CHAPTER 8

EMPIRICAL INVESTIGATION: LIFE STORIES OF ADULTS WITH READING DISABILITIES

The year was 2081, and everybody was finally equal. They weren’t only equal before God and the law. They were equal every which way. Nobody was smarter than anybody else. Nobody was better looking than anybody else. Nobody was stronger or quicker than anybody else. All this equality was due to the 211th, 212th, and 213th Amendments to the Constitution, and to the unceasing vigilance of agents of the United States Handicapper General. — Harrison Bergeron (Vonnegut, 1961/1988, p. 7)

This chapter presents the second of two empirical investigations conducted for the VSD analysis presented in this dissertation. As a complement to the observational study presented in the previous chapter, this investigation involved interviews with ten adults with reading disabilities about their literacy practices, usage of technologies, and the impact that having an RD has played in their lives. The first section provides some background on similar interview studies previously conducted that motivated this study. The study methodology is then described. Each of the ten interviewees are then briefly introduced. Various highlights of their interviews are analyzed, and the implications of these insights are discussed. A summary of the investigation’s findings concludes the chapter.

1 Cases Studies and Semi-Structured Interviews

A major challenge in studying the social aspects of disabilities is the variance in those experiences. The age of diagnosis, the school one attends and its facilities, the response and support from family and friends, and ones interests and abilities all influence the impact that a disability may have on a person’s life. With all of these confounding external factors, conducting studies that are readily and reliably generalizable is difficult. One research approach has been to embrace this complexity by using interviews to develop illustrative case studies of people with disabilities.

As mentioned in the previous chapter, an illustrative case study provides an in-depth exploration and description of a complex phenomenon (GAO, 1990). Collecting data for a case study can be performed
observationally as in the previous study on discussion forum threads, but another method is the semi-structured interview (Taylor & Bogdan, 1998). In such an interview, a set of prepared questions acts as a guide for the researcher. While the researcher will work to ensure that certain key questions are asked of every person interviewed, the semi-structured format also allows and encourages the researcher to interject with additional questions as appropriate. Importantly, however, the flow of the interview is meant to be primarily driven by the participant. The participant is asked to talk openly and freely about whatever he or she views as important and is thus encouraged to elaborate and even take the conversation in an unanticipated direction.

Semi-structured interviews have been used previously in several VSD studies (Friedman et al., 2002; Friedman, Kahn, Hagman, et al., 2006; Miller et al., 2007), and Kahn (1999) also provides guidelines for using semi-structured interviews to probe value issues. More importantly, though, is that illustrative case studies and semi-structured interviews have been used successfully in previous disability research. This method was used by Edwards (1994) to study the educational experiences of recent secondary school graduates with dyslexia and by Cory (2005) to study college students with invisible disabilities. These methodologies have also been used to study the influence of disability on various psychological elements, including queer identity and sexuality (Whitney, 2006), identity development and sense of self in people with dyslexia (Pollak, 2005), and reactions to dyslexia diagnosis and labeling (Riddick, 2000). My own study on the experiences of university students with disabilities taking computer science courses (Deibel, 2007b, 2008, in press) used this approach, and its set of interview questions were partially derived from the studies by Edwards (1994), Cory (2005), and Whitney (2006).

2 Study Methodology

Due to these previous successes in using semi-structured interviews to develop illustrative case studies on social aspects of disability, the same approach was used to conduct an empirical investigation on the role of technologies and literacy in the lives of adults with RDs. The goal of these case studies was to provide insights into the life stories of these individuals by asking them to discuss their experiences with school, work, and home life in relation to their reading disability. As suggested by the earlier conceptual investigations, the interviews emphasized the social aspects of managing their disability such as requesting accommodations, emotional reactions, and how, when, and if they decide to disclose their RDs to others. The interviews also inquired about what literacy practices the participants typically engage in as well as their use of both assistive and mainstream information communication technologies in their day-to-day lives.

2.1 Participant Recruitment

The participants for this study belong to the primary direct stakeholder group—adults with RDs. To ensure that the participants regularly engaged in reading tasks, emphasis was placed on recruiting individuals enrolled
in post-secondary education as the demands of attending school would presumably encourage reading. Calls for participation were distributed to local universities and colleges. Disability student services personnel were contacted at these schools and were asked to pass on the call for participation as well as help post provided fliers in public areas on campus. Fliers were also distributed at a local comic and animation convention due to my previous experiences of having met many attendees with RDs/LDs at such events. To encourage participation, a $20 gift certificate was offered as compensation.

Upon expressing interest in participating in the study, the participant was first screened (via phone or e-mail) in order to meet the following criteria for inclusion in the study:

- The participant was at least 18 years of age. Some preference was given to recruiting younger participants as they would have lived more of their lives with disability legislation such as the ADA (1990) and IDEA (1997) in effect.
- The participant had been diagnosed as having a reading or learning disability sometime in the past. Participants did not have to provide evidence of this diagnosis but had to be capable of talking about how the diagnosis was made. People who self-diagnosed themselves as being dyslexic or having a learning disability were turned down for participation. If the person’s learning disability did not impact reading, that person was also excluded from participating. For example, a woman with only dyscalculia (math and number related learning disability) did not qualify.
- The participant did not have a severe visual impairment. Common eye problems like nearsightedness, farsightedness, or astigmatism were allowed. This criteria helped ensure that any difficulties experienced with reading were due to the reading disability and not a vision problem.

Due to the small sample size and the low prevalence of reading disabilities in the population, no attempt was made to control for ethnicity, gender, or age distribution among the participants.

2.2 Data Collection

Once approved for participation, a meeting time and place was arranged for conducting the study. All of the data for this study was collected during these one-on-one meetings. Locations were chosen to be convenient for the participant and typically took place in a private area such as a study room in a library or an office conference room. The duration of these meetings was between 60–90 minutes. I wrote notes during each interview, and audio recordings were also made of the interviews. These recordings were then later transcribed.

Moreover, the nature of this study was to be exploratory. In that sense, some preliminary analysis was conducted after each interview. The purpose of this analysis was to identify themes and topics not listed in the set of questions or value prompts but were brought up in conversation by the participants themselves. If such items were found, new questions and dialogue prompts were added in order to explore these topics with later participants. The interview process was thus in a state of continuous refinement.
Table 8.1: Semi-structured interview questions used for the life stories study of adults with RDs.

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>QUESTIONS</th>
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</table>
| Disability & Identity           | - Describe yourself. How do you want people to see you?  
                                  | - Describe your reading disability.  
                                  |   - What are its symptoms?  
                                  |   - How and when were you diagnosed?  
                                  | - How has your reading disability influenced your life?  
                                  | - Is your disability part of your identity?  
| Life Experiences                | - Describe your experiences  
                                  |   - in K-12.  
                                  |   - in college and / or graduate school (if applicable).  
                                  |   - with employment (if applicable).  
                                  | - What, if any, positive aspects / experiences have you had regarding your RD?  
                                  | - What, if any, negative aspects/ experiences have you had regarding your RD?  
                                  |   - Have you ever asked “Why me” in regards to having a disability?  
| Interactions with Others        | - Discuss privacy and your disability.  
                                  |   - Who do you tell? Not tell?  
                                  |   - Why?  
                                  | - What has been the role of others in regards to your RD?  
                                  |   - Family? Friends? Teachers and mentors?  
                                  |   - Have you ever been treated with charity or kid gloves due to your RD?  
                                  | - How do you wish people to treat you regarding your reading disability?  
                                  | - How do you wish society / environment would support you in regards to your RD?  
| Accommodations                  | - Have you ever applied for accommodations?  
                                  |   - Why or why not?  
                                  | - If yes, describe the application experience.  
                                  | - If yes, what accommodations did you request / receive?  
| Literacies & Technologies       | - What reading tasks do you engage in on a daily basis?  
                                  | - Do you or have you ever tried to learn a foreign language?  
                                  | - What technologies do you use / have used in your daily life?  
                                  | - How do you wish technology would support you in regards to your RD?  

2.2.1 Demographic Data

At the start of the interview, several elements of demographic data were collected from the participant. In addition to the traditional age, gender, and ethnicity, participants were asked to describe their educational history. This included the year they completed high school or its equivalent as well as a summary of any participation in higher education. For each stage of their schooling, the year, location, intended degree, and field of study were collected. Questions were also asked about their current or recent employment status.
2.2.2 Interview Questions

Following these demographic questions, the semi-structured format was described to the participant. As explained, the goal of the session was to have the participant talk freely and openly about their RD/LD and its influence on the participant’s life, relationships, education, career, and technology use. It was also explained that to help direct the conversation, I would refer to the interview questions in Table 8.1. Covering all questions was not expected as the emphasis was on discussing the topics of most importance to the participant.

The interview questions in Table 8.1 were derived primarily from the protocol used in my earlier study on the experiences of students with disabilities (Deibel, 2007b, 2008, in press). Those earlier questions were edited in order to specifically focus on reading disabilities. Questions were also added regarding the participant’s reading habits and technology usage. Overall, the questions cover the five high-level topic categories as shown in the table.

2.2.3 Value Prompts

After conducting a pilot interview, it was decided that a small validation exercise for the value framework needed to be added at the conclusion of the interview. Using the list of values in Table 8.2, the participant was given one term at a time and asked to perform a free association with the word and provide a definition relevant to his life and experiences. A brief discussion typically followed each response, and sometimes additional questions were asked. For example, for the term “community,” the participant was asked to list communities in which he belonged. If neither the disability nor the RD community was mentioned, this omission was broached to the participant.

The list in Table 8.2 is a conglomeration of the various values suggested in the iterations of the open coding used in the theme-value literature analysis. As the online discussions study was being conducted in parallel with this study, the value of “awareness” was included here. The list is in alphabetical order.

<table>
<thead>
<tr>
<th>ORDERING OF VALUE PROMPTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Access</td>
</tr>
<tr>
<td>2. Accountability</td>
</tr>
<tr>
<td>3. Autonomy / Empowerment</td>
</tr>
<tr>
<td>4. Awareness</td>
</tr>
<tr>
<td>5. Charity</td>
</tr>
<tr>
<td>6. Choice</td>
</tr>
<tr>
<td>7. Community</td>
</tr>
<tr>
<td>8. Fairness</td>
</tr>
<tr>
<td>9. Identity</td>
</tr>
<tr>
<td>10. Literacy</td>
</tr>
<tr>
<td>11. Privacy</td>
</tr>
<tr>
<td>12. Pride</td>
</tr>
<tr>
<td>13. Respect / Courtesy</td>
</tr>
<tr>
<td>14. Trust</td>
</tr>
<tr>
<td>15. Normalcy / Ideal</td>
</tr>
</tbody>
</table>

Table 8.2: Ordering of the value prompts used in the life stories study of adults with RDs.
for “normalcy/ideal.” These terms were saved for last in order to not have these important terms influence responses to the other values. One goal of this activity was to receive feedback from the direct stakeholders about the various value terms that had been considered. Participant definitions would be used to refine the value working definitions as well. Comparing the associated responses with the rest of the interview content was another goal. A participant may show a disconnect between her definition of a term and her actions. For example, she might state that normalcy is unimportant in her life but also describe multiple instances in which she went out of her way to hide her disability from others.

2.3 Analysis

As mentioned previously, some preliminary analyses were conducted between interviews as a means of refining the exploratory nature of the life stories study. After completing the interviews, formal analysis began on the audio recordings and written notes collected during each participant’s session. These were then transcribed and digitized for easier analysis. Per the requirements agreed upon with the University of Washington’s Institutional Review Board for conducting this research, the transcripts and notes were anonymized. All identifying information, such as names, locations, and schools, were edited out and replaced with pseudonyms.

Once this was completed, the original analysis plan was to create detailed participant profiles like those produced by Edwards (1994) and Scherer (2005). Such in-depth case studies would be used to convey the complex social aspects of reading disabilities that shape the disclosure practices, identity management, technology choices, and navigation of normalcy experienced by adults with reading disabilities. Although developing these profiles is planned for future publication, a smaller analysis was instead conducted for the purpose of this dissertation. This analysis focused on insights from the value-stakeholder framework. Emphasis was placed on characterizing the literacy and technology practices of the participants by using the interview questions to identify relevant sections of the transcripts. An open coding approach was also used to identify discussions that involved the values of normalcy, privacy, identity, and community. Instances of other values were noted as well, but these four were chosen due to their direct roles in social interaction.

3 Participant Overview

Table 8.3 lists the nine participants in the order in which they were interviewed for the life stories study. The table itself lists ten participants, however, as one participant’s interview transcript (Alan’s) from my earlier study (Deibel, 2007b, 2008, in press) was included in this empirical investigation. As the interview protocol from that study directly influenced the questions in Table 8.1, Alan’s session can be viewed as a preliminary interview trial. The questions were later refined for the second pilot interview with Kellie, which led to the addition of the value prompt activity in Table 8.2.
Table 8.3: Overview of participants in the life stories of adults with RDs study. Table contains demographic information, age of diagnosis, high school graduation year, and higher education and employment history. Abbreviations in table: HS (high school); PNW (Pacific Northwest, USA); SE (Southeast, USA); CA (California); UK (United Kingdom).

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Diagnosed</th>
<th>HS</th>
<th>Higher Education</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alan</td>
<td>26</td>
<td>M</td>
<td>Caucasian</td>
<td>6</td>
<td>2001</td>
<td>Visual Arts (AA), PNW community college, 2005</td>
<td>Graphic designer at universities attended</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Visual Arts / Disability Studies (BA), PNW public research university, 2008</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Applied Visual Arts / Graphic Design (BA), PNW public research university, 2012</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Graphic designer at universities attended</td>
<td></td>
</tr>
<tr>
<td>Kellie</td>
<td>29</td>
<td>F</td>
<td>Caucasian</td>
<td>7–8</td>
<td>1998</td>
<td>Comic book art (BA), SE private art college, 2002</td>
<td>Webcomic artist</td>
</tr>
<tr>
<td>Tara</td>
<td>48</td>
<td>F</td>
<td>Caucasian</td>
<td>9–10</td>
<td>1979</td>
<td>PNW community college, 2002</td>
<td>Full-time student</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Psychology (BS), PNW public research university (junior 2010)</td>
<td>Previous: Horse therapy with abused children</td>
</tr>
<tr>
<td>Harold</td>
<td>24</td>
<td>M</td>
<td>Pacific Islander</td>
<td>21–22</td>
<td>2004</td>
<td>Communications (BA), PNW private religious university, 2010</td>
<td>Intern at local TV station</td>
</tr>
<tr>
<td>Ashley</td>
<td>31</td>
<td>F</td>
<td>Caucasian</td>
<td>28–29</td>
<td>1997</td>
<td>13 years struggling in college with a major in Nursing</td>
<td>Nanny</td>
</tr>
<tr>
<td>Clarissa</td>
<td>18</td>
<td>F</td>
<td>Caucasian</td>
<td>10</td>
<td>2009</td>
<td>Journalism, PNW community college (freshman 2009)</td>
<td>Full-time student</td>
</tr>
<tr>
<td>Calvin</td>
<td>35</td>
<td>M</td>
<td>African-American</td>
<td>28</td>
<td>1993</td>
<td>General studies, CA community college, 1993</td>
<td>Currently unemployed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>English / Technical writing (BA), CA state university, 2001</td>
<td>Previously a technical writer at a finance company</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Diversity &amp; contemporary writing (MA), UK public university, 2006</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Computer networking certificate, PNW community college, 2010</td>
<td></td>
</tr>
<tr>
<td>Darren</td>
<td>31</td>
<td>M</td>
<td>Caucasian</td>
<td>8–9</td>
<td>1996</td>
<td>International relations (BS), NE private research university, 2001</td>
<td>Full-time student</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Level 1-2 teaching credentials, State of California, 2008</td>
<td>Previously a public school teacher for students with LDs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Computer science (BS), PNW private university (started 2010)</td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>22</td>
<td>F</td>
<td>Caucasian</td>
<td>7–8</td>
<td>2006</td>
<td>History (BA) / Education (minor), PNW public research university, 2010</td>
<td>Academic coach/mentor for local school district</td>
</tr>
<tr>
<td>Nigel</td>
<td>24</td>
<td>M</td>
<td>Caucasian</td>
<td>6–7</td>
<td>2004</td>
<td>Computer game art (BA), UK public university, 2008</td>
<td>Freelance 3D artist</td>
</tr>
</tbody>
</table>

\[a\] Participation from Deibel (2007b, 2008) included in this study.  
\[b\] Pilot interviewee. Did not perform value prompt task.  
\[c\] Interview not recorded.
3.1 Biographical Sketches

A viewing of Table 8.3 reveals that the participants exhibit a wide diversity of traits. These five men and five women range in age from 18 to 48 (avg. 28.8). They have pursued or hope to pursue different fields of study and different career paths. Their experiences with their disabilities also varies in multiple ways. Although space prevents fully conveying their experiences, the following brief biographies highlight key elements of their lives.

3.1.1 Alan

As mentioned previously, Alan was a participant in my earlier study on the experiences of students with disabilities in computer science courses (Deibel, 2007b, 2008, in press). Born with an LD significantly affecting his short-term memory and reading/writing speeds, he is fortunate to have an exceptionally supportive family that helped him by reading texts aloud and being active advocates of his right to receive an education. Unfortunately, he has also faced challenges to this right. Alan was once denied membership (temporarily) to an academic honor society because he used accommodations in his classes. Several instructors have expressed to him that his disabilities made him incapable of achieving his goals and was even told that he could not fulfill the duties of a graphic designer despite having a resume demonstrating successful internship work. Prevented from earning a degree in graphic design at one university (instead earning one in visual arts), he decided to enroll at another university with a graphics design department that is less close-minded. Facing and overcoming these challenges have galvanized Alan into being an active advocate for people with disabilities. He regularly volunteers in mentoring efforts to help disabled students transition from high school to college.

3.1.2 Kellie

Sharing Alan’s interest in art is Kellie. Kellie is a successful webcomic artist and has been producing a popular autobiographical webcomic for over nine years. One of five siblings in her family with learning disabilities, she was raised with a strong work ethic and that her disability was never an excuse. This meant, as she said, many a late night crying at the kitchen table trying to get homework done. Developing alternative strategies and learning to advocate for her learning needs, she persevered and became an avid reader, albeit taking what she perceives to be twice as much time compared to others. She even went to art college to study the art form that got her into reading—comic books. As her RD significantly impacts her spelling, her disability often becomes a visible component of her comic art whether she intends for it to or not.

3.1.3 Tara

Tara, the oldest of the participants, is currently embarking on a major career change by returning to college to earn a degree in psychology with an intent on doing masters level work related to educational psychology and LDs. This desire is a reflection of growing up with a significant RD and ADD/HD. Essentially unable to
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read until fourth grade, Tara only picked up literacy skills after a year of dedicated, focused tutoring. Despite making tremendous gains in her reading ability over that year, her academic performance varied through the remainder of her years in school. Due in part to undiagnosed ADD/HD, school failed to offer the direct feedback and ongoing motivation that tutoring had provided. On her own, though, she could at times personally motivate herself. Loving to read historical and fantasy novels, Tara can immerse herself in a book over several weeks. In doing work where she can help others, such as tutoring or animal therapy with children, she taps into a deep desire to help others enjoy learning and persevering through difficulties. This is the driving force behind her enrolling in college at her age. Although she admits that her confidence abandons her at times, Tara’s personal mantra that she wants to share with others is “I don’t give up.”

3.1.4 Harold

Unlike the previous three participants, Harold was not diagnosed with a reading disability until he was in college. Never an avid reader, he stopped reading books on his own in fifth grade, preferring shorter news and magazine articles. At school, he typically showed an inconsistent strong performance on assignments but failing examination scores. Harold never considered these as possible signs of having an RD until one of his professors suggested he talk with the university’s disability services. With their help, he underwent psychological evaluation which revealed several impairments that make reading comprehension a slow, error-prone process. While he can usually get the high-level, main ideas of what he reads, he struggles to get the details and notice the intricacies in a text. As it was only in college that such deep-level comprehension was regularly expected of him, his reading disability went unnoticed until then. This new diagnosis led to changes in Harold’s life such as developing better skill management and using accommodations such as books-on-tape. Quite happy that the diagnosis has made it possible for him to finish college and go on to a career in television news, Harold does not go out of his way to tell others about his RD. While he is willing to let his successes make him stand out, he does not want his disability to do the same.

3.1.5 Ashley

Like Harold, the next participant was not diagnosed with having an RD until attending college (the same one as Harold). Unlike him, though, Ashley struggled for thirteen years trying to earn a degree in nursing. Always a slow reader, Ashley eventually found the heavy reading loads, poor grades, and repeated failures to be too much and suffered an acute stress attack. Working with a counselor, it was determined that she had an RD and ADD/HD. Moreover, it became obvious that finishing her nursing degree was too challenging and stressful. This hit Ashley hard, as she considers herself a person of strong Christian faith and finds great strength in serving and helping others. Nursing would have allowed her to combine earning a living and serving others. Fortunately, Ashley was able to find an alternative direction. Earning a degree in political science, she has focused on global development and non-government organizations. With the help of accommodations, she has
been able to finish her degree, including several terms doing international studies in Africa. Still, she avoids letting her RD define who she is. She has found that many of the other people she has met who also have ADD/HD or RDs let the disability become the dominant aspect of their identity. Ashley does not want to limit herself to such a “disability box.”

3.1.6 Clarissa

Recently graduated from high school, Clarissa is currently enrolled in a community college and hopes to transfer to a state university’s journalism program after a few years. Excited about being on her own for the first time, she avidly approaches new challenges in life and considers herself to be a fast learner. Expressing and demonstrating her learning, however, is not always easy. Having both dysgraphia and mild dyslexia, her spelling and writing skills are poor. Teachers have ripped up her written homework for being illegible, and friends have mocked her notes and writing. Mistaking letters or flipping word order has also led to some embarrassing misunderstandings when reading. Despite these negative aspects, Clarissa is fairly open about her LDs and willingly tells others about them. She enjoys reading, but finishing a book that becomes boring is often a problem. Another challenge she is facing is in requesting her own accommodations. At the time of the interview, she was currently ineligible for receiving services until she updated her disability documentation. When asked about what accommodations she expects to receive, she included receiving extra time on assignments. When mentioned that this accommodation was uncommon at the college level, Clarissa did not express any concern.

3.1.7 Calvin

Calvin is the third participant in this group whose RD was not diagnosed until adulthood. In his case, he was enrolled in a writing masters program in Britain when instructors noticed that his writing had structural problems they commonly saw in their dyslexic students. Subsequent reading evaluations found evidence of slow reading, comprehension difficulties, and problems with linear tasks such as writing. Calvin exhibited these traits throughout his time in school but were not caught. He suspects that race played a role in his RD not being caught earlier in that the schools he attended were typically 80-90% white students. His struggles academically were stereotypically accepted, even by Calvin himself. Being diagnosed with an RD, however, allowed him to be less critical of himself and to challenge lowered expectations due to his race. Importantly, he does not view the RD as an excuse for failure but rather a clarification of what problems need to be addressed. Not everyone in his life has shared this view, though. Several people have questioned why he went into technical writing despite having a reading disability. When he told a previous boss about the RD, she decided that he did not belong in his job and harassed him continually about it to the point that the human resources department had to intervene. Because of this, he has decided to never again inform employers about his RD.
3.1.8 Darren

Darren, although born in America, spent a portion of his early childhood, including his first two years of school, in Israel. He was taught in Hebrew but also tutored in English. When he moved back to the United States at age 8, he was struggling with reading in English. Although they first ascribed these challenges to his earlier multilingual education, his teachers soon realized that he had a reading disability. When he reads, Darren primarily just scans for the main ideas, skipping over details as a means of compensating for his slower reading speed. He spent two years in a special school for LDs and was then mainstreamed into a regular school where he received an hour of specialized tutoring each day. His time at the special school was not great. Many of the students had severe behavioral problems, and the teachers emphasized general life skills and not future academic success. He appreciated being mainstreamed, although being excused to attend tutoring did make him noticed. Fortunately, he found good friends that accepted him, although several did express confusion as he did not appear to be the stereotypical special ed kid. In high school, the school cut the LD tutoring program, leading to academic struggles, poorer performance, and a feeling of being abandoned by the school system. When he enrolled in college, he used accommodations but graduated with grades too low for what he needed to attend law school. Instead, he opted to go into teaching and focused on students with LDs in an inner city school. Calling on his own experiences in such classes, he deliberately chose to focus only on the kids who showed signs of wanting to be taught, offering only marginal support to the rest. He decided to return to college for a degree in computer science with a long-term plan to develop educational technologies that would help capable but struggling students like he was.

3.1.9 Emily

Also interested in teaching is Emily, a recent graduate with a bachelors degree in history. With her tremendous interest in reading, she has self-admittedly come a long way from the girl who did not learn how to read until fourth grade. First diagnosed with dyslexia in first grade, she spent the next 8 years working with a private tutor. Speaking highly of her time working with Ms. Madison, she shared how the tutoring helped her develop personal strategies for learning. She still deals with poor spelling and found it hard to keep up with reading in her college courses, often only completing two-thirds of what was assigned. Due to her K-12 education in a small, private religious school, Emily found the transition into college challenging at first. She had no previous experience in requesting accommodations and did not even know that disability services were even available. Still, she persevered and completed the courses she needed to eventually become a high school history teacher. In talking with Emily, her dedication to teaching comes through clearly. Every night, she spends at least 30 minutes reading before bed, usually books on education or teaching. She speaks highly of her mentoring and tutoring efforts with a local school district. She tries to pass on the important lesson that it is okay to struggle. Sometimes she will mention her RD, but mainly only to students she knows also have an
RD/LD. Otherwise, she does not go out of her way to tell others. Emily is not ashamed of it but also does not see the need to share that fact openly.

3.1.10 Nigel

The last participant interviewed is Nigel, a freelance 3D computer artist. Originally from Britain, he now lives in the United States with his American wife. When describing himself, he talks about creativity and his passion for games but also mentions his poor short-term memory. This particular symptom of his dyslexia is the only one he mentions openly, for otherwise he remains mum about his dyslexia. This omission is not due to embarrassment about his past as he instead feels quite lucky in many regards as to how his RD has impacted his life. Diagnosed early in school, he was sent to a private school specializing in the education of students with dyslexia. Nigel greatly values the specialized instruction he received at that school. Due to changes in his family finances, his parents could not afford to send his brother (about eight years younger and also dyslexic) to that private school. Nigel shared how he feels his brother has fared less well due to the lack of specialized instruction. Moreover, Nigel sees himself as better off than many of his peers from that school. Many of his friends also had dyspraxia, and their clumsiness often signified disability to others. Nigel recognizes that it is easier for him to hide his dyslexia from others and just pass as a “normal bloke.” He also chooses not to tell employers or coworkers and will sometimes report less hours at work if he feels he spent too long struggling on a job. To Nigel, dyslexia is not the core of his identity, but he also admits that he has no conception of life without it. Being happy in life is how he defines success, and he is greatly appreciative of the help he has received from others, especially the government services for dyslexic students available in his home country of Britain.

4 Interview Highlights

As is suggested by the above biographies, the interview questions and value prompts produced a bevy of data and insights into the lives of these adults with reading disabilities. For the purposes of this VSD study, the following section presents several relevant highlights from the interviews.

4.1 Literacy Practices

One clear conclusion from the interviews is that these individuals do read. Since most of the participants were currently enrolled in university courses, this is unsurprising. Tara and Darren both mentioned that all they had time for were their course readings and textbooks. Other participants went into detail about the enjoyment they gain from reading for pleasure. When asked to describe himself, the first thing Calvin stated was “I love to read.” Since the purpose of the interview may have primed him to mention reading, he was then asked how he would introduce himself if he was meeting someone casually at a bar or party. His response was still to mention his love of reading and his interest in discussing the politics and history he learns from his reading.
Clarissa and Emily similarly discussed how they frequently read multiple books at a time and love to receive new recommendations from friends. Kellie related the amusing anecdote of the time she started reading a new fantasy novel from one of her favorite authors. She started reading at breakfast and only realized that she had spent the entire day engrossed in the book when her boyfriend returned from work at dinner time.

Not all of the reading occurred with books, however. Ashley, also busy with her classes, only made time for reading the newspaper. Harold similarly preferred to read news articles, often going online for them. Nigel follows several blogs on a daily basis and may occasionally read books from his favorite author.

That these participants engage in and enjoy reading beyond what school and work require is of great significance. Studies of lifelong reading habits have demonstrated what is known as the Matthew effect: the rich get richer and the poor get poorer (Cunningham & Stanovich, 1997). This effect describes how the gap in reading performance between poor and good readers grows over time. People who read frequently when younger will continue to read more as they grow older while those that resist or avoid reading when younger will continue to read little as adults. These findings are strong motivators for employing early interventions when a child struggles with learning to read.

In the case of people with RDs, a reasonable expectation would be that the early, often emotionally frustrating, struggles with learning how to read would result in disinterest with reading in adulthood. In a way, Harold is an example of this outcome. Aside from what school required, he stopped reading fiction in fifth grade. On the other hand, Kellie, Calvin, Cassie, and Emily go against this prediction. All reported pains and delays in their early school years but also readily conversed about the enjoyment they find in books. Although they admit that reading can be a slow process, they still do it on their own volition.

4.2 [Assistive] Technology Usage

Since the participants engage frequently in reading, this suggests that there may be some interest in technologies that support the act of reading. However, assistive technologies were rarely mentioned in the interviews. Several of the participants were unaware of what ATs were available for RDs and could only suggest online dictionary websites and spellcheckers when pressed for examples. Tara and Calvin volunteered for the study hoping in part to learn about computer tools that might help them.

4.2.1 Text-to-Speech

In regards to text-to-speech, several participants expressed significant problems with using it. Darren flat out stated that he had no patience for TTS systems as they did not mesh well with the skimming practices he had developed as self-accommodations for his RD. Tara had tried using talking books that she got from a recording service for the blind, but she found that her attention and comprehension were worse than with regular text. Nigel admits he never explored the potential of TTS, partly due to his college courses being more technically focused. Emily chose not to look into TTS as she knew she benefited from the visual aspects of text.
The artificiality of computer-generated speech was highlighted as a problem. Harold and Ashley used audiobooks for their course readings that were produced on a weekly basis from their school’s disability services office. Both had looked into the TTS option, but, since their school provided audiobooks with such efficiency, they preferred hearing the human reader. Harold did use TTS software for small tasks at his intern job at the news station when necessary. Alan, having been helped by his family reading aloud to him, also preferred audiobooks over TTS as he was accustomed to the nuances of human speech when following along with a text. However, his school’s disability office was not always as timely in providing audio versions of his course readings, due in part to delays on the part of his instructors. Constantly falling behind in his classes due to these delays, he opted to use TTS in his last two terms of school so that he could graduate on time.

### 4.2.2 Color Overlays

Only two participants mentioned using color overlays—Calvin and Nigel. This in not that surprising given that only these two participants ever requested accommodations in Great Britain. As mentioned in Chapters 2 and 3, overlays have a controversial history. Although they are accepted more openly in Britain (Evans, 2001), their usage is not as encouraged in the United States (G. J. Williams et al., 2004).

Calvin and Nigel both mentioned the usefulness of color overlays but at the same time did not rave about them. Nigel remembered using an orange-tinted overlay for a time in his schooling but could not recall when he stopped using it. Calvin also said that using a green overlay did enable him to read for longer stretches of time and reduced the frequency of needing to take breaks from reading. In particular, he found that putting one over the screen of a computer was really helpful, but he kept forgetting to use it. Permanently attaching the overlay was not an option as he shared the computer with his wife and because not every web site or software application worked well with that tinting.

### 4.2.3 Other Technologies

While they might not have used many assistive technologies, the participants did utilize many types of mainstream digital technologies. For example, all participants had cell phones and used them frequently. Although Darren stated that he abhorred texting, the others all texted on a regular basis with Harold and Clarissa both confessing to texting perhaps too much. Ashley stated that she prefers texting over talking on the phone as it gave her more time to formulate her responses. Some problems were expressed with texting, however. Most avoided using text speak (e.g., “idk” for “I don’t know”) as they had enough difficulties with spelling regular English writing correctly, although Ashley attributed her avoidance due to her age. The T9 predictive text technology used for making texting more efficient was also a source of disdain. Emily purchased a phone with a full keyboard in order to avoid using T9. Calvin admitted with pride that he had finally mastered using T9 after two years of struggling with it.

Use of different technologies on the Internet varied in regards to whether it was used for reading or writing.
Several individuals would regularly read short articles on the web from blogs or news sites. Nigel, for instance, follows several blogs, although he rarely contributes any comments. Facebook was also checked frequently, although both Clarissa and Darren admitted that they preferred to read and not post messages. Clarissa attributed this hesitancy in part due to her poor spelling and writing skills, a response similar to a dyslexic respondent in the study by March and Fleuriot (2006).

Instant messaging, chat rooms, and discussion forums were also generally not utilized that often. The speed of real-time chatting imposed the challenging expectation of needing to respond quickly. Tara does sometimes use chat to keep in touch with one of her children who is currently in Europe, but she does prefer to use voice chat when possible. Kellie in particular found the amount of information available online as overwhelming and avoided it as much as possible.

A few participants also commented about their experiences reading from computer screens. Kellie noted the experience is very different and that she needs the tactile experience that comes from a printed book. Calvin admitted to often becoming lost due to the linked document structure on websites. He also recalled trying to use a Kindle (Amazon, 2010) but something about the electronic ink display caused eye strain. To help her read certain websites, Tara will adjust the default fonts her browser uses.

4.3 Value Instances

As part of the analysis of the transcripts, particular focus was placed on discussions concerning values of normalcy, privacy, identity, and community. Between the interview questions and the value prompts, the participants readily and repeatedly discussed these values in relation to their interactions with others. Hiding or telling others about their RDs, navigating how to request accommodations, and defining one’s sense of self were all topics of deep discussion.

4.3.1 Normalcy, Privacy, and Identity

As listed in Table 8.2, the last term mentioned as a value prompt was normalcy. Of the eight participants who were asked to define and reflect upon that word, all eight essentially asked the same thing: what is normal? Darren defined it as something defined by television. Nigel felt that normal is unimportant and boring. Emily stated that she would not want to be normal. Calvin distinguished normalcy from the idea of norms. To him, a norm is an impression of what is typical for a population, and norms vary across contexts and points of view. Ashley insisted that society pays too much attention to what is normal.

At first glance, these responses suggest that normalcy is not a value embraced by these individuals. While this is very likely true in terms of their personal value systems, they frequently discussed the negative aspects of their disabilities throughout their interviews. Tara talked about her need to defend her struggles in life, feeling ashamed about her past mistakes. In past moments of frustration, Ashley has expressed a desire to be like everyone else. Clarissa and Emily mentioned times in which their classmates and even their close friends
would openly mock the messy handwriting, error-filled spelling, or difficulty reading aloud due to their RDs.

The participants also discussed making careful actions regarding the privacy of their RDs. Alan usually feels comfortable telling other students and his instructors about his disability. However, he avoided telling the undergraduate teaching assistants in the computer animation course he was taking. The class had a reputation of being difficult, and these teaching assistants were students from previous offerings. Alan was put off by the “bravado...we made it through this class” attitudes they exhibited. Those attitudes, he felt, belittled his own struggles in the course. Alan did not want his disability to provide the TAs with another reason to flaunt their egos at him. In reflecting on normalcy, Nigel similarly commented that he wants others to judge him on his personality, not his disability. Earlier in the interview, he adamantly stated that he would not use a technology at work that would identify him as being dyslexic. When you tell someone you have dyslexia, you end up being treated differently. The other participants expressed similar perspectives. Harold noted that society does not like it when a person is singled out by some means. After his negative experiences with a previous boss, Calvin has decided to never tell an employer ever again about his RD. These deliberations about whether or not to disclose to others reflect a recognition of being different from others and that sharing this difference comes with negative consequences.

A striking example of this attitude is seen with Kellie. The impact of her RD on her spelling is frequently seen in her comics. Readers would often comment on the errors. Some did so nicely, but others would do it in a mocking manner. As her comic gained in popularity, the comments increased to the point that she felt compelled to post an explanation of her frequent spelling mistakes (excerpted below):

yes I fucking know I can’t spell. Do you think that it could POSSIBLY have escaped my notice after 12 YEARS of special education...the CONSTANT reminder and LIFE LONG ridicule SURE AS HELL keeps me fucking awair!! And no I’m not FUCKING OVERREACTING!!!
So if anyone wants to tell me that I can’t spell and to enlighten me on the wonders of a new and fun envention called a dictionary or spell check then I would be over joyed to tell them to GO TO FUCKING HELL AND DIE IN A VAT OF PIG SHIT... No, I’m not bitter. I’ve just had to put up with this shit for my WHOLE LIFE and I’ve sat there and taken it...
words of condolence, apology, ridicule or support are unwanted and unneeded

The visceral emotion in this message cannot be overlooked. When asked about this statement, Kellie recalled the tremendous catharsis of writing those words and still believed firmly in what she wrote. She talked about how she did not know which was worse: the mocking e-mails or those saying that they felt sorry for her having dyslexia. The latter brought back memories of the struggles, shame, and embarrassment she has felt due to her disability. Still, she recognized some value in being as visible as she is. At comic conventions, readers will come up and tell her that they are dyslexic too and that they are grateful for success. Kellie comments that she
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has become an advocate because she cannot hide so readily.\textsuperscript{4}

Similar examples of violating one’s privacy and normalcy were echoed by some of the other participants. Nigel mentioned that there are times when he tells others. While such occasions include when he is struggling and needs help, Nigel noted that he will speak up if somebody is talking negatively about people with dyslexia. At that point, he will offer himself up as a person with dyslexia who is doing quite fine in life. As mentioned before, Emily will tell a student of hers about her RD if the student also has an LD. In doing so, she wants to demonstrate that the disability has not held her down in working towards her goals in life. Similarly, Tara empathizes with others who face struggles in school and this has motivated her to help kids learn to believe in themselves. As part of his ongoing disability advocacy efforts, Alan also readily speaks up when he comes across an instance where a person with a disability is being treated unfairly.

Overall, there is a disconnect between the participants’ views on normalcy and their actions that beget privacy and hidden disability identities. Unfortunately, this disconnect was not recognized until after the interviews were completed, and thus the reasons for it were not adequately explored. One possibility is that because of the suffering they receive from society’s treatment of people who are different, these individuals willingly or forcibly break with their personal value systems. Another explanation for this disconnect is that the participants may have not been reporting their personal views of normalcy and were instead reflecting how society at large views and defines normalcy. Our society has become increasingly more aware and embracing of diversity, going as far to say that we are all the same in that we all different.\textsuperscript{5} The participants may have been reflecting this recognition of social diversity in their responses. Paradoxically, though, saying being different is common technically defines normalcy as a lack of sameness despite the more common connotation of normalcy as sharing sameness.

4.3.2 Community and Awareness

Given its role in the diffusion and promotion of AT usage, the value of community in the lives of participants was an important focus during the analysis process. When asked to define community, the eight participants generally responded with similar meanings, essentially viewing community as a group of people who share a common element such as a place, purpose, history, or knowledge. Harold and Calvin emphasized having aspects in common such as heritage or neighborhood. Clarissa and Nigel emphasized how people in a community help and support each other, and Ashley further emphasized this helping aspect by stating that community is “...people who surround you during trials [in life].”

These definitions were also reflected in the communities in which they considered themselves members. Emily, Ashley, and Calvin talked about their churches. Those currently enrolled in school mentioned their classmates as forming a community, although Ashley felt isolated a bit due to being ten years older than most of the other students. None of the participants, however, mentioned the disability or RD community as one
to which they belong. When this was pointed out, the participants explained their omission. Nigel stated rather fondly that he was a member of such a community when he attended the private school for dyslexics. Nowadays, though, he knows the RD community exists but chooses not to be involved. Calvin echoed a similar view and compared it to his affiliation but lack of involvement in the African-American community. Emily stated that she only knows three other students with dyslexia at her university and that they are at best passing acquaintances. Two participants spoke negatively of disability communities. When he thinks of the idea of an RD/LD community, Darren thinks of the “bums in high school” that were always getting in trouble, and he views it as a good thing that he moved away from his hometown. Ashley mentioned again her interactions with an ADD/HD support group in which she found that the members had let their disabilities become the dominant factor in their lives. She would probably say the same about Alan due to the prominent role that disability advocacy plays in his life. By focusing so much on disability, Ashley feels that these individuals “box” and remove themselves from larger aspects of society.

The reason behind Ashley’s distaste for such isolating behavior can be seen in her responses to the prompt for awareness. She considers awareness to be about reaching outside one’s self in order to learn about what is around and available. She emphasized how particularly important awareness is for people with disabilities so that they can learn how to address their disabilities. Other participants connected as well the notion of awareness to community. Tara’s first response to the prompt of community was to comment, “Really really important...[I] wish they knew how important at times.” Minutes earlier, she had discussed the importance of empathy and being aware of other people’s experiences, needs, and feelings. Emily herself mentioned in regards to awareness that disabilities are not spoken of enough by general society.

These comments about community and awareness reveal an observable tension between what was said earlier about normalcy, privacy, and hiding. Emily flat out states that disabilities should be spoken of more regularly but also admits to not telling others unless there is an opportunity to connect to someone else who also has an RD/LD. Seeking out help in the form of accommodations requires a person to stop hiding and expose themselves to the opinions and views of the community. Importantly, there are implications of a community that readily offers help to its members. In a community that says, “We help people who need help,” the person being helped is, in some ways, removed from belonging to the community (the helpers). The normal action of this community is to provide, not receive, help, thereby separating such individuals and marking them as distinctly different. Moreover, wanting to help others is a desirable and positive trait, thereby making being normal a worthwhile goal, ergo encouraging people to be on the giving end of help.

Awareness among members of a community can provide a means of addressing this tension, however. Using Ashley’s and Tara’s point of awareness being about empathy and reaching outside one’s self, one can see that every person requires help at times. A community can shift what is considered normal by embracing
this and saying, “Every one of us at times needs help, and we as a community will provide that help.” With such a social perspective, asking for help would likely incur less risks and threats to the requester’s sense of identity and belonging.⁶

4.3.3 Accommodations and Fairness

Some help does come from the use of accommodations, however. All ten of the participants used some form of academic accommodations in their college courses. As previously mentioned, there was some limited use of audiobooks and overlays. Otherwise, most of the accommodations did not rely on advanced technologies: extra time on tests, notetakers, and private rooms for test taking. Some of the participants were also allowed to use a laptop instead of writing out answers by hand, and in Nigel’s case, he received a personal laptop through a Disabled Students Allowance grant from the British government.

The participants’ views and actions related to accommodations reflect several values. In responding to the value prompt for “access,” Emily made it clear that accommodations should only be provided when she asks for it. It is her choice and decision as to when she needs it. Alan takes responsibility every term to contact his upcoming instructors about his disability and accommodation requests. Since he uses books-on-tape, advance lead-time is needed to make audio versions of the course text. For the computer animation course, however, the instructor made a last minute change in the course text. This led to Alan falling behind in the course and growing increasingly frustrated with the lack of respect and support the instructor was giving him. Eventually, his parents stepped in after seeing the anger and stress he was experiencing, which led to this 26 year old young man questioning if he was really capable and empowered enough to act on his own behalf.

Darren in particular articulated several fine points about having access to accommodations. As one of his accommodations is to take exams in private, his classmates quickly notice that he is absent during tests. When they ask, he explains to them about having an LD and receiving accommodations like extra time on tests. Some will joke that they would like that advantage as well, to which Darren sarcastically replies, “…if you want to struggle for twenty years with a learning disability.” He recognizes that some people question the fairness of giving accommodations. In response to the concern that some students may be lying about an RD/LD in order to receive the advantages that accommodations like extra time can provide, Darren questions why this is viewed as a problem:

I don’t see what we are losing by all this. If i get additional time and i do well, I have learned the stuff. I can demonstrate my knowledge of the material. Isn’t that what tests are really about? You’re not making the tests shorter. You’re not testing me on material that’s easier…. The reality is that… 90% of Americans would fail. The reality is that giving me that extra hour of time is what helps me do it.

Darren’s argument directly challenges the concerns expressed by Zirkel (2000), Leef (2010), and Vickers
(2010) about the fairness of providing accommodations to students with LDs. Calling on his experiences as a teacher, he is arguing that the time component of these tests is irrelevant. Leef does raise the concern that extra time to make a decision is not a viable possibility for an emergency room doctor. However, Darren is talking about courses such as Calculus II and Freshmen English. These classes do not have the same time-sensitive risks as found in an emergency room. Fairness, as Darren suggests, requires a more nuanced perspective.

Unfortunately, Darren also lends some credence to the concern that some students do cheat the accommodations system. One of his classmates was struggling with passing a math course due to the combined pressures of memorizing formulas and not thinking efficiently enough during an exam. When this friend asked Darren about how to get accommodations, Darren provided advice as to how the friend could demonstrate a learning disability. When taking the neuropsychological batteries to diagnose an RD/LD, Darren advised the friend to do well on one section but intentionally do poorly on another. This way, he would demonstrate the inconsistent skill abilities commonly seen in people with RDs/LDs Edwards (1994). When asked why he helped his friend game the system in this way, Darren provided two reasons. From his own experiences and from teaching students with LDs, he recognized some LD-related traits in his friend. His second reason was his earlier argument that the extra time does not change the underlying importance of mastering the material. Regardless of his reasons, the implications of Darren’s actions shows that the value tension and dam associated with instructors’ concerns about the fairness of providing accommodations are not simply unfounded speculation. Such issues and concerns should be respected, and means of supporting and negotiating these issues is paramount to addressing the value tension and dam.

5 Discussion

The interviews used to develop the illustrative case studies / life stories of adults with reading disabilities presented in this chapter expand upon similar previous studies. Greater focus was placed on exploring their usage of technology and their reading practices. Most of the participants in this study have lived more than half of their lives after the passage of influential disability legislation such as the ADA (1990) and IDEA (1997). The participants’ perspectives on living with RDs reflect in part the changes that such laws have made in society’s perceptions and treatment of people with disabilities. Additionally, three of the participants in this study were not identified as having an RD until they were adults. This delay in diagnosis creates an important distinction in the role of disability in their lives. Instead of growing up with the disability, these individuals have to process and add a new facet to their identities and lives.

As an empirical investigation, these interviews provided insights about many of the observations made in previous chapters. Assistive technology usage was limited among the participants, and several participants specifically mentioned that TTS was not a useful tool for them. The conversations with the participants also
helped to reify and validate elements of the value-stakeholder framework. The value of awareness arose in these discussions just as they did in the online discussion forums. The hypothesized desire to control disclosure of one’s disability was repeatedly demonstrated, although a disconnect was noted between their actions and their views of normalcy. As was also suspected in the earlier conceptual investigation (Chapter 6, Section 3.4.3), the communities these individuals belong to are not defined by their disability status. The reasons several individuals expressed for not belonging (or reluctantly belonging as in Kellie’s case) invoked the problems associated with deviating from what is considered normal. The role of fairness in providing and receiving accommodations was further highlighted in both positive and negative ways.

6 Chapter Summary

This chapter presented an empirical investigation on the reading practices, technology usage, and the role of disability in the lives of adults with reading disabilities. Semi-structured interviews with ten participants were used to develop illustrative case studies. Using the words and experiences of these direct stakeholders, the ten life stories provided validation of the importance of privacy management and hiding as a means of addressing issues of identity and normalcy. Other aspects of the value-stakeholder framework were expanded upon, including the lack of a reading disability community and the complexity of the fairness of accommodations.
Notes to Chapter 8

1 In two cases, technical problems prevented successful audio recording. Excessive background noises made recording of the pilot interview with Kellie inaudible. Battery problems disabled the recorder early in the interview with Ashley as well.

2 The school Nigel attended was similar to the one that Edwards taught at and recruited students from for her interviews Edwards (1994).

3 Another example of this break with the Matthew effect is the previously mentioned Jonathan Mooney (Mooney, 2007). In his memoir, he frequently refers to books and essays that he has enjoyed reading on disability studies, including Foucault (1977/1995) and L. J. Davis (1995).

4 In the fall of 2010, Kellie moved her comic to a new server provider. In the course of the move, she updated the appearance of her website. Included in this change was the removal of the link to the page containing her statement about her spelling. The reason for this is not clear, although the spelling in her comic has improved significantly in the last year. It is possible that she has decided to step back from being visible about her disability, although I cannot confirm this at the current time.

5 Frankly, I find pithy statements such as, “We are all the same in that we are all different,” to be vacuous and rather belittling. The implication is that while one’s differences are recognized, they do not really matter since everyone else is also different. This begs the question as to why certain differences deserve recognition while others are passed over as unimportant.

6 Examples of this community ethos can be seen in various 12-step programs like Alcoholics Anonymous. Members of these groups admit and openly share their problems with each other as a means of establishing a community in which everyone is both a recipient and a provider of support.