



# Successful Ageing in Intellectual Disability (Sage-ID)

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry



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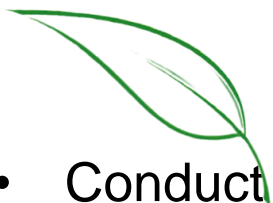
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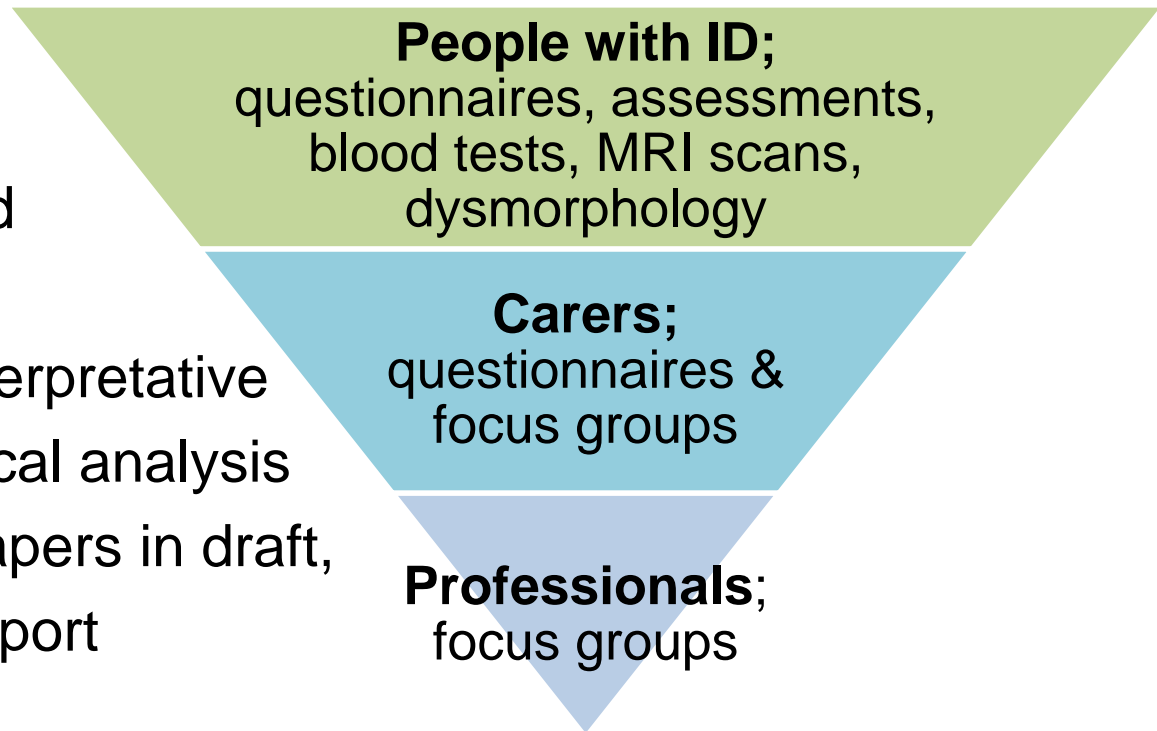


# Aim of research:

- Conduct a comprehensive investigation of the predictors and correlates of healthy ageing, and physical and cognitive decline in people with ID
  - **SP1.4:** Document the experience of people with ID and their carers
  - **SP1.7:** Build an epidemiological profile of people with ID and MH issues, producing accurate stats
  - **SP1.8:** Investigate specific neuropsychiatric disorders in people with ID
  - **SP1.9:** Analyse impact of ageing and dementia in people with ID and identify predictors of healthy ageing
  - **SP3.6:** Investigate the health and MH service needs of people with ID
  - **SP3.7:** Investigate the health and MH service use of carers
  - **SP4.4:** Increase awareness of the health and MH needs of people with ID
  - **SP4.5:** Build the evidence base in the field of ID MH, including collection & collation of accurate epidemiological data & publication of high quality work.

# Overview of what SAGE is doing:

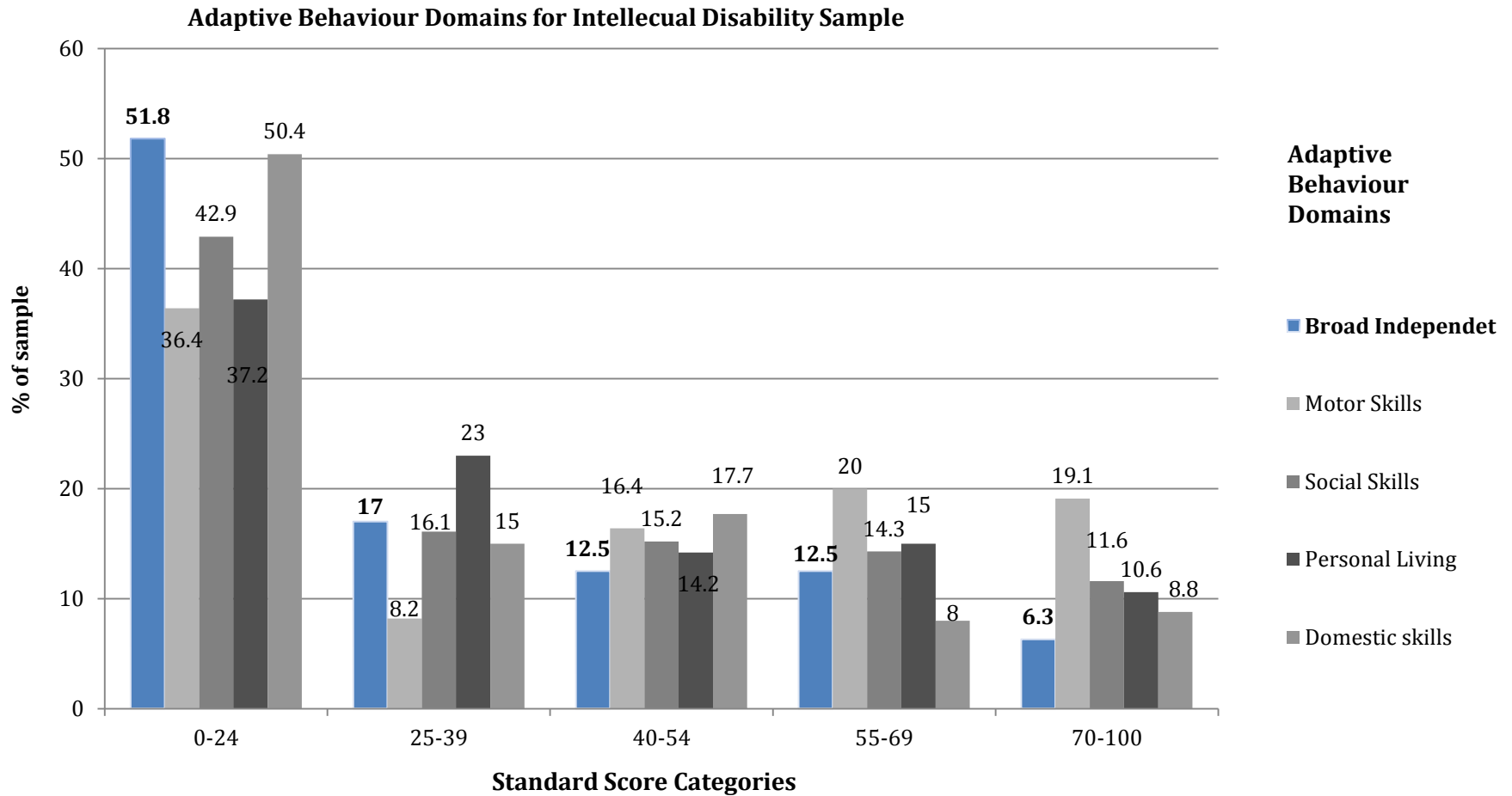
- **Sample:** People with ID  $\geq 40$  ranging mild – profound
- **Location:** Sydney, Illawarra, Bendigo Victoria
- **Measures:**
- **Methodology:** Mixed  
Methods design
- **Analysis:** SPSS, Interpretative  
Phenomenological analysis
- **Dissemination:** 3 papers in draft,  
Conferences, report



# Our T1 questionnaire sample so far... (n=122)

		Male (N=64)	Female (N=58)	Total (N=122)
<b>Mean Age (years)</b>		48.7	50.3	<b>51.2</b>
<b>Marital Status</b>				
	Married	0%	3.4%	<b>1.6%</b>
	Single	98.4%	91.4%	<b>95.1%</b>
	Divorced	1.6%	1.7%	<b>1.6%</b>
<b>Location</b>				
	NSW (Sydney)	45.3%	46.6%	<b>45.9%</b>
	NSW (Illawarra)	35.9%	27.6%	<b>32%</b>
	Victoria	19.8%	25.9%	<b>22.1%</b>
<b>Living situation</b>				
	Home w/family	10.9%	6.9%	<b>9%</b>
	Small residential	50%	41.4%	<b>45.9%</b>
	Large residential	20.3%	20.7	<b>20.5%</b>
	Independently	7 (6%)	13.8%	<b>12.3%</b>
	Aged care facility	0	6.9%	<b>4.9%</b>
<b>Currently have a job (paid/voluntary)</b>				<b>55.3%</b>

# Adaptive Behaviour functioning:



# Physical health:

- **BMI** range 18.5 – 49.9; **75% ranged overweight → morbidly obese!**
- Stroke – 4.1% 1 or more
- High blood pressure – 26.2% (only 13.1% meds)
- **Cholesterol – 25.4%** (only 12.3% meds)
- Diabetes – 19.6%
- Thyroid – 12.3% (Underactive 10.7%; Overactive 1.6%)
- **Fits/Epilepsy – 36%** (30.3% meds)
- **Consulted a psychiatrist/psychologist – 48%**
- Sight problems – 27.7%
- **Physical disability – 36%** (13% confined to wheelchair)
- Diagnosed with Autism/ASD/Aspergers – 15%
- **12 flagged dementia cases** - CCC

# Our T1 carer sample so far... (n=75)

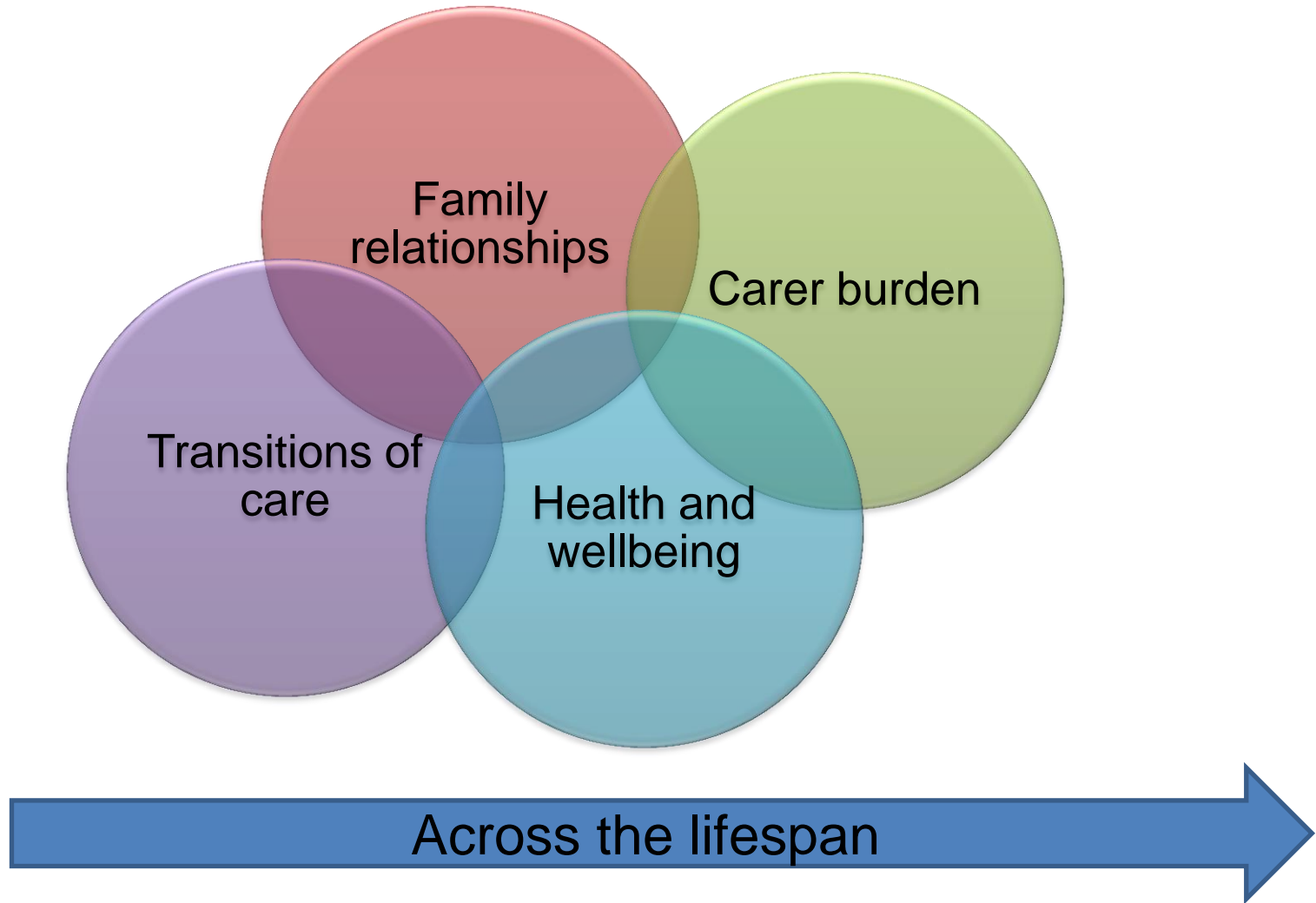
		Male (N=10)	Female (N=65)	Total (N=75)
<b>Mean Age (years)</b>		62.9	68.6	<b>67.8</b>
<b>Marital Status</b>				
	Married	80%	56.9%	<b>60%</b>
	Single	0%	6.2%	<b>5.3%</b>
	Divorced	0%	1.5%	<b>1.3%</b>
<b>Relationship to Person with ID</b>				
	Mother	0%	67.7%	<b>58.6%</b>
	Father	40%	0%	<b>5.3%</b>
	Sibling	50%	23.1%	<b>26.6%</b>
<b>Work Status</b>				
	Not working due to person w/ ID	10%	12.3%	<b>12%</b>
	Not working for other reasons	40%	29.2%	<b>30.6%</b>
	Full time homemaker	10%	38.5%	<b>34.6%</b>
	Working full time	30%	7.7%	<b>10.6%</b>
	Working part time	0	7.7%	<b>6.6%</b>
	Working casually	0	4.6%	<b>4%</b>



## Interesting stats:

- Finance:
  - 1/3 age pension, 41% carer allowance/carers payment
  - 40% gross income = \$33,799
- Mental health:
  - Sig association between marital status and level of anxiety and somatic symptoms
  - Sig association between relationship to person with ID and levels of severe depression
- Physical health:
  - 1/2 carers reported “good” physical health but felt limited in able to do moderate physical activities.

“How does a lifetime of care impact on family carers of adults with an Intellectual Disability?”



# Objectives for the year.....

- **Achieved so far:**
  - Wave 1 participants with ID **N=122**
  - Wave 1 family carers **N=80**
  - Round 1 focus groups w/ family carers **N=19**
  - 2 focus groups with professionals **N=11**
  - 1 case consensus
- **Achieve in 2014:**
  - Wave 2 follow up all participants (30 months)
  - Face-to-face interviews with family carers on help seeking
  - More focus groups with health professionals
  - Run more case consensus'
  - At least 4 publications, 1 ADHC report

# Future planning for project....

- **Funding:**
  - Bupa application already submitted
  - Looking at other grants
- **Spin-off projects:**
  - Intervention study people with ID and dementia
  - Risk and protective factors against decline
  - Family quality of life carers
  - Social network structure/social inclusion of ageing people with ID
  - Training for ID frontline staff and informal carers
  - Development of a parental education/support programme focussing on future planning
  - Develop guidelines for health and social care staff, local voluntary agencies and support groups or working with ageing family carers on 'succession planning'.

