

Reading, Writing, and Friendship: Adult Implications of Effective Literacy Instruction for Students with Intellectual Disability

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Reading and literacy are important not only for instrumental reasons such as knowing exit signs and recognizing initial consonants but also have tremendous human functioning implications in areas such as initiating and sustaining friendships, communicating care and affection, and enhancing work, leisure, and play. Many people with intellectual disability are denied opportunities to learn literacy, which in turn denies richness in life opportunities. This article describes one friendship in which reading and literacy play an important part. We describe some of our experiences learning to read and engaging in lifelong literacy and how literacy affects our friendship and our ability to express affection for others and brings us enjoyment.

DESCRIPTORS: friendship, intellectual disability, Down syndrome, literacy, reading, lifelong learning, loneliness

Our History

We (Ann and Ruth), strangers at the time, were both participating in a meeting about 19 years ago. The meeting went on too long, and everyone was tired and getting antsy. Ann was sitting next to Ruth, but we did not yet know each other beyond the initial introductions at the beginning of the meeting. Our shared interest in policy and intellectual disability created the opportunity. Toward the end of the meeting, Ann passed Ruth a note asking whether we might go out for a drink after the meeting. That act of literacy was the beginning of a friendship.

A friendship is fascinating to the friends. And when the friendship is a long one, the friends often retell the “story” of the beginning of the friendship. Our friendship began with a written note. We like to think that we would

have become friends even without Ann’s note, but the fact is that the serendipitous beginning of our friendship depended in significant part on both of us being able to read and write. Not experiencing this friendship would have been a life loss for each of us. We do not, in this article, attempt to scientifically define or measure our perceptions of our friendship (see Watt, Johnson, & Virji-Babul, 2010), but rather we choose a more poetic framework. “A friend is one to whom one may pour out all the contents of one’s heart, chaff and grain together, knowing that the gentlest of hands will take and sift it, keep what is worth keeping and with a breath of kindness blow the rest away.” (Arab Proverb)

Background of This Article

Several months ago we were asked by the guest editors of this issue to co-write an article exploring the meaning and role of literacy in our lives and, in particular, in our longstanding friendship. We spent time discussing by phone and through e-mail how we might convey to readers the story of how we came to be literate adults and the impact of literacy in each of our lives. We worked separately and together, asking questions, reviewing past work, sending multiple drafts back and forth to each other, commenting on, and editing each other’s work. The result of this collaboration is this article, included as a part of this special issue on literacy. In the article, we describe our experiences learning to read and write, the importance of reading and writing in our lives, and some of the adult implications of effective childhood and lifelong literacy instruction for all. Although not an empirical examination of literacy, this article’s purpose is to consider the role of literacy in all of our lives, including the lives of individuals with disability.

Our Family and Educational Literacy Experiences

Long before she formally learned to read, Ann engaged in and developed her oral language and communication skills. As with all members of her family, she had many

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opportunities to develop and use literacy skills—talking; singing; arguing; having access to newspapers, magazines, newsletters, and mail; and participating in the religious liturgy. Together with her parents and two brothers and a sister, she lived in a literacy-rich environment.

Ann's parents, Bernie and Shirley Forts, were determined from the beginning that their youngest child would not be segregated from the family and that she would participate in all of the activities that were important in their family. Ann needed extra help and time to learn, so, for example, she received about 6 years of speech therapy to improve her communication.

Ann's family described their intention: "Ann has always been encouraged to be friendly, courteous, independent, out-going, and to always try new experiences so that inclusion in school, church and community generally would be a satisfying and realistic goal. Today Annie Forts is our Lakes Region 'Goodwill Ambassador' and a charming, attractive, outgoing, young woman, nationally recognized motivational speaker who travels widely throughout the country, speaking at meetings & conferences." (Annie Forts UP Syndrome)

Remembering Learning Literacy at Home

For both of us, the path toward literacy began at home with strong models of "literate citizenship" (Kliewer & Biklen, 2001) and opportunities to explore literacy in multiple ways. In this section, we describe some of our earliest experiences with reading.

Ann's Memories

My earliest memories of reading were when I was 2–3 years old. I really did not know anything about reading except that I really enjoyed watching and listening to my family, especially my mother and sister, as they read many stories from lots of children's books. I enjoyed the colorful pictures because they helped me to understand and enjoy the stories. They also helped me to understand some of the words on the pages that did not make any sense to me. I could not read any of the words, and I certainly did not understand them except when I was told about different words, like house, dog, or car, that were pictured in the story being read to me. Without my knowing or realizing it, I guess that really was the start of when I began to learn to read (see Koppenhaver, Coleman, Kalman, & Yoder, 1991). I enjoyed listening to my mother and sister read stories to me. After a time, I began to wonder if I would ever understand or be able to read those strange-looking words just like they were doing.

Ruth's Memories

My earliest memories of reading were when I was about 6 years old, sitting in a circle in my one-room rural schoolhouse. Each of us was supposed to take turns reading, but as I didn't yet know how to read I had to memorize what someone else read that was connected to a particular picture in the book and then repeat my memorized "reading." Like Ann, I worried whether I

would ever be able to truly read those strange-looking words, but because I loved the pictures and the entire shared circle of learning from others, it was a pleasure for me even though I knew I wasn't doing it right. At a party in my hometown recently, I guiltily confessed this strategy to my beloved first-grade teacher, Hazel Bjornstad. She reassured me that despite my lingering worries about memorizing, I did a good job learning to read (H. Bjornstad, personal communication, September 18, 2010).

Ann's Early Intervention Classes and Literacy Experiences

Ann's experiences in early intervention built on what her family had started (see, generally, Copeland & Keefe, 2007). She attended early childhood classes that included literacy. Ann shares her memory of these experiences:

When I was a little over 3 years old, I went to a New Jersey ARC pre-school nursery near my home. The teacher and the aides read picture storybooks to me just like my family did at home. The new storybooks kept me interested in hearing, seeing, and learning new words. Without realizing it, by the time I was ready to start school, I had learned to read parts of some of the stories because I was able to recognize some of the words.

Ann's Memories of Public School Education and Literacy Experiences

I started school when I was 5 years old and was sent to schools outside of the town I lived in (see Ryndak, Morrison, & Sommerstein, 1999). All the students in my classes were special and needed help. We were never included in any of the regular classes because that is the way they did things. But that did not bother me in the lower grades, because all my teachers were great and very helpful to me and because I was never shunted away from the activities of my family and neighbors. My teachers started to teach me how to read, and I enjoyed reading in a very simple way. When the teachers taught me new words, they also told me what the words meant and helped me to learn how to spell the words.

As an example, one of the words I was taught when I started school was the word "down." I guess that was because I had Down syndrome. I really did not like the word because it sounded too negative to me, and I have always been an "up" person. When I was 6 or 7 years old, I started to scratch out the word "down" whenever I saw it as part of Down syndrome and would write "UP" above the word "Down" that I crossed out. Ever since that time, I have always corrected or referred to Down syndrome as "UP" syndrome.

Early public school experiences for Ann included a significant amount of time and attention to literacy skills. Ann remembers it as hard work, on both her part and the part of her teachers. Progress may not have been fast, but

Ann's goal was to be able to write notes and letters to valued people in her life. She remembers:

I was taught a lot of reading and writing when I was in the lower grades in school. It took a lot of effort on my part and also by my teachers for me to learn enough words so that I could learn to write. I gradually began to understand how to put words together to form sentences that I needed in order to be able to write notes and letters to my family and friends.

When Ann was ready to start high school, the Forts family decided to move from New Jersey to their New Hampshire home to provide a more meaningful and challenging educational experience for her. In New Jersey, Ann had more than enough experience with a schooling system that was not whole-heartedly providing her with new opportunities and challenges necessary for her to learn how to become a contributing and respected member of her community. In New Hampshire, Ann began to participate with the entire school community, and she benefited from a variety of types of inclusive education and many extracurricular activities as well as targeted instruction. Ann's experiences in high school extended her literacy skills, including research skills or what we now refer to as informational literacy. Sometimes certain aspects of full literacy such as the skill of editing are eliminated from teaching on the grounds that it is not useful or realistic for a person with intellectual disability. Ann picked up the skill of editing at an early age and used it effectively to make her points about UP syndrome. Ann's facility with a wide variety of literacy skills enhances her ability to communicate what is important to her.

In remembering her secondary school years, Ann writes:

One of the most important things that my teachers in high school kept telling me was that I needed to learn how to use a dictionary. The dictionary was probably the most important book that I used in high school. Learning new words certainly made it easier for me to be able to write about things I wanted to tell other people about. Also, a dictionary was helpful to me as I learned how to correctly spell different words that I would use in my work at school and in my letters and cards that I sent to family and friends.

Ruth's memories of public school education and literacy experiences

Although the skills involved in reading eventually became easier for me in the first grade, I seem to have started somewhat later than Ann because my family was not as focused on literacy. It required time, attention, and learning opportunities to become proficient for the activities that are meaningful for me, such as work, friendship, and learning. To this day, I continue my own efforts to be more literate and to use reading and writing more effectively. For example, after graduating from

high school, I continued to work on my literacy and was able to obtain higher education and maintain a desired academic position in part because of my growing reading and literacy skills. Beyond the work benefits, there are community integration benefits that are significant to me. For example, for the last 20 years, I have participated in a book club, a literacy interaction that enhances my reading skills and provides social connectedness and friendship opportunities (see, e.g., Fish, Rabidoux, Ober, & Graff, 2006).

The Role of Literacy in Maintaining Relationships With Friends

Ann is clear about her primary motivation for reading and writing. She uses these skills to build and enhance her relationships, which are an important part of her life and well-being. Ann understands that literacy isn't just something you learn in an academic sense. She understands why she engages in literacy—literacy activities have a clear purpose for her. As Koppenhaver et al. (1991) stated, "The functions of literacy are as integral to literacy learning as the forms" (p. 39). The meaningful context and functions of reading and writing, rather than merely their forms, clearly motivated Ann in her acquisition of reading. She states:

To me, the most important reason for learning to write is that it makes it possible for me to constantly remind my family and my friends just how much they mean to me. Being able to write notes, birthday cards and Christmas cards to everyone gives me the opportunity to let them know that they are a very important part of my life. I send out 10 to 12 birthday cards or notes each month and over 100 Christmas cards to family and friends. I really enjoy writing notes and greeting cards to make people feel good about knowing that I remembered them.

Ruth shares Ann's motivation for writing, saying, "I, too, really enjoy sending cards to friends and family to celebrate special days or events. I want them to know that they are important to me and for them to find a small reminder of my affection for them in their mail." Ann has developed effective processes for using her literacy to communicate effectively with her family and friends. As lucky recipients and senders of many of these communications, Ruth and Ann both state that they are an effective, meaningful, and reciprocal way that we maintain our friendship over a 2,000-mile distance and infrequent face-to-face meetings.

Ann explains her process for keeping in touch with friends and family: Every week I enjoy going to the card shops in town to look over and choose the cards on my list to be mailed that week. I carefully read each card before I buy the card because I want to make sure that the card has the right message that I really want for my

family, or my friends. When I get home, I usually add my own personal handwritten message and a colorful design and/or flowers. I know that I am not a good artist, but I try to make the cards look pretty by adding my own personal touch just to make people know that they are very special to me.

I keep track of birthdays, special days, and anniversaries on a large calendar that I have near my desk in my bedroom. I usually buy my next year's calendar in November so that I can add everyone's name before the start of the New Year.

My address list is always changing because I keep making new friends or meeting different people. At this time I am starting a new address book that I think will make it easier for me to keep my address list up to date. I'm glad that I am working on a new address book, because it will give me the chance to make sure that all of my addresses are correct.

Ruth reflects on her use of literacy to maintain relationships: I use a process similar to Ann's. But my "birthday book" is the same one I have used for many years, so instead of a yearly calendar, I add a yearly sticky note to each month's page to keep track of who I have sent a card to this year. My address book is also important and constantly being updated to reflect life's adventures and new people.

Ann places a high value on friendships in her life, and her use of literacy to meet new people, get to know them, and maintain communication with them shows how integral reading and writing are to her friendships. She says,

I try to be friendly with everyone I meet. As we all know, this world can be a very lonely place without friends (see Amado, 1993a, 1993b; Stancliffe et al., 2007). One of my first efforts at writing more than a short note happened while I was in high school. Our teacher asked all the students to write a story about something we did during our summer vacation. I wrote about my favorite subject—friends. This was my story:

"One beautiful, clear night this past summer, my Dad and I were sitting on our boat dock. We were laying back in our chairs & looking up at the sky waiting and hoping to see some shooting stars.

The sky was filled with lots of blinking stars and I told my Dad, that someday I hope to have as many friends as the number of stars that are in the sky.

Do you know that I really feel that I am getting very close to my wish of having as many friends as the number of stars that are in the sky."

Whenever I give one of my motivational speeches, I always mention how important friends are to everyone,

and I tell them about my experience on that beautiful summer night watching for shooting stars with my dad.

Adult Life, Friendships, and the Future

Literacy involves lifelong benefits as well as requiring lifelong learning (Erickson, Koppenhaver, & Yoder, 1994). Both of us anticipate future literacy projects, such as writing books and articles, which challenge and motivate us. Ann considers her current and future literacy activities:

Maybe some day in the future I might try writing a book about all the different learning experiences I have had and the many interesting people I have met in my life as I grew up on the "UP"-side of my so-called Down Syndrome disABILITY. In the meantime, I will continue to read newspapers, magazines and books. I especially enjoy reading our local newspapers to try to keep up to date on the people I know. I like to read about what they are doing and what is happening around town. Every day I am the first person in my family to read the morning newspaper. I wake up between 5:30 and 6:00 in the morning to get the paper and read it. Then I go back to bed. (Except for the last sentence, this paragraph applies to both Ann and Ruth.)

Ann currently volunteers as a teacher's aide in a local preschool kindergarten program for 4- to 5-year-old children, and the children excitedly ask "Miss Annie" to read their favorite stories to them. She also regularly visits senior citizens in a local nursing home, where she enjoys conversations with the 75- to 90-year-old senior citizens who look forward to her weekly visits (see Table 1 for some of Ann's favorite comments).

Conclusion

In this article, we have focused on how one person with intellectual disability and one without learned to read and write and the benefits of literacy in their lives and in one adult friendship. It is clear from the comments of both authors that there is no uniquely "disabled experience" of literacy. Ann's and Ruth's experiences acquiring literacy are similar, resonate with all literate people, and are (or should be) universal. How frightening that either might not have been given these opportunities and would have faced an illiterate adulthood. Ann's story brings to life the notion that learning to be literate is empowerment and is a human right (Luckasson, 2006).

Literacy is important in a variety of ways. Reading and writing lead to not only instrumental skills but also to an increased number of ways for friends to meet and stay connected and to the possibility of deeper and more meaningful communication within that friendship, as through sharing carefully selected cards and the writing of personal notes. Reading can also enable the individuals to seek desired work, engage in valued leisure

Table 1
Annie's Favorite Comments

- "I hope to have as many friends as all the stars in the sky. I think that I am getting very close to my wish."
- "Don't ever prejudice the limits of our abilities. We definitely will surprise you and sometimes we even surprise ourselves!"
- "Accept us for who we are—without any reservations. With your help and encouragement, we can become responsible and contributing members of our communities."
- "The doctor who discovered Down syndrome many years ago was Dr. John Langdon Down. I really wish that his name was Dr. Up so that today, Down syndrome could be called 'UP' syndrome instead. Then maybe people would begin with a better attitude towards us as they start to understand what we are all about and what we are really capable of doing."
- "Help us when we need help, but only enough help so we can finish what we were doing on our own."
- "You must make things happen—don't wait around for someone else to make things happen for you. While you are waiting, you will be missing out on some great things that you could have made happen for yourself."
- "Please don't ignore us, or look the other way when we approach you. Doing that to us will not make us or our disability go away. We didn't have a choice about our disability, but you definitely have a choice in how you accept us!"
- "I love my life!"

Source: Annie Forts UP Syndrome.

activities, and pursue knowledge (Erickson et al., 1994). In addition, literacy leads to the ability to assume a highly valued social role, that of a reader (Copeland, 2007), and reduces stigma.

The painful stigma of illiteracy is well documented (Beder, 1991). In day-to-day life, this stigma or devaluation of nonreaders can take different forms. For example, recently, Ruth accidentally parked in the wrong parking space and earned a \$100 fine. But worse than the fine was the taunting note left on her windshield by the angry individual whose space she absentmindedly took. The oversized letters were crudely hand scratched on the back of a half page ripped from a date book: "Don't park here. Can't you read?"

Ann's description of how she learned to read and the importance of literacy in her life suggests how critical it is to include literacy instruction for all students. Unfortunately, meaningful literacy education has often been denied to people with intellectual disability. A lucky few, however, have found creative solutions. For example, Joanna Pierson tells about how her oldest sister Marcia learned to read: "Education was very important in our family, and Marcia started school at the age of 5. In those days, it was thought that people who had Down syndrome could not learn to read." Marcia loved sports. So Marcia's workaround was to get her younger siblings, including Joanna, to read her the sports page every day.

"When she was a teenager, she had my brother Robert do this reading. No one had told him that she could not learn to read. As a result, when he got tired of reading the sports pages out loud every day, he taught her to read." (J. Pierson, personal communication, September 21, 2010).

The stories of Ann and Ruth, as well as that of Marcia, teach us that literacy instruction should be available to all, that it should be contextualized in meaning, and that improved literacy for an individual can lead to some of the most important things in life: friendship and access to the world.

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