“You Can Do Anything and Make Sure You Follow Your Dreams”: Experiences of Belonging in Adolescents with Down Syndrome

New research from The University of Birmingham highlights the importance of shared fun, social presence and the belief that anything is possible for establishing feelings of belonging in adolescents with Down Syndrome.

Belonging is important for people from all walks of life as it can lead to significant improvements in mental health and physical health. This is especially true for adolescents who can be particularly vulnerable to social stressors. Previous research found that parents of children with Down Syndrome worried about their children’s sense of belonging. Many parents felt that belonging could be enhanced by active engagement in community activities. Despite some by-proxy research existing, this study is the first to investigate first-hand, how young people with Down Syndrome experience belonging.

Lead researcher, Maggie Rose interviewed six young people with Down Syndrome between 14 and 24 years of age. The interview was guided by a list of questions that had been co-produced with people who have Down Syndrome. Some of the young people also chose to bring and share objects, photographs and videos that represented belonging for them.

The research study found that community engagement alone does not equate to feelings of belonging. For young people with Down Syndrome, it is the opportunity to engage in fun and meaningful activities alongside others (shared fun) that is experienced as important. This ‘shared fun’ seems to be equally important at home as it is at school or in the community.

The study highlights how environments exacerbating existing cognitive and physical difficulties can make it hard for young people with Down Syndrome to engage in shared fun and this can subsequently impact upon their sense of belonging. For example, two young

people shared how noisy environments make it hard for them to concentrate and meaningfully engage in activities with others. For all participants, feeling supported, cared for and comfortable were essential for shared fun to take place. Several participants talked about the importance of physical affection, either from friends and family or from pets. The presence of pets in particular, seemed able to offer a consistent and comforting presence for the young people who took part. The presence of favourite foods such as *"pizza"*, *"sweets"* and *"chocolate milkshake"* also seemed important for enabling the young people to feel comfortable and cared for.

The study highlights the importance of social presence in fostering a sense of belonging among young people with Down syndrome. Participants discussed how both temporary absence and permanent loss can negatively affect this sense of belonging. Several participants also referenced separation from loved ones when describing times, they found it difficult to feel that they belonged. Examples include, parents going on holiday or being away from parents during the school day. Participants also discussed the impact of permanent loss, with several young people describing how the death of loved ones made it difficult to feel a sense of belonging. Technology and transitional objects appeared to play a particularly important role in maintaining feelings of belonging during periods of absence and loss. Being able to "text" family and friends, watch videos associated with belonging, and even interact with technological devices such as *"Alexa"* seemed to have a positive influence. Furthermore, several participants described how objects representing comfort or enjoyment, such as teddies and games, enabled them to carry feelings of belonging with them into new places. In addition, participants shared how spending time connecting with others facilitated feelings of belonging during periods of absence and loss. For example, one participant described how getting *"another dog"* after the death of a family pet helped them feel *"less lonely."* Another participant explained how spending time with their girlfriend and friends

while their parents were on holiday helped them maintain a sense of belonging. The study highlights the importance of cherishing the close connections we have whilst they are present, not only because they are important for belonging but because their impermanence is what makes them so precious: *"You make some time with your love, with your parents, because one day you're going to miss them when they're gone."*

All six participants shared how important feelings of value, achievement and power are for belonging in young people with Down Syndrome. Two participants described how being able to help other young people with Down Syndrome via support groups enables them to feel valued and helps them belong. Three participants described how getting a strike at bowling enabled them to belong because it made them feel *"proud", "powerful" and "strong."* Several participants also shared how important it was to have other people view and respond positively to their achievements via *"clapping"* or the presentation of an *"award."* Television programmes that provide platforms for people of all abilities, including individuals with Down syndrome, to showcase their talents were also experienced as important for fostering a sense of belonging. Four participants referred to programmes such as Strictly Come Dancing and Britain's Got Talent during their interviews. One participant specifically mentioned *"Ellie Goldstein,"* a young woman with Down syndrome who was performing on *Strictly Come Dancing* at the time. Another participant stated, "*I know some people with Down syndrome on Britain's Got Talent… and ever since I watched it, I have a connection with it."*

The study highlights, most importantly, how feeling valued by others enables young people with Down Syndrome to believe in themselves. This self-belief seems to be particularly important for maintaining sense of belonging during times of discrimination, *"they teased me a lot…my superpowers, they just helped me."* Another young person also beautifully captures the importance of self-belief for belonging:

"Sometimes people make fun…and when they make fun, they can be sad or angry. And the thing I want them to know. The message I want them to know is that you can do anything and make sure you follow your dreams."

Several important clinical implications can be derived from the study. Firstly, the research highlights the negative impact that even micro-absences can have on belonging. This illustrates the importance of offering young people with Down additional support, where possible, to help them navigate any upcoming absences or separations. This might include mapping out fun activities and time spent connecting with others during times of separation. The presence of comforting objects or videos associated with belonging might also act as a buffering effect to loneliness during these times. In relation to permanent loss and bereavement, young people with Down Syndrome might benefit from additional support to process their feelings of grief. This might involve finding creative ways to honour the memory of loved ones such as creating memory boxes or memory markers e.g., naming a plant or star after their loved one.

The benefits of animal companionship have also been identified in this study, and it will be important to consider the use of animal assisted interventions in therapeutic settings such as equine based therapy or 'pets as therapy'. Finally, the importance of empowering young people with Down Syndrome during therapeutic intervention is profoundly inferred in this study. Young people with Down Syndrome should be always offered choice and agency and, where possible, offered valued roles in service development.