

The Transition to Adulthood for Children With Special Needs:

Examining If the Needs, Programs and Services Available to Special Needs Children As They
Transition Into Adulthood Are Sufficient to Meet Their Needs.

Zachary M. Jacobs

Purchase College, State University of New York

Abstract

To fulfill the Purchase College Senior Capstone Project, this paper is a supplement to my live video interviews. I describe my job as a Direct Support Professional, and the interest I took in how the individuals I worked with grew up and how their needs were going to be met in the future. I discuss my personal experience working with this population, and how it has affected me personally. I discuss my concerns for their being high quality programs and services along with the funding to meet the demanding and expensive needs of these individuals. I discuss my deep concern for the future and safety of these special people as they age and might not have parents to advocate for them.

Introduction: My background knowledge of special needs individuals

For as long as I can remember, I have always felt compassion for special need individuals. As a young child, I remember watching the Jerry Lewis Labor Day Telethon, which raises money to help offset the enormous financial burden the social and medical needs can burden parents raising these special children. The show profiles individuals and the impact their disability has on their lives. They give a glimpse into the everyday hardship and struggle these children, their siblings and families face. They often showed videos, which helped to capture the essence of these sweet and brave children. I would find tears streaming down my face and an overwhelming mix of emotion, from sympathy to inspiration. It forced me to reflect on my own life and struggles, which were minimal compared to these children profiled on the telethon. It was then that my interest in working with these special people was piqued. I was drawn to them and wanted to see how I could get involved. I knew that working with them would not only benefit them, but I had a suspicion that the rewards that I would gain would be so much greater, than what I could offer them. I followed some of their stories into adulthood, which sadly was not the outcome for all of them.

One thing I was extremely curious about when I watched the show, was what happens to these children as they grow and reach adulthood. It seemed like that had many programs and services available to them when they are young. The kids were also so

adorable and easy to carry and provide care for. The parents were able to assist in their care. I wondered what happens when the child gets older, along with the parents, and the parents are no longer able to care for the child? What happens to the child who is not physically handicapped, but perhaps mentally or socially disabled? How do parents manage the financial responsibility? How do they navigate the legal system to ensure their child is receiving the best possible care as a child and will continue to do so the child reaches adulthood and struggles to find his or her place in society, wanting what every child and human being wants-to be normal, to feel independent, and feel like they are an accepted and productive member of society.

My project entails a writing project and video project. I believe through doing research we gain a strong knowledge and perspective in what we learn. However, through interviewing high-ranking professionals who devote their daily lives towards a certain field, we are given a stronger, more personal and meaningful perspective in the topic, which can't be always be done amongst our own reading.

In first grade I had a friend who had Asperger's Syndrome. My friend spent some time in our class, but generally spent most of his day in a small class with a one-on-one teacher. The kids in my class were not particularly tolerant of this boy, and they were mean and excluded him. Even at six years old, I felt empathy for him, and naturally tried to include him and treat him like a "normal" friend. I left the school after First Grade and we went our different ways. Years later, when we were in our teens, we

reconnected and he let me know that he clearly remembered that I was the only one who was nice to him as a kid, and how much it meant to him and impacted his life. I didn't remember treating him any different than I treated any other friend. I felt sad that I was the *only* one who was nice to him, and what a positive impact it had on his life. It was then that my decision to find out more about and work with special needs individuals was solidified!

I started working for an organization for individuals with special needs at around 17 years old. The name of this organization is Yedei Chesed. I have worked in different programs for this organization. Every program I have worked in serves different ranges of ages, disabilities and purposes. The ages range between nine years old to mid forties. The most common disability individuals face is autism but includes Down Syndrome, Bipolar, Schizophrenia and Epilepsy. Every individual functioning and affected on different levels. I have worked in various programs, day-hab and respite programs, including a young adult group home. My job title is a "Direct Support Professional, by definition, the goal of my job is to provide support to my clients. However, my job entails a lot more than just support, it entails giving each individual the best life possible based on their challenges and setbacks. The main difference between the day-hab and respite program is the age range and goals they serve. The day-hab program is focused on young adults who have recently graduated the board of education entering into society, age ranging seventeen to around thirty. While the respite program is an "After School Program" focused on children ranging from ten until seventeen years old. Most of the individuals in day-hab also live in adult group homes. The main difference between the goals of these programs

is the type of support we provide. For children it involves teaching and showing them simple tasks, like getting dressed or eating properly at the table. For an adult it may include something more intense like teaching them independence and how to work and keep job. In general the idea of all these programs is to look in depth at each individually separately and enable them to feel normal and live happy, successful lives.

It seems like the transition period for children with special needs can be very difficult. Besides for the physical and emotional struggles it may form, the laws, rights and services change as well.

Laws and Programs to Bring About a Healthy Transition into Adulthood

Special needs children need to learn how to be independent in order to transition into adulthood. Although some children do get good education, some aren't put into environments that can help them grow. Children with autism can sometimes do well in a regular school but only if their teachers make their teaching style fit into whatever the student needs. Carnahan, Hume, Clarke and Borders mention that the students with autism who do best in life are those that are active participants in their classroom. Teachers for these students know that they can't really do well when being thrown a big assignment, it is important to focus on smaller details. It really becomes information overload when there is a big picture. When a small detail is worked on the short attention span of someone with this special need they will do better. Doing things in steps also helps these type of students. With the use of this style and the use of a work system, a child cannot better organize themselves and get the task done. When a child is given independence by being given the skills and then learning, they can do the things on their own. Each of these children has their own way of learning (6-9).

According to Haney, it seems like society needs improvement in After School Programs (usually run by parents and teachers) for high functioning special need children with autism. Any child, regardless if they have a disability can benefit from After School Programs such as clubs,

music, sports, or any particular interests. I believe that inclusion in After School Programs is especially important for special need children who sometimes suffer socially. Although there has been inclusions in many schools, some schools are asking these children to children to leave causing frustration to parents. Although some are satisfied with the After School Programs, it seems like improvements can be made in After School Programs to meet the needs of individuals (466-473). Having worked in an After School Program, I have seen difficulty in employers supporting and accepting behavioral issues of special need children. Some of these challenges are no doubt difficult to manage. Sadly, I have seen employers outright disrespect some of these special children. Weather done by taking advantage, laughing, or mocking individuals. We must support the differences in behaviors amongst these children. Some of them may eat,sleep,walk,or talk differently than us however, still deserve the same love and support.

The transition from board of education to post board of education can be especially challenging for children with special needs. Sankardas and Rajanahally mentions how we often emphasize in school logical skills, like time management, problem solving skills and organizing oneself. However, disabled people do not always have the opportunity to learn these skills until much older which places them at a disadvantage to the rest of society. Disabled people make up a large part of our population, and it is important to focus on their needs as well (252-267). In the past there has been job discrimination towards the disabled. Nowadays the overall rights and opportunities for the disabled has evolved. We can see a disabled person working at a supermarket and not think twice. In Yedei chesed, many of the young adults hold basic jobs, the complexity of their jobs differ depending on disability. Some disabled people

even get married and have children. We have come along way in accommodating the rights of the disabled but can of course always make improvements.

Similarly to the Civil Rights Act of 1964 which focused on gender and equality protection, The Americans with Disabilities Act(ADA) of 1990 focused on accommodating and protecting the rights of the disabled. Whether it is job accessibilities, ramps on busses to for the handicapped or programs.

Atkins and Hayman mentions in a review that too many kids had disabilities and qualified for programs which made it difficult to assist every person(174). Along with The American Disabilities Act came The Fair housing Act which states that you can not discriminate housing to from the disabled(175). However, the ADA focuses on what the disabled can and can not do. Therefore, it seems as if the act does not fully accommodate those with disabilities. Unfortunately, this causes society to quickly judge the capability of the disabled. The title 1 act of ADA states that companies with fifteen or more employees should accommodate those with special needs. We should not not assume they can not manage a job and need accommodations. If they really can not its okay, we give them other job opportunities (178). Someone disabled should be able to work freely without being judged. They should also have the same health benefits as other employees. The general goal is to create a culture where accommodation is the norm, studies show that placing people with disabilities in jobs does can be very effective and often works well(180). I personally have witnessed and helped disabled people work jobs and it really changes there life for the better. Especially when entering adulthood it makes them feel like they are contributing to society and playing a significant role in life.

Video Audio Reflection

Ever since I was a young child until today, I was like Curious George, asking questions about every little thing. Asking questions is one of the most beneficial and effective ways to gain knowledge and insight about any topic. My experience in working with disabled children and adults in Yedei Chesed has changed my life and distorted views of the disabled. I felt that composing interviews with Professionals in the field would give society and myself a more personal knowledge of the disabled. I really hope society can learn positive messages from my interviews. The general idea of my interviews is respecting, acknowledging special need people. We have to realize that they are just as unique as anyone else. The interviewing process was not as simple as I originally thought. The process of confirming convenient schedules for myself and the person being interviewed was difficult. However, I made it work. Through one on one interactions with my interviewees I felt a personal connection which I am hoping would be the same for the audience. The actual process of finding questions to ask was manageable as well as the videoing. I procrastinated a little in completing the interviews only because I originally did not have this idea. And the process took some time (almost a month.) Between forming the questions, setting a time and place, editing the videos etc. I really gained insight from conducting these interviews. I wish the same for my viewers. I feel like there is no better way of sending a national message than interviewing people who devote their lives into a specific field. Everyone

in Yedei Chesed seems to have their hearts in the right places which I hope can be transpired to the public.

Conclusion

Between the creative and practical part of my senior project. I have narrowed down my career choices to something involved with therapy. After doing extensive research about special needs people I started realizing that it is not enough to just emphasize for people that have severe challenges but to actually contribute to society and ultimately help to make people happy. Unfortunately, humans naturally judge and label people like products. Every single person in society deserves the rights they are entitled to. Society as a whole has to realize that our actions, views, and perceptions can have a huge affect on others. In all it looks as though there can always be improval in all of the services that these people receive. Although there are programs and laws geared towards these people, they need to be revised and taken more seriously. Families of people with special needs need more tools in order to help their children. From my experience and from the research I have done, there needs to be more change. I would be happy to help bring about that change. This Capstone project has helped me realize I want to get involved more and be a harder worker when working with these people.

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