“Seeking belonging: how parents with daughters with Rett syndrome facilitate friendship and community involvement”

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Parents are doing it!
Overview

• Background information
• Research question
• Methodology
• Findings
• Conclusion
Background

Community Participation
Background

Wanting Friendship
Background

Society wants it too....
Background

How do we know what to do...
What is Rett syndrome?
Summary

- Community connections are good
- People with Rett syndrome don’t have many
- Parents want their daughters to have friends
- Parents are best placed
- Understanding of the challenges they face
How do parent-carers facilitate community participation for their young adult daughters?
Methodology

- Qualitative
- 6 Families
- Social construction of reality
- Ethics

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Findings

I TAKE FOR GRANTED...
I RECKON...
MY VIEWS ARE...
ACCORDING TO ME...
I ATTACH WEIGHT TO...
I SUPPOSE...
I THINK...
I ASSUME...
I ACCEPT...
IT IS...
IT ISN'T...
I PRESUME...
I TAKE AS GOSPEL...
I BELIEVE...
Findings
Findings
Rachel “hangs out” with one of her support workers at the local café where they chat with each other and socialize with the locals over coffee.
“We had this full-on crazy house ... always people around ... they came and went.”
Summary
Conclusion

• What it would take for friendship to be seen as a realistic goal.

• Explore efforts needed to address the issues of safety associated with complex communication needs.
Parents are doing it!

https://c1.staticflickr.com/9/8039/7990072878_f149d47174_z.jpg
Thanks for your attention!

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