

Autonomy and relationships among 'good life' goals

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Families were described as “loving”, “supportive” and “encouraging”, while also “too controlling” and “smothering” in the young adults’ transition to adulthood and desire for autonomy. Credit: Michael Patterson

Young adults with Down syndrome have a strong desire to be self-sufficient by living independently and having a job, according to a study into the meaning of wellbeing among young people affected by the disorder.

The ECU research team, including Dr Kitty-Rose Foley based at the Telethon Kids Institute (formerly Telethon Institute for Child Health Research), aimed to understand "what makes a 'good life'" for young adults with Down syndrome, and what the facilitators and barriers were to a good life.

"We wanted to explore the factors associated with the 'best' outcomes for people with Down syndrome, so we can guide policy and interventions towards maximising the likelihood of these [young people](#) reaching their potential," she says.

"However, we needed to define what that 'best' outcome was for people with Down syndrome, from their perspective."

Participants comprised of six males and six females with Down syndrome aged between 18-29 years.

They firstly partook in individual sessions with a researcher, which lasted between 10-20 minutes and provided them the opportunity for independent expression through drawing and writing on large paper sheets using colourful pens.

Following the individual sessions, participants joined larger group discussions facilitated by a researcher, which enabled them to share experiences.

The group discussions lasted between 45 minutes to 2 hours, and were audio recorded which were later transcribed.

Thematic analysis of the individual and group sessions uncovered four significant themes— relationships, community participation, independence, and hopes for the future.

"These findings highlighted the participants' desire for autonomy, particularly in the domains of living independently and employment," Dr Foley says.

"Family relationships and community services were identified as both facilitators and barriers to participation."

Families were described as "loving", "supportive" and "encouraging", while also "too controlling" and "smothering" in the [young adults'](#) transition to adulthood and desire for autonomy.

Community services such as employment provided a significant opportunity for independence, however the participants expressed barriers such as restrictions around the types of jobs offered and hours worked as preventing them from "pursuing their life goals".

"This research highlights the importance of involving young people with intellectual disability in research, and emphasises they're capable of voicing their own desires and ambitions for their future," Dr Foley says.

She says she would like to see the four goals revealed in this research prioritised by service providers.

Dr Foley says she would also be interested in future research exploring interventions which facilitate young people with an [intellectual disability](#) to live independently, participate in work and employment and be involved in meaningful relationships.

More information: "I have a good life": the meaning of well-being from the perspective of young adults with Down syndrome. Scott M, Foley KR, Bourke J, Leonard H, Girdler S. *Disabil Rehabil*. 2013 Nov 28. [Epub ahead of print]

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