change so they no longer feel alone in the journey with their parent's dementia

Karen Hutchinson

Associate Professor Chris Roberts



Dementia turns the **whole** family's  
world upside down



**BUT**

Society contributes to their **EXCLUSION**  
**DISCRIMINATION** and **EMOTIONAL DISTRESS**

# Qualitative Research Study Focus

- To explore how the social model of disability informs an understanding of the societal influences on young people who have a parent living with young onset dementia.
- Secondly we wished to understand the nature of age appropriate societal support for their complex situation.

# Research Process

- Conducted semi structured interviews with **12** participants looking at their experiences between the ages of 10 to 24 years in NSW, **1** male and **11** females.
- Retrospective data collected from people who were as young as 8 when their parent demonstrated symptoms of younger onset dementia.
- A focus group with 4 participants from the research and 2 Alzheimer's NSW employees
- Held a day workshop with representatives from youth and dementia sectors, health, government, young people, parents with dementia and academics

# Emerging themes from the research

- Invisibility
- Connectivity
- Being empowered

# Taking a unique perspective on the impact on young people in families with YOD



Using the social model of disability as the theoretical framework

# The social model of disability

- The social model of disability shifts our perception of disability from the individual to the interaction in their environment they live, work and play.
- Young people are in effect disadvantaged and disabled by their environment as they often experience exclusion and discrimination as well as emotional distress.

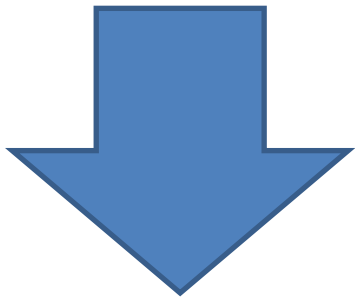
# Young people feel invisible

Young people report feeling outcasts within dementia services

Service and support



- Limited services
- Limited expertise in supporting young families
- Young people are not recognised or engaged



*“ I just felt like they'd look at me and go oh my God, this is above me. When you're going to someone for help, you think I want help; I don't want someone saying oh dear and just having these long awkward pauses, trying to think what could they say or looking like they're going to cry.”*

**Listen to the experts – What do they need ?**



# The big picture

Young people face *socially constructed disablement*

## Young people presently feel

- Disempowered
- Excluded
- Unsupported
- Stigmatised
- Lonely
- Neglected
- Emotional distress
- Disengaged
- Isolated
- Invisible
- Lost in the chaos
- Unrecognised
- Different to their peers
- Disconnected
- Hopeless
- Uninformed



## Young people want to be

- Connected
- Valued as citizens
- Recognised in the family
- Respected
- Hopeful for the future
- Informed
- Included
- The same as their peers
- Safe
- **EMPOWERED**

# Their stories explain it all

*“I think that's why we didn't get a lot of support as well because she didn't look or act like she wasn't well.”*

“I didn't meet people that understood or could say anything that was comforting or could offer any good solutions or wanted to get involved properly.”

*“I think having a mum with dementia left me really isolated as a teenager. I didn't have that one person that I could go to.”*

# The emotional derailment

Young people need to feel connected and engaged throughout as they deal with their own age developmental challenges



## The crisis experiences they describe:

- Nervous breakdown
- Depression/anxiety
- Suicidal ideation
- Psychosis
- Substance abuse
- Homelessness
- Self harm

## Triggers for an emotional crisis:

- Greater length of time living at home
- Transition from adolescent to adulthood
- Parent being admitted to residential care
- Deterioration of their parent with YOD
- Length of time being the main carer
- Other parent not coping
- Financial hardship
- Family conflict

Being engaged and connected with the **right** person that they **trust** can save these young people from being another statistic in youth mental health.

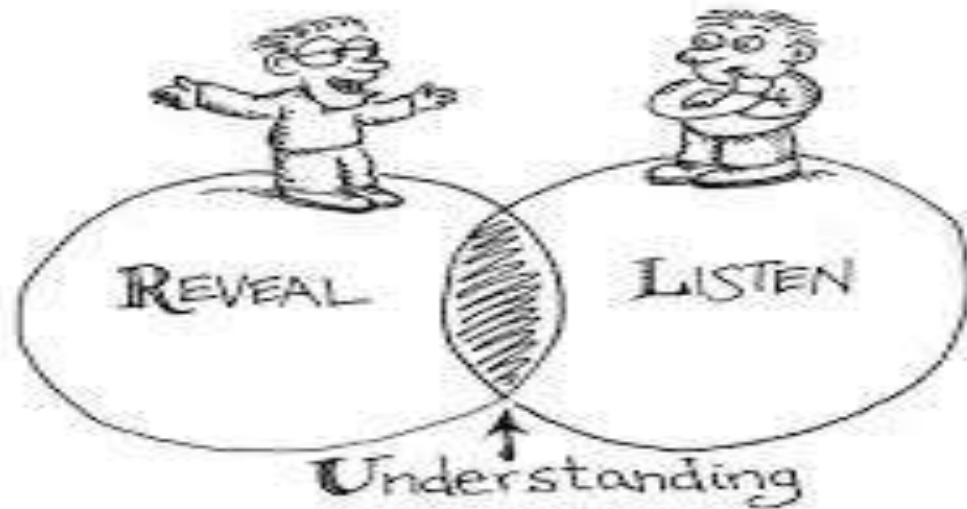
# How to overcome isolation

- These young people need **recognition** in their own right while responding to the changes in the family circumstances and dealing with marginalisation in society.
- Being connected to your social world through building positive relationships helps to form linkages and networks that promote resilience through an overall sense of **belonging**.



# Being Empowered

Taking control of your life and  
make the right connections.



# Making connections are so important

- “But I used to talk to him a lot because I was worried about not being able to go to university and I wanted to study communications then. So I think he made me feel easy, even if I don't go to university that I'll find my way to contribute to the world somehow. It was just that kind of reassuring-ness that it would be okay no matter what happened. That the world would just keep on going. So he was really good to talk to.”

(young person talking about a school teacher )

# Empowering the young person they are the voices of the future

- To develop strong connections within many social contexts underpins successful resilience and break down barriers.
- By maintaining and supporting connections with these various social contexts, family, friends, communities and parents, influences a better sense of self and develops self efficacy.
- Changing how the environment impacts these individuals will greatly affect their future abilities to support change and resilience to cope with further challenges.

# Why Should this matter?

*YOD should not  
define the lives  
or futures of  
these families*



**We should respond to individual needs**

**Taking a more social approach to support  
and service design addressing life's  
personal challenges.**



# REACHING

for a better future with social inclusion and equality

- **R**edefine these families futures
- **E**ngage with the community using the best technology
- **A**ssist listening to the powerful voices of the family using the connected world of social media
- **C**ollaborate with a range of professionals to provide problem focused solutions
- **H**ave a sustainable, integrated and evidence base application
- **I**ncrease confidence and competency in professionals
- **N**ow connect and empower service users
- **G**et the age appropriate support and services they deserve.

# Thee process of empowering

- Collaborate cross sectorially in mutual learning to create belonging and trust
- Be innovative together in developing professional competency and understanding with families living with YOD.
- Establish young people as advocates and leaders to be consulted and included in their part of the dementia experience.

# Lets empower these young advocates

## **No more of this**

Dementia organisations “**didn't really understand what we were going through**. They were very sympathetic, like oh you poor things, but that only makes us feel worse especially at the time when they were like, gosh I don't how you're going to do it or, gosh I don't know how you're doing it.” (young carers looking after their mum)

## **Encourage and support this**

“ I'm happy to talk to everyone or anyone who will listen. I've given lectures at ...University for the med students. I usually cry through my talks so it's not really useful but you know **I'm just telling everybody about it. I'm just trying to educate people.**” (young carer)



THE UNIVERSITY OF  
SYDNEY

# Thank you



- NHMRC Cognitive Decline Partnership Centre (CDPC) for my scholarship
- Supervisors Assoc. Professor Chris Roberts and Professor Susan Kurrle
- Michele Daly and Assoc. Professor Caroline Bulsara
- All the people involved in activity 17
- All the wonderful young people who helped me understand

Contact: Karen Hutchinson

Email: [karen.hutchinson@sydney.edu.au](mailto:karen.hutchinson@sydney.edu.au)