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## Family caregivers: how do they deal with stress?

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## The Protocol

109 invitations posted

Volunteers sent questionnaires:

- ❖ About the person they care for
- ❖ About their own health
- ❖ Their feelings about caregiving

Carers interviewed

## Study participants

Number of volunteers:

- ❖ 16 for the full study
- ❖ 6 for the interview only

The people cared for (n=16):

- ❖ 11 people with Angelman syndrome
- ❖ 5 people with Prader-Willi syndrome

## About the people with IDD

- ❖ 15 born in Australia
- ❖ 15 living in a family home
- ❖ 11 with brothers and sisters
- ❖ 7 of 16 families using respite care

## Food-related problems (possible score 0-96)

- ❖ Angelman syndrome: **41.2** (22-54)  
Average 4 questions/person scored 0  
(i.e. not applicable)
- ❖ Prader-Willi syndrome: **51.8** (35-69)  
Only 1 question scored 0

## Food-related problems sub-scales

- ❖ Preoccupation scale:  
PWS > AS (21 not applicable)
- ❖ Satiety scale:  
PWS > AS (18 not applicable)
- ❖ Negative Behaviour scale:  
AS ≥ PWS (6 not applicable)

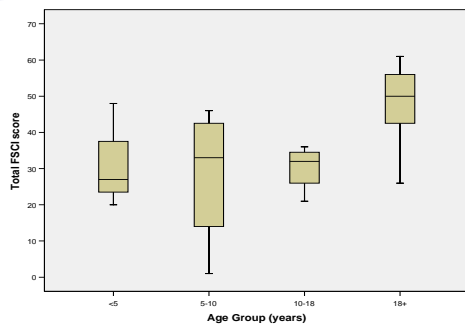
### Carers: personal health and satisfaction

- ❖ Health: 13/16 good or excellent
- ❖ Most persons 'limited by their health'
- ❖ Many people say they feel good about caring for their family member

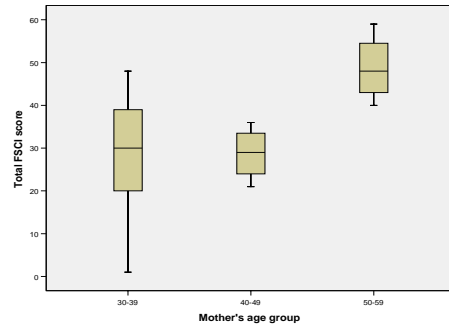
### Stress and Coping (possible score 0-96)

- ❖ Scores: mean 37 (range 1-61)
- ❖ Parents of adults higher scores (48 vs 30)
- ❖ Less stress felt by carers reporting better health
- ❖ Level of carer satisfaction had no impact

### Carer stress scores by age of person with AS/PWS



### Stress scores by mother's age



### Stress and Coping

Major stated concerns:

- ❖ Initial diagnosis
- ❖ Personal needs
- ❖ Service providers and government agencies

Highest for <5 years and >18 years

### Initial Diagnosis

"..it was the biggest kick in the guts.."

"..it was devastating.."

"..once we got the diagnosis, then you can start reading up and preparing yourself.."

"..we went through the 'why me?' the tears, the anger.."

## Personal needs

“I had to give up my career, I was at home with him full-time.”

“..there is no time..”

“..everything’s just been put on hold.”

“..my needs just weren’t on the agenda... and that’s why I crashed.”

## Service agencies

“..they’re just inconsistent...you’re wasting that whole evaluation time..”

“..there is no box for him at Centrelink..”

“..it creates all these issues just to get a box ticked.”

“..the high turnover of staff..”

## Problem-focus coping

“..it’s great that we do have physios and OTs and speech come out..”

“..think it through, come up with a solution, get over it.”

“..once we got some knowledge, that became... a bit of a weapon against the stress.”

## Emotion-focus coping

“..realisation that what you perceive as normal is not or no longer will apply.”

“..you just get used to it..”

“..nice to know other families who have children the same.”

## Limitations

### Self-selected:

- ❖ People who aren’t coping may not reply
- ❖ Advocates are more likely to volunteer
- ❖ Eight carers had a tertiary education

### Small numbers:

- ❖ Lack of statistical significance
- ❖ Possibility of identification

## Sources accessed

- ❖ Gadzelea, BM. *et.al.* (2008) Development and analyses of the coping stress inventory. *College Student Journal* 42(2)
- ❖ Kenny, K. & McGilloway, S. (2007) Caring for children with learning disabilities: an exploratory study of parental strain and coping. *Br J Learn Disabil* 35(4)
- ❖ Nachshen, JS. *et.al.* (2003) The Family Stress and Coping Interview for families of individuals with developmental disabilities: a lifespan perspective on family adjustment. *J Intellect Disabil Res* 47(4-5)
- ❖ Russell, H. & Oliver, C. (2003) *The assessment of food-related problems in individuals with Prader-Willi syndrome.* *Br J Clin Psychol* 42(4)



## **Thank you**

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- ❖ Angelman Association WA
- ❖ Prader-Willi Association WA
- ❖ Genetic Services WA
- ❖ Disability Services WA
- ❖ My supervisors: Alan, Emma and Peter