

Bringing Voices Together – People with intellectual disability and families

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Aims/Objectives: What was the purpose what you did? Why is your topic important? What did you want to change? What difference did you want to make?

The aim of our work is to ensure the voice of families is effectively heard, captured, and represented in Inclusion Australia's systemic advocacy efforts. We recognised that many people with an intellectual disability - including people with high and/or complex support needs - are quite removed from the community and the self-advocacy movement. By involving their families we can bridge this gap and amplify their voices and experiences, ensuring these are included in our work and heard by government. We balance this with the direct involvement of people with an intellectual disability in our work as well.

Methods/Process: Who was involved? What did you do? (100 words)

Our engagement with families involves various levels of interaction, including the Services for One Community of Practice, aimed at advocating for family-focused NDIS processes and supporting the right to self-manage NDIS funding. Through these initiatives, we aim to gather insights, share experiences, and advocate for improved services for individuals with an intellectual disability who have complex support needs. We focus on genuine inclusion and facilitating connection – facilitating the inclusion of the voice of families is often in the best interests of people with an intellectual disability, especially when they may not be able to participate directly in policy work.

Results: What did you find? What changed? What difference did you make? What did you learn?

Our efforts have led to increased representation of the needs of people with an intellectual disability who have complex support needs with government agencies and bodies. A positive outcome has been the development of formal ways to engage with families – these voices are being brought together in a more formalised way. We have seen increased membership in the Service for One CoP. We facilitated targeted workshops for the NDIS Review and on other key policy topics including the development of the National Autism Strategy. We hosted a meeting for the Service for One CoP with the NDIS Registration Taskforce.

Conclusion: How could other people use what you found out? What would you recommend other people do based on what you did and what you found out?

Our findings suggest that by actively involving families in systemic advocacy work, we can enhance the quality of services and supports available to individuals with an intellectual disability. We recommend continued engagement with families through various initiatives such as podcasts, storytelling, and information sharing to amplify their voices and highlight systemic challenges and success stories. This is an important complement to involving people with an intellectual disability directly in our work as it ensures the experiences of people with higher support needs, including people with complex communication needs, are included.

Alignment with the Conference Theme: How does your proposal address the conference theme of ‘New Frontiers’? How does your proposal showcase something new we can do to make the world a better place for people with disability? (50 words)

Our proposal aligns with the conference theme by showcasing innovative ways to empower and engage families in advocating for individuals with an intellectual disability. By promoting collaboration between families and service providers, we aim to pave the way for a more inclusive and supportive environment for people with disabilities.