Young Adult Books: Helping to Prepare Teachers for Augmentative Alternative Communication

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Many educators have reported limited education in their training or preparation programs on assistive technology and communication devices. The present study reported on action research conducted in this area using book study groups. Participants included graduate students enrolled in a face-to-face course required within their special education teacher preparation program. Qualitative data were collected via participants’ reading reflections and indicated that use of young adult literature facilitated constructing new knowledge regarding disabilities, assistive technology, and augmentative alternative communication devices and builds on their reflective practices. Furthermore, these future special educators may extend use of the book study with K-12 students.
The importance of assistive technology (AT) is recognized globally as evidenced within the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) which supported the provision of AT. Since the adoption, about half of the United Nation countries have passed legislation to address providing AT to individuals with disabilities (South-North Center for Dialogue and Development, 2006). In the U.S., AT requirements are included in legislation such as the Individuals with Disability Education Improvement Act, Americans with Disability Act, Assistive Technology Act, and the Rehabilitation Act. These acts define AT as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities” (20 U.S.C. §1401). One category of AT is augmentative alternative communication (AAC). AAC includes “forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas” (ASHA, 1997-2015), including aided assistive technology such as picture symbols, communication boards, and speech generating devices. Estimates of the number of students with disabilities receiving services in U.S. schools who could benefit from AT vary by type of disability category and range from 10% to 100% (Golden, 1999). Moreover, students identified as using AT had an average of seven devices listed on their Individual Education Plans (IEPs) and for many of these students one of the devices was AAC (44.7%) (Stegall, 2007). In other words, approximately 3% of all students with a disability utilize AAC (Blackorby, Wagner, Marder, & Guzman, 2004; Worah, 2011). Although the consideration of AT for all students with disabilities is mandated in the U.S. and research indicated that many students utilized AT and AAC, training on these devices is limited across preparation programs.

In investigating general education teacher preparation programs, researchers found a significant lack of preparation and experience in technology instruction designed for students with a disability, including use of assistive technology (Cavanaugh, 2002; Jost & Mosley, 2011). Likewise, research indicated limited formal instructional training in special education teacher preparation programs on AT. For example, results of a national survey of special education teacher preparation programs indicated that some programs required course work in AT (34.6%) and of those most required only one course (86%). Undergraduate and graduate programs concentrating in severe to moderate disabilities were more likely to require AT courses than programs focusing on mild to moderate disabilities, general special education, or secondary special education. Overall, undergraduate degree programs were more likely to require an AT course than graduate programs (Judge & Simms, 2009). Additionally, researchers found that although programs provided some instruction in AT, many students had limited or no access to actual AT
devices (49%-58%) and few programs required students to demonstrate AT competencies (Bausch & Ault, 2012). Moreover, although university graduate special education program coordinators reported it was important for preservice teachers to be competent in AT (rating them critical to extremely critical), they rated student attainment of these competences as fair (Michaels & McDermott, 2003). Furthermore, many speech-language pathologists (SLPs) reported inadequate preparation in either their undergraduate or graduate program on AT and AAC (74%-78%) (ATIA, 2012). Once educators were working in K-12 schools, AT training and knowledge was still found to be incomplete. For example, general education teachers reported limited knowledge of AT and identified it as an area of need for additional in-service training (Buell, Hallam, & Gamel-McCormick, 1999). Additional survey results revealed that special educators reported limited or no knowledge of assistive technology applications (Puckett, 2004), and many rarely or never had hands-on experience with AT devices (Lesar, 1998). More specifically, just half of special education teachers currently working with students with severe or multiple disabilities (51.3%) reported that their teacher training program and/or experience gave them the necessary skills to improve the communication skills of students using AAC (Soto, 1997). Additionally, many SLPs reported that they did not feel they were knowledgeable in delivering AAC services to students (ATIA, 2012). The limited educator preparation training in assistive technology is problematic for those students with disabilities using AT, and more specifically those using AAC to give themselves a voice.

While in their preparation programs, educators could learn about and become accepting of AT and AAC through reading and discussing fiction and non-fiction books, including children’s literature or young adult books, which deal with the life experiences of individuals using AAC. Literature can be used to facilitate preservice teacher examination of their beliefs, values, and understandings about diversity and disability (Dana & Lynch-Brown, 1993; Tatelbaum, 1984). In addition, it has been shown to develop preservice teachers’ knowledge of diversity and disabilities. Exposure to the use of literature about disabilities has been shown to be an effective means for developing empathy and acceptance (Kurtts & Gavigan, 2008). What is more, the use of literature and identifying with one or more characters or events in that literature can be used to teach the complex issues a student with disability, their teachers, and/or family face (Iaquinta & Hipsky, 2006). Although no studies were found that specifically addressed the use of children’s literature or young adult literature including characters using AAC with preservice teachers, it is possible that similar results regarding the development of preservice teacher’s knowledge, empathy, and understanding of the specific challenges teachers, families, and children who use AAC would be seen
as well. In turn, teachers can then incorporate these children’s or young adult books into their own classrooms to teach and prepare their K-12 typical students about disability and diversity (Dana & Lynch-Brown, 1993) and facilitate their school age students with communication disorders’ growth (Tatelbaum, 1984).

In selecting children’s and young adult literature including characters with disabilities, Landrum (2001) offers the following suggestions or criteria: the novel should contain a realistic plot involving the character with a disability, the focus of the character must be on their abilities not just their disability, the portrayal of the characteristics of the disability ought to be accurate, and person-first terminology should be used. Blaska (2004) used similar criteria with a few additional suggestions for evaluating literature involving characters with disabilities: the storyline should promote empathy and depict acceptance and the illustrations have to be realistic. Keeping these factors in mind, literature which includes a character utilizing AAC could be selected and used in a teacher preparation course to expand preservice teachers’ knowledge, empathy, and understanding of AT and AAC.

**Methods**

To this end, action research was conducted by an instructor at a small northeast university. The action researchers’ role was to select the young adult book, develop reflection assignments and rubrics, facilitate discussions, and analyze data. Participants included 10 graduate students seeking certification in general special education. Participants were enrolled in a required 8 week on-ground course, Communication and Special Education. As part of the course requirements, participants engaged in textbook reading, classroom lecture, and small group activities with AAC devices. In addition, the course required a book study group assignment using the young adult fiction book “Out of My Mind” by Sharon Draper (2010). This book was chosen by the instructor because the main character utilized AAC and was depicted as capable, resourceful, and an active participant in the story plot. She interacted with others and showed character growth. By describing actions or events in school, home, and community settings, the storyline had the potential to open up discussion on current practices involving students with disabilities in multiple environments. In preparation of class sessions covering AAC topics, participants were to individually read the book and complete three journal entries: a double entry journal (which includes both information directly from the text and the reader’s reaction), a reflection journal, and a response to participant selected discussion questions posed by the book’s author. Then in class, participants discussed in small groups their reaction to the readings. Qualitative data from reflections and discussions were analyzed and topic themes emerged. These themes centered on depictions or understandings of the disability, need for communication, the
communication device, the ability to relate to family dynamics, teachers and education, the desire for friends, and the possible impact on their teaching practice.

Results

The book study led to understanding of cerebral palsy (CP) through the main character Melody, a 13 year old girl with CP. She was non-verbal, used a wheelchair, and required assistance with mobility and personal care. One student reported that the book provided numerous examples of the physical impact of CP such as what happened if she wasn’t strapped in properly, when she got so excited about winning that she was unable to control the kicking and squealing, and saving her dinner so she didn’t have to let other kids see her being fed by her mother.

Further understanding of the disability was demonstrated through many students’ double entry journals which included referencing Melody’s explanation of realizing she had a disability. “I guess I figured out I was different a little at a time. Since I never had any trouble thinking or remembering, it actually sort of surprised me that I couldn’t do stuff. And it made me angry” (Draper, 2010, p.9). As with many children with CP, the character in this book had average cognitive abilities. Additionally, one participant expressed compassion when reading about the reactions of the character’s classmates to her disability, for example, “how she [Melody] felt about her classmates who assumed that her mind was as dysfunctional as her body was heartbreaking to read.” Not only were the characteristics realistically portrayed, but they were not the only defining traits to Melody. Journal entries reflected this, such that students remarked on the character’s strength and determination. For example, when describing why Melody entered the quiz team, one student stated “she wanted to show people that a disability does not define you and it does not mean that you cannot learn or succeed.” Another student wrote “I think some people see a person with a disability and only see the disability. They don’t realize that there is a real human being sitting right in front of them.”

One of the main themes in the story and discussions was the importance of communication and how it impacts all areas of life. For example, the main character was asked whether she would rather be able to walk or talk and she responded “talk, talk, talk”. Several participants reported that the author stated it best for Melody in that “Everybody uses words to express themselves. Except me. And I bet most people don’t realize the power of words. But I do” (Draper, 2010, p. 7). The author also used an analogy of a fish in a fishbowl to a child’s lack of communication and this analogy resonated with the students. For example, one student wrote that
I really liked the comparison of Ollie [fish] and Melody. Both are trapped and unable to express themselves. Melody is trapped in her body and unable to speak and Ollie is stuck in the bowl. I think this scene also showed how communication is such a struggle for Melody and her family. There seems to be a lot of misunderstandings due to the lack of communication or communication devices.

People are often unsure how to communicate with individuals who are non-verbal. The author illustrates this through an inner dialogue of the main character “Sometimes people never even ask my name, like it’s not important or something. It is. My name is Melody” (Draper, 2010, p. 4). This quote resonated with one of the participants who shared that she had witnessed “many times where people will almost ignore individuals with a disability. I don’t think it is to be rude or ignorant but I think it is because people might feel uncomfortable or assume that they will not understand”. Not only does communication impact the family life, but it also impacts the educational experience. As one participant wrote “she is unable to raise her hand or get the teacher’s attention. Knowing the answers or wanting to participate in class but not having the means to communicate is very difficult and frustrating for her”. Another participant commented that “she is probably the smartest 5th grader in her class, but her teachers aren’t asking questions in ways that Melody is able to demonstrate what she knows.” Thus the participants were able to empathize with and relate to the character’s experiences and their own daily life. For example, one participant wrote

This chapter really got me thinking about how often we do take the ability to talk and communicate for granted. Our society thrives on sending texts, or emails without thinking about how lucky we are to have the ability to communicate with words to our peers. It also made me think about how important it is to actively work on getting students the ability to communicate and giving them that voice they are missing.

Through the persistence of many individuals, the main character acquired AAC, specifically a speech generating device. One student summarized the importance of the device as follows,

the Medi-talker is a life altering piece of equipment for Melody. Having all of these thoughts and feelings stuck inside her with no real way to tell people what is going on with her has to be almost too much to bear. Then to be able to tell your parents for the first time in your 13 years of life that you love them would have to be such a release. She is now able to show the world that she is
smart and that she has thoughts and feelings just like everybody else. It is a small release from the prison of silence that she has endured for her entire life.

The importance of AAC was further noted with reflections such as “the device not only gives her speech, it gives her the power to make choices”, the “use of communication devices is not static but changes as the needs change”, and “I don’t believe the device changed her potential, I just believe that it allowed teachers to see what she truly knew.”

Likewise, participants were also able to gain knowledge on the importance of proper programming of devices. For example, one student wrote that

Melody wanted McDonald’s but she could not communicate that to her father. She could communicate that she was hungry and wanted to eat, but could not communicate exactly what she wanted. When giving someone a device to communicate, it is important that things are included on the communication board that are of interest and importance to the individual.

Further, students were able to identify challenges for providing instruction to students using AAC. “It can’t help overcome all barriers. Discussions are still difficult due to the time it may take to type things out or select words.”

Several family dynamics were explored through the book study including parents’ feelings when their child was treated differently, the struggles of the family to choose a communication method and obtain a device for their child, and the various aspects of daily life that are a challenge for parents with a child with significant health or physical needs. One quote from Melody’s character prompted much discussion on how parents might blame themselves for the disability. “I wanted to tell Mom that I was sorry she was so sad and so scared. That it wasn’t her fault. That I was just the way I was and she had nothing to do with it” (Draper, 2010, p. 73).

Several story events took place at school which illuminated various aspects of educating students with disabilities. One of the special education teachers failed to review the characters’ previous school records, assess their abilities, or collect data during instruction and thus spent the entire year working on a few letters of the alphabet. One participant wrote

This entire chapter got to me. I just couldn’t believe that this teacher didn’t even take the time to find out what level her students were on or their interests. It also drove me insane how nothing about how she ran her classroom was age appropriate even in the slightest. If I was Melody, I would have a meltdown too in that situation. I, again, was so happy that her mother stood up for her daughter instead of blindly following the ‘expert’s’ advice like so many do.
Fortunately, there were examples of a good special education teacher and paraprofessional as well. As one student reflected, “the book also shed light on insightful teachers who understood that the students needed to be pushed and that they could and should have access to the general education curriculum”. The main character, Melody, also participated in inclusion classes and several teachers were introduced to illustrate the contrasting ways teachers respond to having a student with significant needs in the general education classroom. One reflection indicated that the way that a few of the teachers talked to Melody is a major reason, in my opinion, why most of the students treated her the way they did in the book. If the teacher is telling the rest of the class to be welcoming to their visitors or that Melody getting the only perfect score must be a fluke, of course the rest of the students would follow suit with that mindset.

Another student shared that “teachers set the tone for the classroom. She will not accept name calling or making fun of other students and her actions back that up.” As with most children, the main character had a strong desire for friends. Several of the students specifically discussed the social benefits of inclusion and that how a teacher treats the child using AAC will also have an impact on their peer relationships. For example, one student wrote that “Melody begins to realize what students outside of H-5 [the self-contained classroom] have the opportunity to do and begins to yearn for those chances and to be able to hang out with people outside of school.” The college students were surprised that students with disabilities would be in class with the same students with disabilities for several consecutive years as this is quite different from their own K-12 experiences.

The inclusion program changes Melody’s school experiences in many ways. Unlike other children, Melody has been in the same classroom every year with exactly the same classmates. They tend to do the same things over and over, year after year, from learning the alphabet to assembling the holiday snowman decorations. For Melody going to different classes with a variety of kids is novel, interesting, and a little nerve-wracking.

One participant summarized the character’s educational experiences as follows, “Overall the inclusion program helps Melody to break free, not only is she trapped within herself because she can’t communicate, she was in essence trapped in room H-5 also and it was keeping her from reaching her full potential.”

Lastly, the book study activities provided the participants with an opportunity to reflect on their own attitudes and consider what they could do when they are teaching students with communication difficulties. As one participant pondered,
reading the text ‘I have never spoken one single word. I am almost eleven years old (pg.2)’, kind of stopped me in my tracks. I can honestly say that I don’t think I have ever thought this way about students who are non-verbal. I have never considered how much they may actually have to say, but we aren’t giving them the proper means of communicating those thoughts. I wonder how many teachers provide their students who are non-verbal with as many forms of potential communication as possible?

Finally, participants connected what they had learned from the research and topics discussed in class, to story events, and to their future teaching. This was indicated in the following reflections, “Research shows that students need to be included with peers that do not have a disability to benefit from every student socially. It definitely made me look at my future practices and ways to include each and every student in the classroom.”  “We need to ask ourselves the following questions: How can we truly include students who are non-verbal in our classrooms; have we listened hard enough to what they are trying to tell us?”
Discussion

Results of this small action research study indicated that book study activities involving young adult fictional literature could be used in a teacher preparation course to expand preservice teachers’ knowledge of AAC and understanding of AT. Although the findings of this study were limited to use of one young adult book at one university, the results were similar to those of other researchers regarding development of teachers’ knowledge and empathy though children’s literature including disabilities in general (Dana & Lynch-Brown, 1993; Iaquinta & Hipsky, 2006; Kurtts & Gavigan, 2008; Tatelbaum, 1984). Hopefully, in turn, these future teachers will use children’s and young adults’ literature in their K-12 classrooms to assist typical children in acquiring knowledge about students with disabilities (Inquinta & Hipsky, 2006; Dana & Lynch-Brown), specifically those utilizing AAC. Several participants indicated their intention to do just that. In addition, they could use this same reading with students using AAC to order to improve their self-efficacy, perceptions of self-worth or self-image, and interpersonal relationships (Tatelbaum, 1984).

Other teacher preparation programs from around the globe could incorporate children’s literature or young adult books including characters using AAC who also represent the people, culture, and language of their country. The present action research utilized the book ‘Out of My Mind’, though other books may be chosen. Landrum’s (2001) and Blaska’s (2004) criteria for book selection should be followed. This is not as easy as it sounds! Altieri (2008) reviewed children’s fictional books including characters with disabilities and found that only a few of the characters received assistance from technology (2008). Furthermore, Prater (2003) found that just 20% of the books reviewed realistically depicted students with a disability. This author reviewed over 30 books for the study and found only 5 that would be appropriate (see Table 1). The book chosen was easy to read, could be completed within a short time frame, and topics supported course textbook reading assignments. Participants indicated that they liked the reflection and discussion activities and have recommended the book to other teachers.

In summary, as part of required coursework within a graduate special education class, students were required to participate in several activities as part of a book study of a young adult’s book involving a student with a disability who used AAC. Through the discussions and reflections, participants indicated increased knowledge of students with disabilities using AAC and development of empathy for these students, their teachers, and families. As a result, the young adult book study will be a required component in future offerings of the course. Further, this
activity may be one of many strategies used to improve the AAC preparation of general educators, special educators, and/or speech-language pathologists around the globe.

Appendix:

Selected Children’s Literature and Young Adult Fiction Books with Characters who Utilize AAC

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<tr>
<th>Author</th>
<th>Title (Year)</th>
<th>Summary</th>
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<tr>
<td>Sharon M. Draper</td>
<td>Out of my Mind (2010)</td>
<td>This book is written from the viewpoint of Melody, a 5th grade girl with CP. Melody is very smart, but unable to show it as she is non-verbal until she is introduced to a voice output device. Through some heart-warming events, the reader sees Melody’s struggle with physical difficulties and typical teen challenges. In the end, Melody realizes that she is no different than any other middle school student; she faces challenges, wants to fit in, and just wants a friend.</td>
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<tr>
<td>Elizabeth Helfman</td>
<td>On Being Sarah (1992)</td>
<td>Sarah is 12 years old, has CP, and is nonverbal. She uses Bliss Symbols on a board on her wheelchair to communicate. After attending a special school for elementary school, she is to begin middle school in a public school. The events in this book center on her relationships with her family and classmates.</td>
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<td>Cynthia Lord</td>
<td>Rules (2006)</td>
<td>This book is told from Catherine’s viewpoint, a 12 year old girl whose brother David has autism. Catherine meets Jason, a young boy who uses a wheelchair for mobility and picture symbols for communication. In order to help Jason voice his thoughts, she creates new, colorful picture symbols – awesome, whatever, stinks a big one. Through some typical adolescent experiences, Catherine realizes that being different is ‘normal’.</td>
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<tr>
<td>Linda Mitchell Maddox</td>
<td>Resonating the Sound (2011)</td>
<td>As the author stated, “This is a story about obstacles and ways the middle school age characters in the book choose to deal with them in their lives”(p. 6). Two years following a traumatic brain injury, Jana is unable to speak and chooses to try AAC. Eli, a fellow student who has Gifted Aspergers, helps to personalize the device.</td>
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<td>Patricia Mervine</td>
<td>How Katie got a Voice (and a cool new nickname) (2012)</td>
<td>This story was told from the perspective of one of the students in a 4th grade class in an unusual school (all the students and teachers had nick-names). Katie, who uses picture symbols and eye gaze to communicate, begins school there. Her peers have a difficult time communicating with her until she gets a communication device.</td>
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<tr>
<td>Liane Shaw</td>
<td></td>
<td>There are two main characters in this story: Alexandra or Alex (who chooses not to</td>
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The Color of Silence (2013) talk following the death of her friend) and Joanie (who has a degenerative muscular disease and cannot speak). As part of Alex’s community service she was to visit Joanie in the hospital. There an SLP tries Eye Gaze communication with Joanie. The author provides a good description of the device and some of the struggles in getting it programmed. With the device, Alex realizes that Joanie is funny and knows how to read and spell.
References


