

Positively Impact Your Son or Daughter's Transition Direction: Three Essential Questions You Must Ask

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The transition phase when the young adult leaves school is often a complex and frightening time for the young adult and the family. This

is the time when the parents struggle with the fear and uncertainty of the future because their child has now reached adulthood. Most parents see their typical teenager leaving home for college or to live in an apartment after high school as a natural part of the family cycle. Yet even imagining the separation of the young adult with a disability living apart from the family is a great concern for parents.

Often parents receive a list of many tasks that need to be completed during school transition, including setting up a guardianship or applying for a Medicaid Waiver. Completing them is emotionally and financially draining, especially when programs such as Medicaid Waivers have long wait lists for services in many states. And this wait may lead to the young adult's increased negative behaviors because of a lack of daily structure. As a result, parents become lost in the details of caring for a young adult; all that is seen is the small picture: the problems, issues, and specifics of what needs to be done each day. These moments constitute the heart of daily living (Blue-Banning & Turnbull, 2002).

Parents play a significant role in their young adult's transition phase. If your son or daughter has significant communication limitations or other challenges, you probably have been your son or daughter's eyes and voice throughout the years. My son is 33 years old, and I still continue to be involved as his advocate.

Here is what we parents seek for our young adult:

- to have a meaningful day with supports.
- to be involved with enjoyable activities.
- to feel safe with others who acknowledge their challenges.
- to have an opportunity to continue to learn and grow.

All of these in combination reflect quality of life for a young adult.

How do parents and their young adult move forward? Turnbull (2007) offers a guideline to use during the transition phase. She defines the criteria for reaching a quality of life for individuals with developmental disabilities where: (1) one's needs are met; (2) one enjoys life; and (3) one can do things or have things he or she considers important. While these criteria appear simple, it requires effort to build these into a person's life. Based on Turnbull's criteria for quality of life, I offer these questions written from the teen or young adult's perspective. The goal is to highlight his voice and self-determination about his or her life.

- What are *my* (the young adult) individual needs?
- How will *I* (the young adult) enjoy my life?
- What are the things that are important to *me* (the young adult) and must be part of *my* life?

There are no right or wrong answers to these questions, only answers that are personally right for the young adult. It is important to realize the questions apply to all individuals regardless of the person's level of disability, severe or high functioning, because the criteria of quality of life are the same for all.

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Application

Let's apply each of the questions to the young adults with autism whose parents were interviewed in my qualitative research.

Introducing Sarah. What are Sarah's individual needs? Sarah is a beautiful woman in her 30s, who is severely disabled with autism. To have a meaningful day, Sarah needed structure and personnel to guide her through activities. Receiving the Medicaid Waiver, Sarah's parents established a consortium with two other parents who have daughters with developmental disabilities. The three women share a house and live integrated in and connected to the community. The parents set policy regulations for hiring staff. The staff reinforces Sarah with behavioral supports that meet her challenges and daily activities that allow her to be a community member.

Introducing Randy. Notice how Randy and his parents considered this question: How will Randy enjoy his life? Randy is 20 years old and has high functioning autism as well as challenges in social belonging. He enrolled in a community college where his parents arranged for him to live in a dorm on the campus. In high school, Randy was well-known for his strong memory and knowledge of sport statistics. His parents and other advocates negotiated with the college's sports media department that Randy be allowed to volunteer using his interest and knowledge in sports. His volunteer work later became a part-time job.

Introducing Kirk. He is 23 years old and has high functioning autism. Kirk explained that performing by using his musical talent was most important because of his superb musical gift as a pianist who plays classical and contemporary pieces. After high school graduation, Kirk wanted to live independently in his own apartment and to continue developing his talent. His parents arranged for him to receive occasional support from an independent living agency.

Additionally, his mother noticed his relaxed presence around the elderly residents when he visited his grandfather in a nursing home. Therefore, Kirk's mother approached local nursing homes and arranged for him to entertain the

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patients and staff during the recreation hour. Because Kirk knew all the popular '40s tunes, the residents liked him. When they heard the tunes, they recalled the days when they were young. Today Kirk is self-employed performing on his keyboard in the local nursing homes.

The notion of accessing what is needed and pursuing what is enjoyable and most important in a person's life can be supported through White's definition of the effectance motive: that is, people have a basic drive to make things happen and have control over their environment (1959, as cited in Haidt, 2006, p. 220). He states that “making things happen” in one's environment is as vital as food and water. Please note that it is not like hunger that vanishes for a short period of time after eating a meal and then reappears after the food has digested. The effectance motive is continuous in a person's life.

As we parents support and gently guide young adults to access what is true and important in their lives, we can make a positive difference in their

capability to participate and grow. Youth with autism and related disabilities need us to acknowledge their challenges and provide the supports and opportunities that promote their individuality, thereby impacting their capability to make things happen on their own behalf.

As a parent, do you know your young adult's school transition needs, such as how he or she wants to live and the necessary supports and goals to set in place? And if you are a young adult, you might well know your own skills and talents, yet you may be unaware of how to further develop or use your strengths in employment, volunteer work, or pursuing college.

Try this exercise. There are 10 sections to work through. The items in each section represent life skills and supports that can help young adults adapt. Read each item. Next, rate each item by placing a number 1, 2, 3, 4, or 5 by each item. The higher the number, the greater the priority of need. The lower the number, the less important. You may choose to complete this activity with your son or daughter.



ONE

- To participate with family and close friends in a variety of everyday or holiday activities. _____
- To receive supports for a Medicaid Waiver Program for community living. _____
- To practice *willingness* to learn new skills or tasks. _____
- To use one's strength/talent in a meaningful way. _____
- To access a support person (a coach) to practice life skills in the community. _____

RANK**SIX**

- To receive information and benefits from the Social Security Administration on Supplementary Security Income (SSI) or Social Security Disability Insurance (SSDI). _____
- To use the cell phone or email, to communicate with others. _____
- To interpret and express one's own feelings or emotions. _____
- To have a job or hobby. _____
- To pursue training or college classes online. _____

RANK**TWO**

- To ask for help when needed (i.e., reporting illness or emergency). _____
- To receive vocational rehabilitation services for job training or life skill training. _____
- To use an interest in a new setting. Example: singing in a church or community choir. _____
- To accommodate new situations, change, or challenging events. Example: the dentist office, or a new, enjoyable activity. _____
- To receive information about a good college that offers supports for students with disabilities. _____

RANK**SEVEN**

- To use tools, strategies, to communicate one's thoughts and desires. _____
- To access a support system (people) to help create supports (when one is not eligible for supports through a state agency) so the individual may have options to access and participate in the community. _____
- To explore one's enjoyment of a skill, talent, or interest in a new setting. _____
- To receive behavioral supports or other type of therapy. To explore a good training program that offers supports for persons who have challenges in studying and organizing. _____

RANK**THREE**

- To access a support person to connect the individual to an enjoyable community activity among peers. _____
- To further develop a gift or talent by training with a professional. Example: painting or playing the guitar. _____
- To adjust to or adapt to unfamiliar people in life in order to participate in a setting. _____
- To practice following instructions to accomplish a work task. _____
- To receive supports for community exposure and meaningful experiences. _____

RANK**EIGHT**

- To practice compassion to help someone else: Example, grandmother, volunteer with others, hold door for an elderly person. _____
- To access a job coach who understands one's challenges and capabilities. _____
- To use strategies in navigating a college campus. _____
- To access or continue to use a particular therapy that has been successful for individual. _____
- To explore options and supports for a volunteer job. _____

RANK**FOUR**

- To experience overall wellness, thus receiving medical or dental services. _____
- To explore a new activity or setting for fun or learning: Example, a museum with a dinosaur exhibit. _____
- To use self-talk, relaxation techniques, or other approaches to manage obsessive/compulsive or aggressive behaviors. _____
- To establish people supports to aid in participating in a new setting learning a new skill, example taking a cooking class. _____
- To find a training program that understands one's challenges with autism or other disability. _____

RANK**NINE**

- To understand one's own disability challenges and communicate to a teacher, administrator, or professor the necessary supports for completing class assignments and taking tests. _____
- To acquire information about guardianship/special need trusts. _____
- To accept correction or redirection by a support person while in a community setting. _____
- To access or continue diet or other bio-medical interventions. _____
- To explore options for a hobby. _____

RANK**FIVE**

- To use tools such as an iPad, calendar, or checklist to follow a schedule/routine. _____
- To receive a voucher through HUD Housing to live independently, with a roommate, or with other person support. _____
- To receive support or action steps in order to manage ridicule or peer pressure. _____
- To feel or express emotion for personal accomplishment or loss. _____
- To find environments that appeal to sensory needs of the individual. _____

RANK**TEN**

- To access supports to pursue exploration for a job or hobby. _____
- To access transportation to get around the community. _____
- To have supports to continue to use a diet that is most beneficial to the individual. _____
- To develop strategies to join clubs/other events on a college campus. _____
- To initiate and/or respond to another's comment or greeting. _____

RANK

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Insert the numbers you assigned to each item in sections 1–10 into the appropriate column. Total each column. The columns with higher numbers reflect the young adult's greatest needs.

	Traditional Supports	Social Belonging	Social/Emotional Stability	Job/Volunteer Hobby	Training College
1.	_____	_____	_____	_____	_____
2.	_____	_____	_____	_____	_____
3.	_____	_____	_____	_____	_____
4.	_____	_____	_____	_____	_____
5.	_____	_____	_____	_____	_____
6.	_____	_____	_____	_____	_____
7.	_____	_____	_____	_____	_____
8.	_____	_____	_____	_____	_____
9.	_____	_____	_____	_____	_____
10.	_____	_____	_____	_____	_____
TOTAL	_____	_____	_____	_____	_____

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Considerations: What Does This Say about Your Son or Daughter's Transition Needs?

- What does this say about the need for traditional supports (e.g., vocational rehabilitation, Medicaid Waiver)?
- What does this say about setting short-term and long-term goals?
- What did you learn about the young adult's immediate needs to reach a quality of life?
- What particular areas of interests and enjoyment were noticed so these might be developed into transition or life goals?
- What particular areas were of personal importance to the young adult's quality of life?

If you want to learn more about how to meet your son/daughter's transition or quality of life needs, please visit www.drjackiemarquette.com.



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