

## A pilot investigation of post school options for young people with intellectual disabilities

### STaR Association Research Team: Led by Dr. Sarah Carlon

The advent of early childhood intervention, deinstitutionalisation, and later the inclusion movement, drew community attention to the rights and needs of children and adults with a disability. Parents began to keep their children with intellectual disabilities in the family home, providing them with the same experiences of family and community life as their children without disabilities. Many children, who would have been institutionalised up until the 70s and 80s, are now receiving early intervention support and have access to government and non-government schools, with many being educated in mainstream schools or classrooms.

The *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, established in April 2019, has adopted the human rights approach to education set down by the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). This includes the right to an education. The issues paper on education and learning produced by the Royal Commission (October, 2019) covers early childhood and school education but there is only passing mention of further education. The papers include issues of concern to individuals with a range of disabilities with only one with a focus on individuals with cognitive impairment, this being a paper relating to health care. What seems to be overlooked for this population is the quality of education received post school.

The STaR Association, which has been supporting Early Childhood Education and Care (ECEC) centres to promote the development of infants and young children with disability within inclusive early childhood services since 2001, is revising its mission to now include lifelong learning for all individuals with disability. The model that will be used is the same coaching and mentoring model that has been used to support young children and their families since the program's inception. The impetus for pursuing this new direction is the reports from families whose children were supported by STaR prior to school entry and who are now in post school programs. Concerns with the quality of programs offered to young adults with disabilities and fears for the future prompted the STaR research team to investigate the perceptions of families of individuals with disability of their children's post school services.

To this end, a pilot survey was developed and completed by the mothers of three young adults (two females, 20 and 21, and one 20-year-old male) who were supported by the STaR program in the early 2000s. The aim was to fine tune the survey and open it up to the families of other young people with disability whose children are now in post school services. The two girls attended special schools for the whole of their school education. The boy attended a mainstream class in primary school and a support class in high school. Survey questions included demographic items and questions about the education and support received by their children prior to school, during school, and post school. The following data extracted from the surveys will be used to fine tune the survey and inform follow-up interviews with a sample of survey respondents.

The two girls who have significant intellectual disabilities are now accessing a combination of activity/day programs and one-to-one community support. Although both mothers indicated that they were satisfied with their children's early intervention and school services, both indicated that they were dissatisfied with the post school program. Comments made by the mothers included:

*"Over 2 years [my daughter] is about to commence in her 4th day program. I am appalled by the quality of care, planning and programming. This is a complete halt of [my daughter's] learning. It is like a play group for adults. I fear that [my daughter's] learning is decreasing and her days are boring and meaningless" (Mother A).*

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*"Finding where to go, and what the options were, was/is really difficult. There is a significant lack of information and the system is so disorganised. It was very stressful knowing school life was coming to an end. The feeling that her educational life, connection to her friends and teachers and weekly routine is ending so abruptly and she didn't understand that. 3 years later (my daughter) is still asking for school...." (Mother B).*

Mother C's son has a milder intellectual disability, is currently in an assisted employment program and is working 25 hours a week. Although she was not satisfied with her son's school education, this mother is satisfied with his post school program. She reported that her son has continued to develop skills and knowledge since leaving school. However, she is concerned that there is not enough support for families to negotiate the system post school as indicated by the following comment:

*"It is hard to find the correct path. There doesn't seem to be an organisation which can help form a holistic idea of work, accommodation, social, skill development for young people with intellectual disability. As a parent, I am searching around for information but often on wild goose chases. We have had 3 or 4 NDIS LACs [Local Area Coordinators] who do not keep in touch, disappear and provide the briefest of information when pushed. It is slow and frustrating and often I feel like I'm going around in circles. I seriously don't know how people with disabilities, without advocates, manage to navigate the system and find what they need." (Mother C).*

The girls' mothers both reported that their daughters had either not learnt new skills since leaving school or had gone backwards in their learning:

*"2 steps backward, 1 step forward. Very difficult to find a decent program. No guidance. Untrained staff. All about the money/funding not the needs of your child and what is best for her." (Mother B).*

*"I am truly devastated that my young daughter's options for quality learning are NIL. These carers are not qualified or skilled. I am yet to find a provider who has employed ANYONE with teaching skills/qualifications who can develop a meaningful program based on my daughter's current skill levels.... The fact that I cannot find services to provide my daughter with purposeful, meaningful and stimulating days DESPITE the NDIS funding available is devastating. Her learning has progressively diluted over the past 2 years. The lack of skill in the disability sector is unacceptable. We need to shift the mindset from "minding/babysitting" to "adult learning setting". I feel an enormous sense of failure – My daughter has the right, as I do, to continue learning for life YET because she has a disability she cannot access a setting to do this-they don't exist." (Mother A).*

The purpose of the pilot survey was to fine tune the survey, develop an interview protocol, and to determine a set of research questions. The purpose was not to evaluate post school options for young adults with disability. However, the responses received from these families pose some important questions that the proposed survey and subsequent interviews may help to answer. Some of these questions can also be answered by surveying and interviewing providers of post school services.

1. What is the relationship between level of disability, school placement and parent satisfaction with the school education, and post school provision?
2. What is the role of the NDIS in assisting families of young people with disability to secure opportunities for life-long learning in post school programs?
3. What level of programming (including assessment of entry level skills, implementation of evidence-based instructional strategies, and data-based instruction) is included in post school programs for young people with a range of disabilities?

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4. How well do post school program staff collaborate with the families of the young people with disabilities accessing their services?

As Mother A has articulated, all individuals have a right to life-long learning and that requires post school services to include staff who have the qualifications and skills needed to enable this to happen.



**STaR Association Research Team**  
**Led by Dr Sarah Carlon**

## References

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (October, 2019). *Education and Learning issues paper*. Retrieved from <https://disability.royalcommission.gov.au/publications/education>

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