

Final Paper

Introduction:

Introduction to disability studies has been a unique type of course that is very different from anything that I had ever taken before. It was really interesting to study the course material while also attending an internship that sent me out into the field. This allowed me to draw connections between the readings and discussions for class and the real world. The whole semester has been incredibly eye opening. My internship placement was at the Arc of Oneida-Lewis County. The Arc was originally founded in 1954 by parents who wanted a full life for people with developmental disabilities; it was established as The Association for the Help of Retarded Children. Today, it is now just referred to as the Arc because it was deemed inappropriate to use the word “retarded” in the acronym. The Arc is a huge organization that helps individuals with mental and developmental disabilities. Unfortunately, I wasn’t able to experience all of the many programs that the Arc has to offer, but I was lucky enough to be able to work with three different divisions: Coordination Services, Venture Day Rehabilitation Hub, and Saturday Night Friends (children services). Thus, I was able to see the bureaucratic side of the organization while also helping out with the more hands on services. In this paper I will outline what the Arc provides to the disabled people that it services and I will describe my experience working with the Arc as well as what I’ve learned.

Coordination Services:

The Arc's coordination services department consists of three teams, headed by two assistant directors and a deputy director. Each team ranges from three to six service coordinators and each service coordinator services approximately 20 individuals. In order for an individual to receive a Medicaid service coordinator, he or she must have a documented diagnosis of a developmental disability, be enrolled in Medicaid, and must demonstrate a need for ongoing and comprehensive service coordination. Some services that are available through Medicaid service coordination are respite, residential habilitation, environmental modifications, family reimbursement, and more. Until recently, each MSC was required to see each individual at least once a month; however, recently, the rule was altered so that a phone call will be sufficient. Service coordinators describe many of their tasks as "mothering" the individuals in their caseload. They help the disabled people schedule appointments and do the average tasks that they have trouble with as well as offering transportation to appointments.

While working with the service coordination team, I was able to shadow one service coordinator, Natalie. Natalie has twenty individuals in her caseload. Of these people, ten women were currently pregnant, which seemed to add a lot of stress to her job. She claimed that most of them probably aren't qualified to properly raise a child and take care of an infant. One day I got to go with Natalie while she picked up one of her individuals for an appointment at CareNet. At CareNet, the individual had the opportunity to take maternity clothes free of charge.

This experience not only allowed me to witness what Natalie does for her individuals, but also introduced me a new nonprofit organization that serviced people who don't have the money to afford certain necessities. In addition to maternity clothes, CareNet also provides mothering classes, baby clothes, and diapers.

While shadowing Natalie, I also got to go on tours of other Arc facilities such as the workshops at Arnold Avenue and the Gore Road facility. I was really impressed by the Arnold Ave. workshops. It was a much bigger facility than I expected with numerous rooms that took on various tasks. These tasks included stuffing envelopes, packaging CDs and other products, putting together packets of information and more. I didn't realize how useful this service is not only to the individuals working there, but also to the organizations that utilize the service. In one of the rooms that we went through, the individuals were stuffing packets of information for a hospital in my hometown on Long Island. The participants get paid practically nothing, but they enjoy doing the work for a sense of accomplishment. Arnold Ave. also provides a socialization aspect; without this opportunity to go to work, many of these individuals would be stuck sitting at home everyday. The love to get out into the work world and many of them claim that they want to work forever!

The Gore Road Facility is home to the CHOICES program at the Arc. The individuals at Gore Road were generally on the elderly side. At CHOICES, they could design their own schedule and decide what they want to do. They could choose between working, which consisted of workshop type work, and recreation. There

were numerous rooms that had different activities. While at Gore Road I was lucky enough to be able to sit in on two ISP meetings. For some reason, it was pretty unorganized. People were very late and some people didn't even show up. According to the service coordinator who I was with, the meetings usually aren't this unorganized. Regardless, I was able to witness how an ISP meeting was executed. The individuals have the option of whether or not they want to attend their meeting. When I was there, one came to his meeting while the other did not want to. For one of the meetings that I was at the people present at the meeting were the individual (optional), the service coordinator, the person in charge of the Gore Road program, a representative from the group home that he lived in, and a nurse that works with him on ambulating. They discussed his current ISP and how he is doing at home and at Gore road. The service coordinator asked how happy he seems and if there is anything that she should make a note of. Everyone who was in attendance had to sign that they were present and had to sign a confidentiality agreement.

My final task with service coordination was doing office work. Each individual has his or her own binder with all of his or her monthly reports as well as any incident reports or any other paperwork relevant to his or her needs. The binders were incredibly full and had hundreds of pages. My task was to go through all of the binders page by page and write down any monthly reports that were missing from within the last year. Although this was extremely tedious and incredibly boring, it really showed me all of the work that Medicaid Service Coordinators were required to do according to state law. I saw how detailed the

documentation has to be and how they really have to keep track of absolutely everything.

Overall, I am thankful for my experience with coordination services because I was able to see a lot of what goes on behind the scene of many Arc programs. However, it was incredibly frustrating to show up on Monday mornings and report to the person in charge of and have her say, “oops, I completely forgot that you were coming today.” Then, I would have to sit upfront and wait for her to figure out something that I could do. Many times she would just throw me with “Natalie” who was usually going out at that time. In the end, this wasn’t so bad because I got to see all of the different places that I mentioned above, it just wasn’t what I was expecting. I was initially told that I would be surveying individuals about their experience with the Arc, which never happened.

Many times service coordinators can inspire optimism within their individuals. They can be just as influential as Dr. Mac was for Martha Mason. In her memoir Breath, Martha Mason describes Dr. Mac: “when things have seemed hopeless, he has showed me hope” (Mason, 47). For many disabled individuals the face of his or her service coordinator can be the sign of hope; the sign that there is someone who cares and that there are facilities available for assistance.

Venture Day Habilitation:

The Venture day hub is designed for individuals with developmental disabilities who wish to contribute to the community through volunteering. Venture

services young adults ages 18 to 35. Currently, the oldest individual is 31 years-old and the average age is 23 years-old. There are eighteen people in attendance at a time with thirteen staff. A majority of the individuals live with their family (only two live in residences). Generally, Venture serves as a stepping stone or a transformation period; most individuals come after high school (which they can attend until 21 years-old) and work on social skills to prepare them for the future either for employment or for college works, which is another program that is run by the Arc that allows individuals with disabilities to attend college and study vocational areas. A majority of the individuals who attend Venture are on the autistic spectrum and/or have Down's syndrome or some type of unspecified learning/ processing disorder. Approximately half of the individuals attend Venture full time, while the other half attend Venture part time and go to the workshops or other programs. Venture provides a nurse, PT, OT, and speech therapy for those who need. The program also goes on "outings" and does in-house volunteer work, which I will go into more detail about later.

Each individual has two skills that they work on at a time, including kitchen safety, nutrition, seasonal appropriate activities/ clothing, money skills, and more. One girl at venture, whom I spent a lot of my time with, was on the autistic spectrum and was also physically disabled and was in a wheelchair. Every morning when I arrived she would have her lunch out and would be counting calories. As part of her skills training, she calculated the calories in her lunch. She had a specific amount of calories that she was supposed to eat a day and, once she figured out what was in her lunch, she could determine what she could have for dinner. She was always very

excited when she accomplished this task. It made her more aware of the food she was eating, which allowed her to live a healthier lifestyle. Her second skill was working with money. There was a box with fake dollars and coins and one of the staff members would work with her and have her count change. She would also have to “pay” for something and figure out how much to give the staff and check to see if she received the proper change. These skills will be very useful in the real world.

Venture also took the individuals on “outings” into the community to do volunteer work. Some of the places they went to include, supermarkets, a nursing home, girl scouts, various stores and more. Although they generally only do busy work, such as taking out the trash, the people at venture love going on outings. They really enjoy getting out into the community; for them, going out is more about the social aspect than actually working. I was able to go on one outing with a small group to Clare Bridge nursing home in Clinton. When I was told that we were doing to a nursing home, I assumed we would be volunteering/ helping with the elderly. However, when we arrived there I realized that I was mistaken. All we did at the nursing home was set the dining room tables. The group of about five individuals that I went with changed the tablecloths and folded napkins. While doing this they also got to practice basic math skills in terms of napkins. For example, if we needed ten napkins and three were already folded, then how many more do we need to fold? They struggled with basic subtraction, making this good practice for them. Overall, going on this outing taught me how much these individuals value getting out into the community and helping with any type of work that they can do.

The outings that the individuals participated in were a great way for everyone to contribute to society by volunteering and doing charity work. One of our readings argued, “charities usually do more for *nonsidabled* people” (Russell, 90). Marta Russell argues that charities “hire nondisabled employees, appoint nondisabled people to their boards, and contract with nondisabled service organizations who don’t employ disabled people” (Russell, 90). However, the charity work that the individuals did through Venture proved to be incredibly meaningful for them on multiple levels. Not only were they given the opportunity to socialize in the community, but they were also able to develop a relationship for the person they worked for. For example, there was one individual at Venture who knew everything about comic books and cartoons. The Venture staff reached out to the owner of the local comic book store and got this young man the opportunity to volunteer in the store. To this day, the owner and the comic- fanatic autistic individual still have an ongoing relationship, even though he no longer volunteers in the shop. Thus, there are benefits that come from certain types of charity work that goes beyond simply raising money and the bureaucracy of organizations.

In addition to volunteering in the community, we also did a lot of in-house volunteer work. The work that I helped out with was stuffing envelopes for the Kirkland Library and rolling silverware for the Hope House. The individuals at venture were proud to be able to contribute to these organizations. For me, the most fascinating part was observing how the individuals worked together. Everyone in the program seemed to get along really well. This was very apparent while they were doing their volunteer work. A group would sit around a table and

form an assembly line. While rolling silverware, one person would gather the fork, the knife, and the spoon, the next person would wrap the silverware in a napkin, and the next person would seal it with a sticker. They always made room for anyone who wanted to participate and helped each other out if one person was falling behind.

Overall, I spent most of my time socializing with the individuals at Venture. A majority of the time we played the card game Uno. One of the most noteworthy things that I observed at Venture was that they staff encouraged the individuals to do “age appropriate activities.” For example, even though they loved to do crafts projects, they weren’t allowed to very often because crafts were considered childish. However, this didn’t seem totally fair to me. There are a lot of adults who do crafts and crafts can be a good way for a person to express himself or herself. Also, many of the people at Venture have the mentality of a much younger person. I understand that they have to learn how to act their age in a sense, but I don’t see the harm in drawing a picture every once in a while.

Venture definitely showed me how disability is socially constructed. Simi Linton writes about how “knowledge about disability is socially produced to uphold existing practices” (4). Because people are only disabled according to societal norms, it is possible to have a society in which nobody is a disability. For example, if ramps were the norm rather than stairs, the people in wheelchairs would not be disabled in terms of being able to access buildings. At Venture, nobody seems disabled because having a disability is the norm of the group. In the outside world, disability language attributes “life, power, and intention to the condition and

disempowers the person with the disability, rendering him or her helpless and passive” (Linton, 25). Thus, Venture serves as a place where individuals can escape the demeaning language of everyday society and his or her label as “disabled.”

A large majority of the individuals were autistic and it was clear that their processing skills were delayed. Judy Singer notes Temple Grandin’s explanation of how her autistic mind works, “It’s like if I was a computer I’d have a hundred gigabyte hard drive but very little processing. You give the person extra storage but it’s at the expense of processing” (Singer, 66). This explanation really illuminated a lot of what I was observing at Venture. Many of the individuals seemed brilliant, but their reactions were extremely delayed, making them come off as “slow.” Even though they were slow in the sense that they needed more time to process information and questions, they still had the ability to answer adequately.

Children Services- Saturday Night Friends:

For my final experience at the Arc, I had the opportunity to attend a Saturday Night Friends program and work with children who were mostly autistic. There was a large age range; the youngest child there was three years old and the oldest child there was eighteen years old. The children were at the facility from 2:00pm to 8:00pm. The program not only allowed the children to be able to socialize with one another, but also provided a break for the child’s parents or caregiver. When the children arrived at 2:00pm, there was free play, so the children could choose what they want to do. There were four available options: 1) a playroom with various

toys, 2) a “sensory room,” which had a ball pit, a swing, and other objects that provided a sense experience, 3) an outdoor playground, and 4) a crafts corner. The staff encouraged the children to try new things and to play with each other. After about two hours, we opened the music room to add an additional option for the children. At 5:15pm the kids were given a fifteen-minute warning for dinner; this was key because a few children had a tough time with transitions, so they needed to be prepared. At 5:30 dinner was served (macaroni and cheese and hot dogs). At dinner we observed one of the girl’s birthday and then, once everyone was done, we watched a movie (Cars 2) until 8:00pm when all of the children were picked up.

This was my first encounter with a child who is nonverbal. I was surprised to learn that she made sounds as if she was speaking, but there were no words. At dinner my job was to go around and give each child either apple juice or water. When I got to her, I didn’t exactly know how to approach the situation. She not only couldn’t tell me which one she wanted, but she also couldn’t understand what I was saying. After a few minutes of trying to communicate with her, I put the two pitchers in front of her and pointed to both. She was then able to touch the one that she wanted. It felt really good to be able to think of a way to get through to her.

Overall, Saturday Night Friends was probably my favorite experience throughout the whole internship. I really enjoyed being able to observe how the children interacted, especially the interactions between those who were severely autistic and those who were pretty high functioning. It was nice to see those who were high functioning looking out for their peers. It was similar to Venture in the sense that there weren’t any fights (which is incredible for this age group) and it

wasn't cliquey at all. Everyone was very welcoming to anyone who wanted to join in his or her game. I have a lot of respect for the staff there because it is clearly a challenging job. They can't turn their back for a second. They were constantly making sure that no child was left alone because they tend to wonder off.

Many of the children were very autistic and were considered visual learners. In order to understand and process information, they would have to internally translate information into pictures. Thus, to make it easier for the children, some of them had books with Velcro strips. The staff would put pictures of what the child was supposed to do so that the child can see what is about to happen. For example, fifteen minutes prior to dinner, a staff member would put pictures on the Velcro strip in order to prepare the child for dinner. Temple Grandin writes about her visual thought process and claims, "when somebody speaks to me, his words are instantly translated into pictures" (Grandin, 3). Tools, such as the books with the Velcro strips, are great ways to help visual people process information.

Conclusion:

Although I was initially disappointed with my internship placement, I ended up having a great experience with the Arc. I'm really grateful that I was able to see the more bureaucratic/ administrative side of the Arc as well as getting to work hands on with the young adults at venture as well as the children at Saturday Night Friends. Not only did I learn a lot about various disabilities (especially autism) and the services provided for the disabled, but I also learned a lot about myself. Coming

into this course, I was considering a career in special education, which is why I was hoping to be placed in a school or a resource room. I'm still considering this career path, but I feel like I am now more aware of the wide range disabilities can take on. By describing a person as "autistic" doesn't really say much about the individual's needs. I am now much more aware of the autistic spectrum and how each case of autism is significantly different. This made me realize why individualized education plans and ISPs are incredibly important. By simply classifying a person as "autistic," doesn't say enough about the person's specific needs; it's important that every person is treated individually and simply lumped into an "autistic" category.

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** All names have been changed to protect the identity of those discussed.**