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# What was that again, Congenital Disorder of Glycosylation?

JANELLE ROBERTS



Janelle Roberts is a junior in the Dual License Program studying Elementary Education, English, and Special Education. The research was conducted in Fall 2011 as part of an Adrian Tinsley Semester Grant under the guidance of Dr. Edward Carter from the Special Education department and BSU's Children's Physical Development Clinic (CPDC) administrative staff. Janelle has presented at the 2012 BSU Undergraduate Research Symposium as well as the 2012 National Conference on Undergraduate Research in Ogden, Utah. She looks forward to her career as a teacher and impacting the lives of children.

**N**ew technology and research are continuously changing our understanding of the human body, and newly emerging diseases are continuously being discovered, such as Congenital Disorder of Glycosylation (CDG). This disease creates challenges for Special Education teachers and others who work with children affected by CDG. The purpose of this project was to increase Special Education teachers' understanding of the rare congenital disease CDG. Specifically, this project examined the augmentative communication strategies used with persons with CDG who are nonspeaking. There are approximately 1,000 diagnosed cases of CDG worldwide, and these figures are low estimates given that CDG presents like many other syndromes and disorders such as those along the autism spectrum. This project included a literature review of CDG research and a case study of a child with CDG. Using my hands-on experience with a 7-year-old boy with Congenital Disorder of Glycosylation, I tested with Talkables IV, a direct-selection communication device designed to assist individuals with speech or communication disabilities. The case study indicated that the 7-year-old, non-speaking child with CDG was able to use Talkables IV to communicate his essential needs. For example, the child could select what physical activity he wanted to do, given four different choices. Each choice on the Talkables device was programmed with a picture and voice output that says the activity chosen. Data collected during the research study showed that communication strategies used with children with other neurodevelopmental disorders, including autism, can also be effective for non-speaking children who have CDG. This research contributes to a better understanding and awareness of children diagnosed with CDG and assists Special Education teachers to develop strategies for communicating with such students.

Although a special educator needs to understand each child on a clinical level, it is important to understand each child on a personal one as well. The teacher needs to use the knowledge that they have gained over many years to apply to the situation and help the child to achieve what they are capable of. It's not just about academics, but helping the child accomplish goals that others never thought they could achieve. It is about the child knowing he did well and learning how to acknowledge that. But more important, it is about helping the child feel like any other student in his school. Although my personal experience was not based in a classroom, it achieved the same outcomes as one may see in a classroom; we set goals for a boy with special

needs, we worked hard to achieve them while having the support of his family, and we helped him feel like any other child his age.

### **Personal Tie**

I came to Bridgewater State University not knowing much about the Special Education field. I was hoping that the Introduction to Special Education class I was attending would provide new experiences and information. During the semester we were assigned a research paper to learn more about one disorder. The assignment required that I write about what I had learned and how, as a teacher, I might adapt it to classrooms. I did not know where to begin or what I would study for the paper. Simultaneously, I participated in an extracurricular activity called Children's Physical Developmental Clinic (CPDC) that allows undergraduate students at Bridgewater to interact with children with special needs from the surrounding community for eight Saturday morning sessions of the semester. As a clinician for one of the children at PDC, I set up three goals to complete by the end of the eighth Saturday. Two goals were focused on gym activities ranging from balancing on a balance beam to shooting baskets from the free throw line. The third goal was to swim in the prone position while controlling and coordinating arms and legs in the pool. All of these goals had to be within the child's capabilities while also pushing him a bit beyond his limits. This "hands-on" experience was just what I needed to develop the confidence to work with children with special needs.

Before the first session where we meet the assigned child, my co-clinician and I looked through the child's folder to understand what to expect before we actually met the child. We found ourselves saying, "CDG? What is that? Oh, Congenital Disorder of Glycosylation?" All the information in the folder was too detailed for me to even comprehend. We flipped to the back of the folder to his picture. He looked so cute and eager to interact and have fun. My co-clinician and I were excited to get started!

The first meeting wasn't as simple as I had imagined. His whole family showed up that morning. This was a great sign because we understood that the program was meaningful to the family, and the opportunity to watch the little boy grow was something the whole family enjoyed. We soon learned that he was nonspeaking except for very few words such as "Papa," which he uttered often because his grandfather was prominently positioned in the bleachers cheering him on with his parents and siblings. Being nonspeaking, this boy could present a challenge. We learned very quickly that without reliable communication, there was no way for us, or him, to convey when he wanted to finish an activity or what he wanted

to do next; so when he decided he was done, he would run to the next activity. If you could have seen my co-clinician and me that Saturday, you would have thought we were running a marathon. One minute we were across the gym, shooting hoops and the next we were downstairs in the hallway riding bikes. It soon became overwhelming and unpredictable. For the seven Saturdays remaining in the Clinic, we couldn't continue to run around the gym aimlessly chasing this boy from one activity to the next. There had to be something we could do.

### **Problem**

After that first Saturday's experience in the Clinic, one problem was solved and another one discovered. The problem solved was the idea for my paper for my Introduction to Special Education class! I was going to research the disorder CDG and in the process of my research, it would help me understand the child I would be working with over the next seven weeks. The problem discovered was much bigger and more complicated than I expected. I couldn't allow myself to have this child go eight weeks without communication between us. Communication is the key to any relationship and especially a relationship between clinician and child. If we didn't discover some method of communication, the three of us would be running around the gym nonstop, potentially unproductive and unsafe. This problem seemed bigger than I could solve on my own, but only a few days later, a solution emerged.

In the same Intro class in which I was writing the paper, we learned of an opportunity to apply for grant money to help with our research. We would receive a sum of money to buy books, materials, and anything we would need to enhance the development of our research papers. I decided this would be the perfect opportunity to discover how this child and I could communicate better. I would do my investigation and purchase an augmentative device to help break down the communication barriers. An augmentative communication alternative is a non-traditional method of communication for children with physical and other disabilities who cannot use speech or legible writing<sup>1</sup>. I found it intriguing how these two circumstances, CPDC and the Adrian Tinsley Grant money, could be bridged together to get a completely unique experience. I became aware that this is the type of situation that Special Education teachers frequently experience in the classroom. If communication is broken between two or more people, one must know how to solve the problem, and it is more than likely an augmentative device could help bridge the gap. I realized that I needed to learn more not only to help myself but also to be able to help the child we were working with. The literature search conducted for the paper helped me to help him. Many times the medical information was more in-depth than I needed to know, but I began to put the pieces together and came to my own understanding of what CDG really was.

I very quickly learned that this was a rare congenital disorder and that there are only 1,000 known patients with this disease worldwide, but that number only includes those who are correctly diagnosed. It is hard to find information about this disease in medical books, journals or even through doctors' anecdotes. In 1980, the first article about CDG was published in *Pediatric Research* by Jacken et al., and it described twin sisters with the disorder. Problem areas that were identified in the twin sisters were psychomotor retardation, cerebral and cerebella levels and fluctuating hormone levels. After 15 years of studying the twin sisters, doctors were still unsure of the nature and cause to their problems. What they did know was that their plasma protein transferring was underglycosylated, so the disorder became known as Carbohydrate-deficient glycoprotein syndrome, or CDGS<sup>2</sup>. Congenital Disorder of Glycosylation is one of several rare inborn errors of metabolism in which the Glycosylation in different tissue proteins or lipids are defective<sup>3</sup>. Glycosylation is a process by which sugars are chemically attached to proteins and together they form glycoprotein, which produces energy for the body within the blood<sup>4</sup>. In CDG, the sugars and the proteins are unable to perform this task. The type of CDG that a person has is determined by the characteristics of the two categories, which are Type I and Type II. Type I deals with just the beginning of the glucose process, whereas Type II deals with the process as a whole<sup>5</sup>. Each category has sub-categories that have different aspects and characteristics. Interestingly, because it is such a newly discovered disorder, not all the subcategories are determined. The child I was working with had a type of CDG that fit into Type I, but not a subtype, so his mom told us the doctors called his CDG, Type Ix.

The child we were working with had many of the typical symptoms of a child who has CDG. From what we learned at the Clinic and through his parents, he has weak leg muscles as well as weak arm strength. When he runs, he wobbles from side to side, demonstrating his lack of balance. He wears glasses because he has poor vision. Some days he wore them and other days he didn't, because they often fell off his face due to the lack of control while doing activities. He is cognitively impaired as well as nonspeaking. When we met him, he had just turned seven and he was learning how to spell his name out loud. He was always energetic, willing to try anything. He had a short attention span that made continuing activities for several minutes difficult. At times when he didn't feel like doing a task, he became very stubborn and would want to take toys away from other children and throw balls when not instructed to. Then a few moments later, he would be ready to go and perform the next activity. He had a charm about him that would light up the room and make everyone smile<sup>6</sup>.

After doing the literature search, I learned that the reason

CDG is so commonly misdiagnosed is because at birth, it presents like many other disorders such as cerebral palsy. Doctors have come to realize that they misdiagnosed children with CDG in the past. There is no treatment for most people with CDG. However, some patients with CDG-Ib are able to have mannose supplementation to relieve symptoms<sup>7</sup>.

Now that I had a knowledge base for CDG, I became more familiar with the child himself. I came to the conclusion that because it is a vastly misunderstood disorder and there is not much research on the disorder, I would need to understand more about augmentative devices and figure out which way would be best to communicate with the child. I knew I needed something simple and accessible so we could carry it around with us during the mornings while accomplishing our goals in the gym and in the pool.

### **Communication Techniques**

With limited research data on CDG, researchers have experimented with learning techniques used for other children who are nonspeaking or experience varieties of communication breakdowns. Those techniques, particularly ones used for children on the autism spectrum, can also help children with CDG learn to communicate more effectively. Communication has a huge impact on what the child comprehends and expresses and as a result, if the communication is clear, the personal outcomes can be achieved. Nothing is more frustrating to a child than not being able to communicate their wants or needs, as my co-clinician and I quickly experienced on that first Saturday. It was not only frustrating for him, but for us as well. As much as we didn't want to show how frustrated we were, he easily sensed our frustration, which made it more challenging for him to concentrate on one activity.

When children go to school, they are no longer communicating with just their families. They are interacting with their peers and teachers. Special Education teachers are aware of how to communicate with children with special needs, but effectively communicating with other children in the classrooms, when one has a myriad of developmental, physical, and cognitive needs can be tricky. What might have worked at home with the parents might be ineffective with teacher or peers. Since CDG is still not well understood and strategies are not fully developed, students with CDG are vulnerable and may not receive the help they really need<sup>8</sup>. Just as teachers in the classroom need to adjust their practices to each child, at the CPDC we needed to do the same. It may have required more work to help a child with CDG to achieve his goals, but in the end, the smile on his face and the trust he developed for us, made it all worth it. These have been the most rewarding experiences I have had in the educational field.

When children are very young and have not yet learned how to talk, they use expressive language to portray how they feel. This is exactly what nonspeaking or disabled children do. Many times one is able to tell that a child has a developmental disability due to the lack of developing language competence. Both conventional and idiosyncratic nonspeaking behaviors are demonstrated by some individuals with disabilities<sup>9</sup>. Communication breakdowns occur when one is not able to convey a message to someone. Communication breakdowns happen more often in children with developmental disabilities such as cerebral palsy and autism than with their typical peers<sup>10</sup>. These types of communication breakdowns are characteristic of a child with CDG. This is especially true in the case of the child described in this paper.

In a 2004 study done by Brady, Marquis, Fleming and McLean, it was found that “children’s communication rate and parents’ responsiveness to children’s changes in behavior predicted children’s overall level of performance in expressive language”<sup>11</sup>. This study emphasized that improvement was found in the child’s paralinguistic language and also in the responsiveness of the partner with whom the child was communicating. After a communication breakdown has occurred, the repair has to happen. A communication repair is a second attempt to communicate a message when a breakdown is encountered<sup>12</sup>. While repairing communication breakdowns, repetition was the most frequently used approach in all conditions<sup>13</sup>. Repairing communication breakdowns is an important strategy for any two people, especially between a student and a teacher<sup>14</sup>. My experience communicating with the child on that first Saturday was a lot of waiting for the child’s responses to our questions. The challenge was that he didn’t know how to respond to us in a way we could comprehend. Even the idiosyncratic sign language that he used with his parents, was not comprehensible to us. For example, on the first day while we were doing an activity, he suddenly placed his arm across his chest and stood there. We didn’t recognize what he was trying to communicate and we wasted valuable learning time trying to figure it out. We later learned from his family that crossing his arm meant “all done.” Later, we used this sign to tell us when he was finished with an activity. These experiences were the preludes to experimenting with augmentative communication strategies.

Augmentative communication is a non-traditional method of communication for children with physical and/or other disabilities, who cannot use intelligible speech or legible handwriting<sup>15</sup>. There are two types of augmentative communication systems--aided and unaided. Aided systems are devices a person uses that can be as simple as paper and pencil strategies, or as complex as a computerized device with

synthetic voice output. Unaided systems involve one’s individual body<sup>16</sup> such as using up/down eye gaze to communicate yes or no. There can be some problems with both systems. If an aided system is too complex or has too many pieces, it could become a distraction and not work as effectively as desired. Even though unaided systems are the most readily accessible, some children may not produce a signal effectively because of physical impairment, or the person receiving the sign may not understand it.

While some unaided signs helped us once we understood the code, there was still a need for aided technology. We purchased a communication device called Talkables IV<sup>17</sup>. This augmentative device is set up with four buttons and four slots above the buttons for pictures. For each button, an individual can voice record what the picture shows. The voice could be changed at any time and the picture could as well. To use this device at CPDC, I was able to make my own various activity cards. These cards included the following: basketball, swimming, a bicycle and trampoline. I would put four of the pictures into the slots of the device and each week record my voice naming each of the activities. When the subject pressed the button he would hear my voice name the activity and know that the picture matched the name. This became our way to communicate to each other which activity was next.



Figure 1. A co-clinician and the child working with the augmentative communication device, the Talkables IV.

In addition to using an augmentative device and unaided signs, we employed interactive modeling strategies. Interactive modeling is verbal guidance accompanied by the instructor literally leading the student by the hand so that the student sees him/her doing it. While a child is learning, it is important for the teacher to deliver physical, verbal and social responses such as, “Good Boy!” or “Good Job!” These responses are used as rewards for the student to be aware of appropriate behavior<sup>18</sup>. In many circumstances, my co-clinician and I used this technique.

His responses were overwhelming when we praised him or clapped when he completed a task. He would have an ear to ear smile and give us hugs. One could tell from his smile that he was also proud of himself. Teaching students to learn certain behaviors is more demanding when working with multiple students with special needs. We used all these techniques to help shape the positive results that we were hoping to accomplish.

## Impact

Armed with the augmentative device, my co-clinician and I saw major progress in our communication with the child. We had a means by which we could complete the goals we had set at the beginning of the eight week period. After our first meeting with the child, we came up with major concerns that we had for his physical demeanor. From these major concerns we established terminal goals we would work towards in the eight weeks. Once the three goals were set, the clinicians established three behavioral objectives to help reach the end goal.

It wasn't until the third week when we had the augmentative device to help us communicate with the child that we felt empowered to help shape the child's interactions, skill development, and goal achievement. Once we had the communication device, what a difference! We sat down at the beginning of the clinic and explained to the child what the device was and we showed him how to use it. When we covered everything, we got to work. We asked the question, "Which activity would you like to do first?" After the question we placed the device in front of the child. At first he pressed all the buttons and pulled out all the pictures. We explained again what the device was and we helped him put the pictures back into the appropriate slots. We then repeatedly showed him how to use the device, pressing only one button at a time. The next time he tried it, he pressed one button, heard the voice recording and it immediately reinforced his choice. We took his hands and started to walk towards the activity he had chosen and talked to him about how excited we were to participate in the activity he had chosen. We did this a few times and he began to understand the process of communicating his choices using the augmentative device.

The next Saturday however, when he first walked in, we went through the same process again. He wanted to press all the buttons and take out all the pictures. We understood that there was a week in between each clinic and he may not remember after the first one. We explained it to him again and by the end of the day, he knew what was expected and was making progress. He knew that if he wanted to move on to the next activity, he would have to go to the device and choose which activity he wanted next. Every Saturday we would re-introduce the device.

Not only was he making progress using a new communication tool, but he was also making amazing progress with his goals. By the end of the eight weeks, he was swimming by moving his arms and legs. Although his movements were not in rhythm or at the same time, he would try to move them when encouraged to do so. From where he started, this was a huge leap. At first, he wouldn't even move his legs because he knew we were

**Table 1. Child's Major Concerns, Terminal Goals and Behavioral Objectives**

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### Major Concerns:

- A-1: Lacks movement in arms and legs while swimming
- B-1: Lacks ability to bounce a ball with strength and accuracy to a clinician in front of him
- C-1: Lacks control and leg strength

### Terminal Goals:

- A-2: Move arms and legs in bilateral motion in prone position while in the pool
- B-2: Bounce a basketball to a clinician standing in front of him
- C-2: Improve leg strength by peddling on a bike the length of the hallway (20ft)

### Behavioral Objectives:

- A-3.1: Enhance ability to move legs in bilateral motion for half the width of the pool
  - A-3.2: Enhance ability to move arms in bilateral motion for half the width of the pool
  - A-3.3: Enhance ability to move both, arms and legs, in bilateral motion for half the width of the pool
  - B-3.1: Enhance hand-eye coordination by bouncing a basketball to a clinician standing 3 feet in front of him
  - B-3.2: Enhance hand-eye coordination by bouncing a basketball to a clinician standing 5 feet in front of him
  - B-3.3: Enhance hand-eye coordination by bouncing a basketball to a clinician 7 feet in front of him
  - C-3.1: Ride a bike moving legs continuously for the length of the hallway with maximum assistance
  - C-3.2: Ride a bike moving legs continuously for the length of the hallway with minimum assistance
  - C-3.3: Ride a bike moving legs continuously for the length of the hallway with no assistance
- 

supporting him in the water, and he would just splash his arms to move forward. Eventually, he was able to swim the width of the pool with our assistance. He saw how proud we were of him as was his family, and we believe this helped motivate him to continue to practice and trust that we were there for him. One instance that is prominent in my mind occurred after he swam across the pool. We were congratulating him and he pulled me towards him, pretended to whisper something in my ear, and

then splashed me in the face! He thought it was the greatest thing and could not stop smiling.

With his second goal, he was able to accomplish bouncing a ball to a clinician 3 feet in front of him successfully and is continuing to work on longer distances. He preferred bouncing a basketball to other balls. Once in a while after bouncing, he would shoot hoops and he enjoyed doing that. He was able to work on his hand-eye coordination while having fun.

After the first clinic, his parents soon told us that he loved anything with wheels<sup>19</sup>. Getting him to ride a bike was never a challenge. He would go down the stairs to the bikes very excited. He knew he needed a helmet and even learned to buckle it himself. In the first weeks, he would choose a bike that was too small for him because he was comfortable with it. As the weeks went on, he began to feel comfortable with a bike that was just the right size. Once on a bike that was the correct size for him, he was able to learn the motion the legs make when riding a tricycle. During this time, he learned balance that is needed when riding a bike for his size rather than a bike that was too small for him. He was used to the smaller bike, where all the wheels were on the floor so this was progress as well for him. He would always have trouble starting the peddling on the bike, because of his lack of leg strength. So we would help him get started and then encourage him to continue. By the second to last clinic, he was able to start peddling by himself and continuously peddle after that. Although it was only for a few feet, we could tell that he knew it was a true accomplishment and we did too.

## Conclusion

I think back to all that was accomplished and I still can't believe it. He made so much progress and he recognized when he did something exceptional. He would look back at us, smile and wait for our reaction. Then I think about what might not have happened if I hadn't figured out how to solve our communication dilemma. The three of us would have continued to run from activity to activity. We would have wasted valuable time trying to figure out what he wanted. Instead we solved the problem and used that time to work towards his goals.

What made this whole experience even more remarkable was being able to help him feel just like any other child doing activities in the gym or pool. He accomplished what seemed like the smallest goals. But these were major accomplishments for him. After the communication device was introduced, he trusted us and we understood what he wanted. The barrier that was blocking him from being successful was broken.

Special Education teachers accomplish small goals that are major accomplishments every day when working with challenged students with unknown potential to learn. They take a circumstance that they may have never encountered before and use their problem solving skills, their creativity, and their determination to create solutions. Just as we used the augmentative device to help the child we were working with, Special Education teachers bridge the communication gaps with their students as well. These augmentative devices help the child express feelings like any other child and help them to adjust to new environments, new people, and new expectations more readily. Many children have unique disabilities and no case is exactly the same but they can be helped to reach goals greater than first thought possible. That is just what we did at CPDC.

My unique experience with a student with CDG taught me that it doesn't matter what the "disability" is. An individual uses everything that they know and all their resources to help make each experience better. The condition of CDG helped me understand this. There are many other children out there with similar situations. The communication device took a problem that seemed to have no solution and turned it into a successful outcome for the child and for ourselves. The three of us were placed into a circumstance that involved a rare disorder that we seemed to have no control over. The augmentative device made communication an option when we never thought we would have one. Even though CDG is not widely known, it presents situations just as other disorders may and the same key idea stands in all situations: communication. Using an augmentative device is what helped me communicate effectively with the subject. As with all relationships, communication is key.

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## References

1. Kirk, S., Gallagher, J.J., Coleman, M.R., Anastasiow, N. (2012). *Educating Exceptional Children* (13<sup>th</sup> ed). Canada; Wadsworth. Print.
2. Membrane Transport Protein Disorders. *Congenital Disorder of Glycosylation*. (2011). Wiki Series, Memphis. [http://en.wikipedia.org/wiki/Congenital\\_disorder\\_of\\_glycosylation](http://en.wikipedia.org/wiki/Congenital_disorder_of_glycosylation)
3. Kirk, S., Gallagher, J.J., Coleman, M.R., Anastasiow, N. (2012). *Educating Exceptional Children* (13<sup>th</sup> ed). Canada; Wadsworth. Print.
4. Merriam-Webster Dictionary. (2011). *An Encyclopedia Britannica Company*: <http://www.merriam-webster.com/dictionary/glycosylation>.
5. Membrane Transport Protein Disorders. *Congenital Disorder of Glycosylation*. (2011). Wiki Series, Memphis. [http://en.wikipedia.org/wiki/Congenital\\_disorder\\_of\\_glycosylation](http://en.wikipedia.org/wiki/Congenital_disorder_of_glycosylation)

6. Roberts, 2011. Anecdotal Record Forms CPDC. Unpublished manuscript, Department of Special Education, Bridgewater State University, Bridgewater MA.
7. Membrane Transport Protein Disorders. *Congenital Disorder of Glycosylation*. (2011). Wiki Series, Memphis. [http://en.wikipedia.org/wiki/Congenital\\_disorder\\_of\\_glycosylation](http://en.wikipedia.org/wiki/Congenital_disorder_of_glycosylation)
8. Spencer, T.D. (2008). Picture Exchange Communication System (PECS) or Sign Language, *Teaching Exceptional Children*, 4, 40-47.
9. Meadan, H., Halle, J., Ostrosky, M.M. & DeStefano, L. (2008). Communicative Behavior in the Natural Environment, *Focus on Autism & Other Developmental Disabilities*, 23, 37-48. doi: 10.1177/1088357607311444
10. Snell, M.E., Chen, L.Y., Allaire, J.H. & Park E.(2008). Communication Breakdown at Home and at School in Young Children with Cerebral Palsy and Severe Disabilities. *Research and Practice for Persons with Severe Disabilities*, 33, 25-36.
11. Snell, M.E., Chen, L.Y., Allaire, J.H. & Park E.(2008). Communication Breakdown at Home and at School in Young Children with Cerebral Palsy and Severe Disabilities. *Research and Practice for Persons with Severe Disabilities*, 33, 25-36.
12. Meadan, H., Halle, J., Ostrosky, M.M. & DeStefano, L. (2008). Communicative Behavior in the Natural Environment, *Focus on Autism & Other Developmental Disabilities*, 23, 37-48. doi: 10.1177/1088357607311444
13. Snell, M.E., Chen, L.Y., Allaire, J.H. & Park E.(2008). Communication Breakdown at Home and at School in Young Children with Cerebral Palsy and Severe Disabilities. *Research and Practice for Persons with Severe Disabilities*, 33, 25-36.
14. Meadan, H., Halle, J., Ostrosky, M.M. & DeStefano, L. (2008). Communicative Behavior in the Natural Environment, *Focus on Autism & Other Developmental Disabilities*, 23, 37-48. doi: 10.1177/1088357607311444
15. Kirk, S., Gallagher, J.J., Coleman, M.R., Anastasiow, N. (2012). *Educating Exceptional Children* (13<sup>th</sup> ed). Canada; Wadsworth. Print.
16. Spencer, T.D. (2008). Picture Exchange Communication System (PECS) or Sign Language, *Teaching Exceptional Children*, 4, 40-47.
17. Adrian Tinsely Semester Grant. Undergraduate Research Office. Bridgewater State University, Bridgewater, MA. Fall 2011.
18. Biederman, G.B. & Freedman, B.(2007). Modeling Skills, Signs and Lettering For Children with Down Syndrome, Autism and other Severe Developmental Delays by Video Instruction Classroom Setting, *Journal of Early & Intensive Behavior Intervention*, 4, 736-743.
19. Parents. Personal Communication. Children's Physical Developmental Clinic, Bridgewater State University, Bridgewater, MA. Fall 2011.