

Transitioning young adults with severe autism from school to a day program; A Qualitative Study.

Background:

I work at an organisation called Giant Steps. We run an autism-specific school in both Sydney and Melbourne for children between the ages of 4 and 18. In Sydney, we also operate an adult day-program for clients aged 18 and over.

We utilise a trans-disciplinary service model, with teachers and educators working alongside OT's, speech therapists and music therapists daily. In the adult day-program, support-workers and therapists also work together all day every day running programs for the clients.

Our adult day-program, known as Adult Autism Services by Giant Steps, or AASGS, is funded through the participant's NDIS packages and parent fundraising, and most participants have transitioned from the school directly into the day-program. We take a client-focused approach, working directly with the participant's families and carers to design programs that meet the NDIS goals, the family's goals and most importantly, the client's goals.

Identification of Need:

The challenges associated with the transition from school services to adulthood for individuals with disabilities are well documented. The process can often be a very overwhelming and challenging one as families worry about the individual's future: What kind of job will he have? Where will she end up living? Will he ever be independent? What will make her the happiest?

Every individual with autism is different and as a result, there is no "one size fits all" plan for the path to adulthood. A transition plan involving job training and skill development that is fitting for one person with autism may be ineffective for another. The most important factor in creating a plan is to focus on the individual. His or her strengths, needs, challenges and preferences will play a critical role in ensuring a successful transition process.

Earlier last year, staff at the adult day-program began to notice that many of our young people were struggling after transitioning into the day-program from other environments. We were noticing an increase in challenging behaviours and a regression in skills including communication and self-care skills. Another noticeable change was an increase in the clients' anxiety, leading to a decrease in functioning across contexts.

Upon discussion between school and day-program staff, we realised that there were significant differences between the school and day-program format including the client's occupational role, staff and therapist roles, and client expectations. We decided to explore the factors that influence a student's transition process including those that determined success and where there were gaps in our practice.

Methodology:

To investigate what makes a successful transition, I distributed a qualitative survey to Therapists and Educators across both the school and day-program who had been involved in previous student transitions. Open-ended questions were used to investigate staff opinions and draw on their experiences, including questions such as "What skills do you think students need to be able to

successfully integrate into an adult day-program?” and “What can we do to prepare our students for the transition out of school?”. Responses were then analysed to identify common themes and determine which factors are viewed as key to a successful transition. I’m going to explore each of these factors in detail.

Results:

Our students and clients have a large range of varying communication abilities and many are non-verbal. Many of them use gestures, vocalisations and visuals to receive and express messages. The key difference noted between the school and day-program in regards to communication is the number and variety of supports used. It is common for students in the school to have many environmental cues such as visual aids, forewarnings and schedules for all activities across the day, personalized communication systems and a larger speech therapy input. The day-program has only just begun involving speech therapy into our services and the integration of formal communication supports is still developing. Clients still use personalized communication systems, but there is less staff training in how to support the use of these.

Students in the school typically access the community 2 or 3 days per week, for approximately 1 to 2 hours at a time. In the day-program, clients are out and about in the community every day, completing a range of work and leisure programs. Clients are encouraged to be as independent as possible in the community and staff often let client’s lead the day and choose the activities they wish to complete. The big change in the frequency and type of community access has resulted in challenging behavioural responses from some students.

As a result of these findings, it was recommended that we aim to increase the student’s participation in the community in their final year of schooling to prepare them for the day-program format. It was also recommended that day-program develop a larger speech therapy presence to further support staff and client’s in the use of expressive and receptive communication systems and to increase the amount of non-verbal communication systems across the day-program.

Self-regulation and difficulties managing change is a common problem for many people with autism. Across Giant Steps, change is an integral part of the school and day-program and students and clients are encouraged to learn how to make choices from a very early age. As the day-program is community-based, the environment is naturally more unpredictable than a classroom environment. Planned changes are implemented wherever possible within the school to encourage self-regulation in students. However, when the student’s occupational role changes to an adult within the community, there is an expectation to manage more complex changes for example, a planned expedition being cancelled due to the weather, which can result in distress and possible challenging behaviours.

The ability to make choices and give consent can be very difficult for individuals with autism. When moving from the school to the day-program, client’s daily programs are individualized based on their NDIS goals rather than the NSW curriculum and many are funded for 1:1 support. As a result, the opportunity to participate in a wider range of choices across their day is more evident and choices are based within a larger context. Clients are advocating for their day by designing their program where possible, given their understanding of consent and communication abilities. Whereas the consent to participate in activities was heavily anticipated by student’s caregivers, as an adult they are expected to give or refuse consent to a range of activities themselves.

It was recommended that we continue to give students ample opportunities to participate in planned changes at school. By teaching student's strategies to cope with change and explore their choice-making abilities, we can help to build resilience in student's before they transition. When student's transition into the day-program, they should be given increased support to prepare for unexpected changes and to give informed consent. Staff and carers should be educated about the increased expectations of the client's new occupational role and how to support any difficulties they may have.

As client's move into adulthood and their occupational role changes from "student" to "adult" the ability to self-occupy across a range of activities becomes a priority. In the classroom setting, students are supported in leisure time to choose and engage in activities with support from teachers. As they leave the classroom setting, clients are expected to design their own self-occupying activities, which can prove challenging in their new occupational role as adults.

It was recommended that from a young age, therapists and teachers work to explore a number of activities, whether they be leisure or productivity-based, that students can engage in without staff involvement that can be carried across to a day-program.

Conclusion:

Understanding what skills students require and what supports we must provide to create a successful transition has further informed the role of the Therapists and Educators in our secondary school and day-program. Staff are more informed on how to best prepare students for the transition period and are starting the transition process earlier in the student's final year.

In 2019, we are transitioning 2 students from the secondary school into the day-program and are currently designing a "Post-School Transition Protocol" to be used as a guide for future transitions. The emerging protocol presents the 5 stages of a successful transition as:

- information sharing between school and day-program staff
- observations of the student across contexts
- involving the student in day-program activities in their final school year and gradually increasing the amount of time spent there
- designing programs for the student that focus on their needs and wants
- and finally, educating all day-program staff on how to best support and interact with the student

Discussion:

In the near future, we hope to complete and implement our "Post-School Transition Protocol" and conduct further qualitative surveys of staff and parents to evaluate our success. We will engage with parents who have experienced the transition process with their children and gain insights into their view of success. We will use our findings to begin the transition of students into our Melbourne day-program which is currently under development, close to our Melbourne school. And lastly, we also hope to distribute our findings to services and education facilities that may benefit from our research.