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# Lived Experiences of Adolescents with Learning Disabilities

#### **Abstract**

Research indicates that young people with Learning Disabilities (LD) can suffer academic and social difficulties, lower levels of self - esteem, and social isolation. However, several research studies indicated that some children with LD were able to overcome these challenges through self - advocacy, peer support, and self - acceptance. Seeking to build on those results, the research question guiding this study was: What is the lived experience of adolescents with LD in regards to peer support, self - advocacy, and self - acceptance of LD? Interview data from a small purposive sample of four adolescent participants reportedly thriving with LD were analyzed using techniques inspired by Interpretive Phenomenological Analysis. Results suggested protective factors consistent with the prior studies (e.g., self - advocacy) and also raised hypotheses about additional protective factors: multiple forms of social support (peer, family, and mentoring) and the importance of developing a personal understanding of LD/ADHD. It is hoped that these hypotheses on protective factors derived from the voices of a few adolescents thriving with LD will spark larger scale research that continues to place the authentic lived experience of young people central in research findings

#### Keywords

Learning Disabilities, Interpretative Phenomenological Analysis, Self - Advocacy, Peer Support, Qualitative Research

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# **Lived Experiences of Adolescents with Learning Disabilities**

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Research indicates that young people with Learning Disabilities (LD) can suffer academic and social difficulties, lower levels of self-esteem, and social isolation. However, several research studies indicated that some children with LD were able to overcome these challenges through self-advocacy, peer support, and self-acceptance. Seeking to build on those results, the research question guiding this study was: What is the lived experience of adolescents with LD in regards to peer support, self-advocacy, and self-acceptance of LD? Interview data from a small purposive sample of four adolescent participants reportedly thriving with LD were analyzed using techniques inspired by Interpretive Phenomenological Analysis. Results suggested protective factors consistent with the prior studies (e.g., self-advocacy) and also raised hypotheses about additional protective factors: multiple forms of social support (peer, family, and mentoring) and the importance of developing a personal understanding of LD/ADHD. It is hoped that these hypotheses on protective factors derived from the voices of a few adolescents thriving with LD will spark larger scale research that continues to place the authentic lived experience of young people central in research findings. Keywords: Learning Disabilities, Interpretative Phenomenological Analysis, Self-Advocacy, Peer Support, Qualitative Research

In the United States, 4.8% of school enrolled children aged 3 to 21 years old were served during the 2010-2011 school year as young people with specific learning disabilities under the Individuals with Disabilities Education Act (Digest of Education Statistics, National Center for Education Statistics, 2012). Adults with learning disabilities (LD) constitute the highest percentage of people with disabilities at secondary and postsecondary institutions (Gregg, 2009). These statistics are likely to be low estimates regarding the prevalence of LD in the total population due to controversy in how to define LD and should be considered broad estimates (Goldstein, 2011). Thus, the prevalence of LD in the total population is likely to be greater than what is reported here.

Historically, researchers have largely overlooked the personal accounts of children with LD (Kelly, 2007) in terms of what has appeared this far in the worldwide literature. Research that includes the voices of adolescents with LD has the potential to make a major contribution to the psychology and education literatures and to change perceptions about the potential of young people with LD across the world. The purpose of this study is to capture the lived experiences of adolescents with learning disabilities (LD) through individual interviews and data analysis inspired by Interpretive Phenomenological Analysis (Smith, Flowers, & Larkin, 2009).

# **Learning Disabilities Defined**

The definition and diagnosis of LD has long been a source of controversy (Ames, 1998). During the 1970s in the United States, Kirk and Elkins (1975) claimed that LD was ultimately operationalized as a reading disorder with lower intellectual functioning. However, the definition of LD established by the federal legislation was not intended to include an association with lower intellectual functioning. According to the National Joint

Committee on Learning Disabilities (NJCLD) federal law states that the term LD refers to a disorder in one or more of the basic psychological processes in relation to understanding or using written and/or spoken language. The resulting effect is explained as difficulty in listening, concentrating, speaking, spelling, writing, or doing mathematics (Hall, Spruill, & Webster, 2002; Kirk & Elkin, 1975; NJCLD, 1981). Again according to federal law, a learning disability may be diagnosed when an individual's *subscores* on achievement and intellectual ability tests show discrepancies in at least one of several areas including math, reading, listening, written expression, basic reading skills, mathematical calculation, and mathematical reasoning (NJCLD, 1981). In this article, LD is defined as the presence of a significant difference in an individual's ability as compared to his or her performance in one or more specific areas resulting in a variety of difficulties.

The NJCLD (1981) proposed that people view learning disabilities as a complex and heterogeneous group of learning disorders, yet lack of agreement on the nature of learning disabilities has resulted in individuals with LD being thought of as a homogeneous group requiring similar assessments and interventions. While the NJCLD endorses the notion that learning difficulties arise from a myriad of factors, they maintain that LD is the result of intrinsically different processes of attaining information due to the central nervous system. Recently, however, there has been a broadening in the understanding of LD as researchers and professionals begin to see it as more than just a neurologically based disorder. Some theorists have proposed that LD may be also the result of a complex interaction of individual, family, school, and sociological factors (Ames, 1998). This lack of a clear and common definition of LD is at the root of problems regarding further research, diagnosis, and treatment (Brueggemann, Kamphaus, & Dombrowski, 2008).

Fuchs, Fuchs, and Speece (2002) attributed controversy in assessment of LD to the increase in the number of children diagnosed with LD since the field's inception. According to Jakobson and Kikas (2007), LD has a high comorbidity rate with Attention Deficit/Hyperactivity Disorder (ADHD), which may present confounding factors in studies. ADHD is characterized by the inability to concentrate and/or control hyperactivity and impulsive behavior. This disorder can be difficult to diagnose properly as there is no exact method but rather many different rating scales and tools for assessment. Most of the commonly used diagnostic tools are based upon self-report questionnaires and inventories (Rostain & Ramsay, 2006). Therefore, it is important for researchers to explain and distinguish among disabilities and or disorders, with which the participants identify and what diagnostic tools were used. Clarity in this respect has the potential to facilitate more accurate generalizations of results in study data as well as better clinical applications. Since the present study is concerned with the experiences of adolescents who have been identified as having some sort of learning difference, and not the technical distinctions and diagnostic differences between ADHD and LD, I will use the term LD to encompass adolescents with a sole diagnoses of LD or ADHD or those with the combined diagnoses of LD and ADHD.

#### **Previous Research**

Individuals with LDs often perform daily activities in unconventional ways, thus they may not fully amalgamate into the traditional classroom environment (Coughlin, 1997). Students with LDs frequently encounter a number of difficulties during their academic careers (as cited by Hall et al., 2002). They report lower levels of self-esteem, less emotional support, more problems with academic and emotional adjustment than their peers without LDs. Students with LDs may also experience feelings of social isolation and not fitting in with their peers. These factors often present barriers to their academic and social success.

Throughout history, however, some of the most celebrated individuals have since been identified as having LD. The list includes Albert Einstein, Thomas Edison, Leonardo Da Vinci, Woodrow Wilson, and Hans Christian Anderson (Acker, 1994). The question begs how these adults with LD were able to succeed despite pervasive discrimination and the other barriers to success described in the latter paragraph.

#### Factors Associated with the Success of Adults with Learning Disabilities

Raskind, Goldberg, Higgins, and Herman (1999) conducted a 20-year longitudinal study aimed to determine characteristics of successful adults with LD. This study included analyses of both quantitative and qualitative data. Success was measured by employment status, educational attainment, and living arrangement. Six common attributes identified in successful adults with LD were self-awareness, proactivity, perseverance, emotional stability, appropriate goal setting, presence and utilization of support systems.

In addition to these factors, self-advocacy, self-acceptance, and peer support are among the success factors that have also appeared in the literature as an important factor to the success of individuals with LD (Lock & Layton, 2001; Sahlen & Lehmann, 2006) Self-acceptance, which Raskind et al. (1999) identified as a success attribute, has been seen to increase in children with LD who were given peer support by others with LD (Acker, 1994; Carabine & Downton, 2000). Self-advocacy and peer support were two prominent themes, associated with success of individuals with LD, found in the literature to date.

# **Self-Advocacy**

Self-advocacy for people with disabilities emerged with the People First movement in the 1980s in the United States (Aspis, 2002). People First is an organization that is operated by people with LD with the purpose of promoting self-advocacy among individuals with disabilities. As a result, self-advocacy is a behavior employed more and more by individuals with LD. While there are many definitions of self-advocacy, People First defined it as being independent, defending one's rights, asserting oneself, and taking responsibility for one's self. Though the self-advocacy literature is sparse, self-advocacy appears in the literature primarily as either movement or an action of an individual (Adams, 2008).

While researchers have yet to fully agree on a conceptual framework of self-advocacy, some attempts at creating a basic model exist in the literature (Adams, 2007). Test, Fowler, Woods, Brewer, and Eddy (2005) created a comprehensive model of self-advocacy based on a review of the literature, with four basic components: self-awareness, knowledge of rights, communication, and leadership. While not universally accepted, the Test et al. model (2005) has provided a working baseline for new studies.

Many authors in the special education literature have stated the importance of self-advocacy skills to the success of students in postsecondary schools, especially to those students with learning disabilities (Lock & Layton, 2001; Sahlen & Lehmann, 2006). Sahlen and Lehmann (2006) claimed that students coming from a special education classroom must possess self-advocacy skills in order to continue receiving accommodations in postsecondary education. The system for requesting and receiving accommodations in postsecondary settings is quite different than it is in high school, when more responsibility for learning is transferred to the student. Then in postsecondary education, Lock and Layton (2001) emphasized the importance of self-advocacy skills for students with LD, since very few professors and academic counselors in postsecondary institutions have received training in working with students with LD. Services that are tailored to the individual college student's learning styles are rarely provided.

To date, there have been few empirical studies that provide evidence for the importance of self-advocacy skills. In one of the few studies, Adams (2008) evaluated student adaptation to college in students with and without disabilities in participants selected from six institutions in the United States. Students in the group with disabilities were registered at student disability resource centers at their respective universities. The group with disabilities was compared to a control group of students without disabilities on selfreport measures of social adjustment, personal/emotional adjustment, institutional attachment, and attribution style for positive and negative events. Also the group with disabilities was assessed with a self-report measure of self-advocacy skills developed by the researcher. Results vielded significant differences between groups, where students without disabilities scored significantly higher for social adjustment, personal/emotional adjustment, and institutional attachment. Students with disabilities scored higher on attribution style scales, which suggest a more internal, stable, and global attributional style for both positive and Self-advocacy skills were associated with an increase in psychosocial negative events. adjustment as well as increases institutional attachment and academic adjustment.

# **Peer Support**

Peer support for individuals with learning disabilities is a fairly new idea has not yet been formally operationalized in the literature as a construct. For the purpose of this proposal, peer support is operationalized as interactions characterized empathy between children with LD. Peer support, in this sense, can occur in any situation where individuals with LD are surrounded by their peers and given the opportunity to talk openly about their disabilities.

Thus far, studies regarding group counseling for people with LD present perhaps the best possibility for examining the effects of peer support. Two separate studies, demonstrated that group counseling has increased self-awareness in children with LD (Acker, 1994; Carabine & Downton, 2000). The Carabine and Downton study (2000) evaluated the effects of peer counseling on high school students with LD from a school in New Hampshire, where a group of male students participated in four group sessions over the course of a 10-week period. Two older boys with LD were selected to fulfill the role of peer counselors. While this study precluded the use of a control group and precise pre and post measures, results were based on reports and comments from the male students participating. Overall, it appeared that the participants improved in their academic performance and self-perceptions.

A more definitive study by Acker (1994) examined the effects of group counseling on scores of academic achievement, self-esteem, and acceptance of LD in children with LD. Participants in the study were children with LD selected from special education classrooms in the public school system in Washington, D.C., where all of the students in the sample participated in a group counseling intervention. Again without control group, participants were given self-report measures of academic achievement, self-esteem, and acceptance of LD before and after the group counseling intervention. Participants' scores of academic achievement, self-esteem, and acceptance of LD increased after the group counseling intervention, which provides limited evidence regarding the benefits of group counseling for children with LD Group counseling provided the children with an opportunity to meet with their peers. Since group counseling involves member support of each other, the construct of peer support may have been a factor that influenced academic achievement, self-esteem, and acceptance of LD.

While these studies by Acker (1994) and Carabine and Downton (2000) provided conjecture about the effects of peer support through group counseling, much more research on peer support in other forums is needed. Since it is not clear whether it was the group

counseling intervention or the peer support that caused positive effects, outcomes for peer support of children with LD should be studied directly.

In summary, Raskind et al.'s (1999) 20-year longitudinal study identified a number of characteristics intrapersonal and interpersonal attributes and skills that are associated with successful adults with LD. The common attributes identified provided an excellent foundation and rational for future studies. For example, Adams' (2008) novel study regarding self-advocacy skills in students with LD showed that such skills were associated with an increase in psychosocial adjustment as well as increases in institutional attachment and academic adjustment. The studies regarding peer support by Acker (1994) and Carabine and Downton (2000) provided strong evidence that the effects of peer support in children with LD also merited future research. With these studies as a backdrop, this present study attempts to take the literature one step forward by asking children with LD about their experiences as they relate to self-advocacy and peer support while leaving room for the discovery of themes that may not have yet been identified. Therefore the research question guiding this study is: What is the lived experience of adolescents with LD in regards to peer support, self-advocacy, and self-acceptance of LD? The young person's voice may reveal new important hypotheses for future research.

# **Present Study**

The present study aimed to gather information about adolescents' experience of having LD from their own frame of reference as adolescents with LD. Higgins, Raskind, Goldberg, and Hermann (2002) provide a strong argument for doing research in the area of LD with an "emic" approach, meaning the importance of gathering information from a cultural insiders' point of view as opposed to the researchers' cultural perspective. The present study reflects this "emic" perspective, by using a research design best able to capture the lived experience of adolescents with LD in regards to peer support, self-advocacy, and self-acceptance of LD. To date, both authors' training and professional activities have focused on understanding phenomena from the perspective of lived experience. Because adolescents with LD are frequently disenfranchised in school systems and often misunderstood by their peers, this project was particular important to both of us from a social justice standpoint. We believed that if adolescents could talk about their experience from their perspective, adults would have the opportunity to learn more about what it is to walk in the shoes of an adolescent with LD.

# Method

# **Participants**

Five adolescents, recruited through convenience sampling, between the ages of 15 and 17 volunteered to be interviewed for the study. The participants were between 14 to 18 years of age; three were male adolescents, and two were female. Four of the five adolescents completed the interview. One adolescent girl out of the five participants did complete the full interview, yet appeared to avoid following the interview protocol, instead preferring to talk about unrelated content. Though I, the interviewer, restated gently the interview protocol questions several times, I allowed her to answer freely. As a result, her conversation was unrelated to the purpose of the study, so was not included in the results. The four participants included in the study identified as heterosexual; two participants identified as Caucasian, and the remainder as being connected with several ethnicities including Chinese American, Native

American, and Latino. Three attended private schools, and one attended a public charter school.

I announced the study through a special forum organized by a parent advocacy group in the San Francisco Bay Area called Parent Education Network (PEN: <a href="http://www.pen.org">http://www.pen.org</a>). This forum was held at the first Education Revolution Conference on held April 22<sup>nd</sup>, 2009 for parents and their children with LDs. The purpose of this conference was to provide an opportunity for people with LD, particularly children and adolescents, to meet others with similar experiences and build a support network. Education Revolution also helps connect families with resources regarding LD/ADHD. Families interested in being contacted for the study provided their names, telephone numbers, and/or email addresses to me for later contact. I explained in my announcement that potential participants must identify as having LD and/or ADHD. All participants identifying as such were included in this study (as explained above, ADHD is considered one form of LD). The resulting list of 16 potential participants was put aside until the study proposal was developed and approved by an Institutional Review Board (IRB).

Once approved, the potential participants were randomly selected from this list of interested families and contacted first by email and then by telephone to explain the study and inquire as to their interest in participating. The list was exhausted after obtaining interviews with two volunteer participants. Needing more participants, I obtained additional IRB approval to contact an individual active in the PEN network, who worked with a group of adolescents at the conference. Through this individual, 41 new potential participants were contacted about the study. I obtained three more volunteer participants in this second round of recruiting—five in total through the two recruiting methods.

#### Instrumentation

Open-ended questions guided by an interview protocol addressed the following areas: school experiences, identity, self-advocacy, and peer support. See Appendix A for a complete list of open-ended questions. This open-ended design was meant to examine themes already in the literature as well as to allow for new themes to emerge.

# **Procedure**

I conducted all individual interviews in a conference room with the adolescents brought by their parents for the study. Each parent and adolescent participant provided written consent for the study. Once signed, the parent waited in another area, while I conducted the interview with the adolescent. First, I asked the demographic questions about gender, education, ethnicity, cultural affiliations, type of LD, and accommodations. This was followed by the open-ended interview questions. In an effort to make the interviews accessible to the participants with varying learning and attentional disabilities, the participants were able to choose the format or mode by which the interview was conducted (written, verbal, and/or both). All four participants found the traditional oral interview to be the most comfortable option. All participant interviews were recorded using a digital recording device, and subsequently transcribed through a transcription service.

# **Data Analysis**

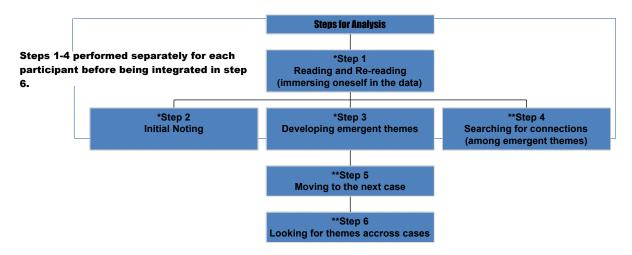
A total of 163 pages of transcripts were generated. I analyzed the transcript data using techniques consistent with interpretive phenomenology analysis (IPA), as outlined by Smith, Flowers, and Larkin (2009). IPA is geared toward understanding and explaining the way

participants make sense of their experiences and is helpful in preliminary studies of emotional experiences. Figure 1 shows the IPA step-by-step analysis procedure. Because raters are not included in Smith, Flowers, and Larkin's IPA procedure, I adapted their analysis process to include the use of three raters, which is reflected in the figure. In order to reduce individual researcher bias and increase the overall validity of the results, which is a technique recommended by Miles and Huberman (2005), three raters coded the transcript data—myself and two other graduate-level student raters. For Step 1 Reading and Rereading, designed to immerse researchers in the original data, all three raters read each of the transcripts. For Step 2 Initial Noting, intended to be an initial analysis of the data on an exploratory level, each rater made notes separately for each participant. For Step 3 Developing Emergent Themes, designed to develop initial themes for the participants separately, the raters and I independently looked at the initial notes for each transcript separately and identified emergent themes, sometimes verbatim, sometimes changing the wording into theme-like phrases. Subsequently, we independently reviewed the notes from Steps 2 and 3 and selected the most salient and significant themes for the specific participant. This resulted in each rater creating a list of themes for each participant.

For *Step 4 Searching for Connections*, intended to be a deeper level of analysis, each rater input themes into columns of a table—each rater created one table per participant.

Step 5 Moving to the Next Case denotes the act of each rater completing steps 1-4 for a participant before reviewing another participant's data. After receiving a table for each of the participants, I analyzed each of the case tables separately, looking at the similarities and discrepancies in our themes. The three of us discussed each of the case tables and decided on a comprehensive list of themes for each participant, resulting in four separate lists, one list of themes per participant. Then to create a hierarchy of themes, I printed the four lists of themes and cut the individual themes into movable pieces (separately for each case), and organized the themes into a visual hierarchy of themes. I did this for each participant. From these, I made four separate tables, and reviewed them with the other two raters, incorporating their feedback. After changes were made and we all agreed on the themes for each participant, I began to work on the final step.

For *Step 6 Looking for Themes across Cases*, which was designed to illuminate patterns across participants, I used the tables for each participant to search for themes across participants. A pattern of themes emerged across participants. As a result, I created an integrated table of themes, which was again reviewed with the raters.



<sup>\*</sup>Performed by all three raters simultaneously

<sup>\* \*</sup>Performed by principal investigator with interrater consultation

*Figure 1.* Interpretive phenomenological analysis process by step adapted for use with multiple raters (on the basis of the protocol for IPA outlined in Smith, Flowers, & Larkin, 2009).

#### **Results**

We present the following results according to traditional IPA standards described by Smith, Flowers, and Larkin (2009). We begin by providing an overview of emergent themes. Next, we provide a detailed description of each theme and include excerpts from the interview transcripts—that is the young adolescent voices—to illustrate the lived meaning. In this way, we provide direct evidence, along with our researcher interpretations, in order to preserve transparency of the process. With this process, readers are invited to form their own relationship with the data and check their conclusions against ours in hopes of sparking ongoing professional interest.

The qualitative analysis of the results revealed four superordinate themes, each with a varying number of subthemes. The results are presented herein according to the four superordinate themes of social support, school experiences, understanding of LD/ADHD, and self-advocacy, and the subthemes within each. See Table 1 for a complete list of these themes and subthemes.

**Table 1** *Master Table of Themes* 

Superordinate themes	Subthemes
Social Support	Family support. Validation from knowing peers with LD. Mentorship.
School Experience	Elementary school was a struggle. Feeling comfortable now. Best moments in school.
Understanding of LD/ADHD	Explaining/difficulty explaining LD/ADHD. LD/ADHD impact in school and outside too. LD as a learning experience.
Self-Advocacy	

# **Social Support**

**Family support.** The participants discussed their experiences at home, each making special reference to the support they received from their mothers. Three out of the four participants have mothers who became special education teachers after learning that their children had some form of LD. All four of the participants spoke about their homes being a safe and comfortable environment especially in relation to having LD/ADHD. For example, one participant said:

- Like with a lot of family support and -- you know. My parents have always been there for me, which has been really great. (P2)

#### Another participant explained:

- I feel home is a really comfortable environment, due to my parents' understanding and my dad having dyslexia. Um, it's a lot safer at home. I could read out loud any time I want to and say the wrong word and I have no one to judge me. (P1)

Another participant explained the strong influence of his parent by saying:

- Well, there was one teacher -- who wasn't really my teacher, but a teacher, which is the reason I work so hard right now -- is my mom. She's a Special Ed teacher. Like, I'm the reason she became a teacher is because I was struggling in school. (P4)

Validation from knowing peers with LD. Each participant had an experience of connecting with peers with LD at a different stage in his or her life. For example, one participant said:

- Adults have it. Maybe your parents have it. Friends have it. It's just nice. And that'll like – helps me get through my life, I guess, knowing that there's other people. (P1)

Another explained, referring to his experience in attending a school for children with LD/ADHD:

- First of all, it was really nice just to be in an environment where everybody else has either the same problems or, uh, oftentimes even worse problems, uh, which, I mean, makes you feel a little bit better about yourself. (P3)

The participants described these experiences as a sense of validation or relatedness in discovering or just knowing other people with LD.

**Mentorship.** Some participants had similarly validating experiences when identifying with adults with LD. Commonly, the adults were teachers and thus already in mentoring roles however, the participants related to them on a different level upon learning about the common ground they shared. Some participants described the experience as:

- This year I feel a lot comfortable with them because, for one, I have a teacher who's ADHD so it's nice to relate with that. (P1)
- They did, they just understood and they -- I mean, that was why they were hired was they knew how to deal with this. Uh, but yeah, it was really helpful. (P3)

There are other examples of participants describing teachers who were understanding about LD/ADHD in the classroom. However, having a teacher who was understanding because of a shared experience appeared to add a level of relatedness that deepened that feeling of acceptance and support.

# **School Experience**

**Elementary school was a struggle.** One marked theme among participants was the experience of struggling in school during the elementary school years. In some cases, the stigma associated with being LD or outwardly learning differently in front of other students appeared to be the salient piece of their experience. One described their experience in elementary school as, "felt like a prison" (P1). Another remembered in reference to the prospect of going to elementary school each morning, "I would lock the door to my room and hide under my bed" (P3). Still another reported feeling:

- Underappreciated. Well, not underappreciated because I didn't really know. At that age I don't know if I could have been appreciated at all but I felt like I was stupid, I guess. (P4)

This same participant described a particularly poignant memory from his elementary school years:

- Well I remember, I was the only one that wasn't reading at the same level and then like when it was time to read -- I think it was "Frog and Toad" or something else. I remember that my teacher just made me stand out from the whole class by saying, "These are the kind of books you should be reading right now." Even back then, I knew that was horribly wrong for a teacher to say. (P4)

It appeared that the focus for these participants, was not on the struggles they faced academically, but on the emotional component to being in the classroom environment or in being misunderstood by a teacher.

**Feeling comfortable now.** Another common theme was that, in general, participants presently felt comfortable in school. Several described high school as being where they began to relax in school. One participant described this by saying:

- It is. It's become a-a lot, um, safer environment for people who have learning disabilities so – and they're coming out more and talking about it, which is good. (P1)

### Another reported feeling:

- I think at that point, was comfortable -- much more comfortable with a lot of the teachers. (P3)

# Another said similarly:

- Well pretty much all the teachers I've met in [name of high school], in my high school, they understand me pretty well. (P4)

These more positive experiences appeared to be related to a number of factors involving the development of strategies, increase in confidence in abilities, awareness of self, and validation from peers and teachers.

**Best moments in school.** There were moments in school that participants identified as positive. Participants spoke about these experiences as new and validating. For example:

- Recently it's just good moments. They've just been like done better than the majority of the class or did something right, or just managed to get something that other people didn't. (P3)

Or similarly, one participant cited:

- Getting a report card back with no C's. (P2)

Interestingly, these moments described were generally connected with achievement or success as measured by conventional academic standards in mainstream U.S. culture.

# **Understanding of LD/ADHD**

**Explaining to lay people.** As per one of the interview questions, each participant shared their idea of how they would explain LD/ADHD to a person who had no prior experience or background in the area. Several participants struggled to define it in general terms. However, each participant demonstrated knowledge about the specifics of their own learning style and experience: For example, one participant said:

- I guess I would I would say, that there are traits that trace back into long in history. That some people mistakenly see it as a condition or a disease or something. It's a trait that makes people neurologically different. (P4)

This same participant qualified this by stating:

- There are certain parts of my brain that work differently than normal people do. Like, ADHD isn't a deficit. It's like extra attention that's divided. (P4)

Another participant explained:

- I'd describe it as kind of certain things not connecting in the brain. Uh, like I always go back to my reading, when I was younger, was I just couldn't -- I could tell what a word meant. But I couldn't string them together properly. So I couldn't read-read it well or read it, actually. (P3)

Another participant said:

I would probably first start off with: it's not something that you can identify on the outside. That would probably be where I would start with them. And then I would explain what ADHD would be and, um, dyslexia and all the other disabilities, and really explain the impact it has or had on my life, um, just for them to understand. (P1)

One participant shared a unique perspective, using his own experience of reading as an example:

- I try doing this a lot, trying to describe dyslexia. It's not viewing words backwards; that's what everyone always says...It's almost like the way in which I view text is -- I almost view it more like kind of an image, instead of like individual characters almost. If that makes any sense at all. (P2)

Though the perspectives varied considerably, each participant demonstrated knowledge about the specifics of their own learning style and experience.

**LD/ADHD impact in school and outside too.** Two participants made special mention of the generalized nature of LD/ADHD. Specifically, they clarified the common misconception that LD just affects you in the classroom or when doing academic work. For example, one said:

- For instance the question about how your LD affects you in your day-to-day life. It's there; it doesn't just only relate to school and home. It can also be like the passing periods in between, and things like that. (P2)

#### Another said:

- The only thing I don't think she understands is how it takes me several times as long to do things as she does. Like, sometimes I help my mom with the laundry. But there's once, when I did it myself, and then when she thought that I was done, I wasn't. She saw that I wasn't done. I don't think that she sees school and housework as the exact same thing, which, I think that she's a little naïve about still. (P4)

These participants aptly described the experience of living with LD and how it affects more than one area of functioning.

**LD** as a learning experience. Two participants elaborated on their understanding of LD/ADHD and spoke about the experience as an area of personal growth. One participant explained:

- For example it's making me kind of just as an individual a lot more driven and a lot more self confident about myself compared to other classmates. (P2)

The same participant elaborated on this effect, referring to a peer support group for young people with LD/ADHD:

- I always viewed it as a disability, like something that would be holding me back. But ever since I've kind of joined this Safe Voices and just kind of -- I don't know, become involved with them, the LD community, I've kind of learned how it can also learn to be a strength.

Another participant reflected on the impact his experience with LD has had on his life, saying:

- And it was just a process of continuing to learn from it all" partially just 'cause of the change in like the workloads and everything, with that still affected by my LDs as well. And it's again, a matter of some time, some effort put in to

kind of just figure out what needed to get done or how it needed to be done. (P3)

It appears significant that these participants discussed their struggle with LD/ADHD as an important component of their overall learning experience and maturation process—which suggests an adaptive resiliency.

# **Self-advocacy**

Several participants spoke about self-advocacy without being prompted. For example:

- One of the things I always do whenever I approach a new school year is I always go up to all my teachers and I tell them that I have dyslexia. And the accommodations that I applied for, and the accommodations that I need. (P2)

Another explained how important self-advocacy is as a tool:

- It's helped me, yeah, exponentially. It's, uh, I mean without it [advocating for myself], I would be having to wait until the teacher approached me, which would be after-after, of course, I would have been failing things or doing badly, at which point you can't really reverse that too much. (P3)

Another participant illustrated how she utilized self-advocacy:

We [my advisor and I] talked about it and we both said we should send e-mails to all my teachers saying I should have the – I have these disabilities, I have these accommodations that I need, and I would go into each teacher and talk to them myself. And, you know, they-they, uh, they really appreciate self-advocacy so, uh, that's how I [get to be] more comfortable with my teachers. (P1)

#### Another participant reflected:

- I guess, from being involved with like SAFE [Safe Voices—a peer support groups for young people with LD/ADHD] and all that stuff, I'm kind of used to it. But I know for a lot of the kids in my class it's kind of a struggle. And some kids don't even say anything, which is even sometimes hard for me to watch, because I can see that they're struggling but they won't go that extra mile to help themselves. Which is kind of difficult. (P2)

While some participants shared their experiences with advocating for themselves, others seemed to have empathy for those students who had not yet developed these important resiliency skills.

#### **Discussion**

The present study shed light on the lived experience of adolescents with LD in regards to peer support, self-advocacy, and self-acceptance of LD as well as other themes not previously identified. The four adolescent participants in this study expressed a number of super-ordinate themes: Social Support, Experiences at School, Resilience, and Understanding

of LD/ADHD. These themes represent a variety of underlying experiences, which are further detailed by subthemes and direct quotations from the interviews. For these participants, negative experiences associated with their LD/ADHD seemed to start in elementary school while home remained a safe constant. Success factors, which served to compensate for these negative experiences, were having supportive parents and a mother who dedicated herself to helping her child succeed in school. Later, when participants got involved with other peers with LD/ADHD and started to have better experiences in school, they reported feeling more validated and began to see the personal growth they had achieved in their personal struggle. The identification of these themes illustrates the importance of mentors with LD as well as supportive home environments.

Participants showed great understanding of their own specific learning style yet some still struggled to define LD/ADHD in conventional terms, which ironically allowed for unique perspectives on their own lived experience of the phenomenon. Self-advocacy was identified as a crucial tool, and the participants were aware of how their skill in advocating for themselves developed over time. Quite significantly, these participants demonstrated positive indications of forming a positively internalized identity related to LD/ADHD and their associated strengths. This adds a level of depth to prior research by Higgins et al. (2007) regarding acceptance of LD. Higgins et al. (2007) examined the stages of acceptance of LD, while the present study elaborates on how it actually manifests in these four participants' understanding of and the role of LD/ADHD in their lives. The depth and range of findings that emerged in this study, in terms of social support, school experiences, understanding of LD/ADHD, and self-advocacy speaks the power of understanding LD/ADHD by asking adolescents to share *their perspective* on something that they have lived with, been put down for, sought and received assistance/support for, connected with others on, internalized an understanding of, and developed mastery over throughout their young lives.

The limitations of this study are the small sample size and limited diversity among the participants. The participants in this study were all diagnosed with LD/ADHD in elementary school. They all come from middle class households in the Bay Area and at least one of their parents or guardians is an educator. Additionally, all of the participants belong to at least one support/awareness group for individuals with LD/ADHD. Caution is warranted for readers when making generalizations or conclusions about people beyond the individuals who participated in this study. Further research in this area with a larger sample size and a more diverse sampling pool would be a significant contribution to the literature.

#### Conclusion

The purpose of this study is to capture the lived experiences of adolescents with LD. By asking four adolescents about their experiences in an accessible and creative manner, themes related to social support, understanding of LD, school experiences, and self-advocacy emerged. This study highlights the need for more research concerning the voices of adolescents with LD. Learning more about the lived experiences of this population can help to identify areas in which they can be supported and encouraged.

Constructs of self-advocacy and peer support have been noted empirically as important in the success of young people with LD/ADHD. The present study adds depth to the understanding of the role of family as well as more about the impact of school experiences. The importance of young people understanding LD/ADHD also emerged in this study. Together, the themes appear to suggest that adolescents with LD have the potential to form a positive internalized identity related to LD/ADHD. It is hoped that this small study exploring the lived experience of four adolescents thriving with LD will spark more interest in future research and provide more much needed contributions to this field. Further research

identifying the strengths and uncovering the emotional experiences of young people with LD may help to develop deeper understandings and therefore more effective early interventions, so that more young people with LD have the opportunity thrive.

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# Appendix A

# **Open Ended Interview Questions**

Now I am going to ask you a few open-ended questions about your experiences at home and in school. I have a series of general that will get our conversation started. Please feel free to share whatever comes to mind. Even though I am taping our conversation, your name and identity will be kept confidential. I would like us to feel comfortable together as we talk. If we venture into a topic that isn't comfortable, just raise your hand, and we will go on to something else.

# School experiences.

- 1. I'm interested in what school is like for you.
  - a. How do you feel when you are at school?
  - b. Prompt for the opposite of above response: How about a time when you have really enjoyed (not at all enjoyed) school?
- 2. How about your teachers this year:
  - a. How comfortable do you feel with them this year? How so?
  - b. Have your ever felt really understood by a teacher? How was that for you?
  - c. Have your ever felt really misunderstood by a teacher? How was that for you?
  - d. If you think back across your entire school career, what teacher has had an impact on you and what type of impact was it? It can be positive or negative.

# Identity.

- 1. Describe yourself for me.
- 2. How would you describe your LD and/or ADHD to someone who does not know anything about LD or ADHD?

- 3. What does having an LD and/or ADHD mean to you?
- 4. How is your LD and/or ADHD a part of your life?
- 5. How would you describe your experience in school as a person with a LD?
- 6. How would you describe your experience at home in your family as a person with an LD?
- 7. How do you feel about yourself as a person with a LD?
  - i. At school?
  - ii. At home?
- 8. How do you think others feel about you as a person with a LD?
  - i. At school?
  - ii. At home?
- 9. How would you like others to feel about you as a person with a LD?
  - i. At school?
  - ii. At home?
- 10. Tell me about your best moment at school?
- 11. Tell me about your worst moment at school?
- 12. How did having a LD influence the moments that you just talked about?

# **Self-advocacy.**

- 1. What does self-advocacy mean to you?
- 2. In what ways do you self-advocate?
  - a. At home?
  - b. In school?

# Peer support.

- 1. In what ways do you advocate for others with a LD?
  - a. At home?
  - b. In school?
- 2. Tell me about your friends. What are they like?
- 3. Who do you relate to most and why?
- 4. When you are around other people your age, in what ways are you aware of your LD?
  - a. How about when you are around adults?
  - b. How about when you are around children?
- 5. In what ways are people with LD part of your life?
- 6. Is there anything that we haven't talked about that you feel would help me understand your experience with having a LD?
  - a. In school?
  - b. At home?

#### **Author Note**

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