

Parental attitudes to employment for adults with Angelman syndrome and Prader-Willi syndrome



Making it real together!

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Outline

- Overview of the study
- Expectation of work
- Out of reach
- Where to from here?



Study description

- 21 families
- Offspring with Angelman syndrome and Prader-Willi syndrome
- Family Stress and Coping Interview
- Work placements and employment



Why does having a job matter?

- Social role
- Community participation
- Parental lives
- Continued development



Theme 1: Employment as an expectation

- Right to a suitable job
- Appropriate supports
- Opportunities



Right to a suitable job

- ...we know that just as passionate as...we are, that he will have open employment...
- You're supposed to be supporting disability...hey, this job isn't appropriate...he should be in the store...packing the shelf or doing something out the back."



Appropriate supports

- We went to a workshop...techniques...tips on...how to up-skill him...teaching him travel
- ...big organisations...say, “...we’re going to support them...give them a program they can come into.” And once all the pictures are taken and they’ve all been in the papers, things go back to normal.



Opportunities

- ...it'd have to be a very small part-time job...a simple job, pulling levers and piece of steel falls into a bucket...haven't been able to find exactly the thing for her.
- ...we tried for ages and that's when I got frustrated and my son lost his self esteem.
- ...I felt that he had the ability to work...

Theme 2: Employment as out of reach



- Low expectations
- Lack of awareness



Low expectations

- ...he just doesn't have the tolerance or patience to sit there.
- He just can't – he doesn't follow instructions...yeah, he just can't do it.
- ...anything task-based loses her interest within 30 seconds. So her concentration span is very, very limited.



Lack of awareness

- ...I guess there's something out there...
- ...saw someone working at Coles...very obviously special needs, and I'm thinking 'could my child do that?'



How to make it real, together

- Look for opportunities
- Work with service providers and employers
 - Adjustments
 - Supports
- Encourage participation



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