

INFLUENCES ON THE SELF-CONCEPT OF
ADOLESCENTS WITH INTELLECTUAL
DISABILITIES

By

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1995

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2006

Submitted to the Faculty of the
Graduate College of the
Oklahoma State University
in partial fulfillment of
the requirements for
the Degree of
DOCTOR OF PHILOSOPHY
July, 2009

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ACKNOWLEDGMENTS

It is difficult to find the words that adequately express my appreciation to others. The completion of my doctoral degree would not be possible without the unwavering support of those who have encouraged, guided, and journeyed with me along this road. I want to start by thanking my advisor and mentor, Dr. Patricia Self. Patti is a rare jewel whose value is known to far too few. She is uniquely gifted in her ability to simultaneously challenge and support her students. We have had great fun and I look forward to many years together in the future as colleagues and friends.

I am extremely fortunate to have had a brilliant and supportive committee. Dr. Laura Hubbs-Tait has been instrumental in my graduate studies' success as both a committee member and graduate coordinator. I have been the fortunate recipient of her knowledge, kindness, and dedication on too many occasions to count. Dr. Lucy Bailey gave selflessly of her time and expertise; her insight into the qualitative data was remarkable. Dr. Janice Miller answered countless questions with such patience and Dr. Whitney Brosi broadened my understanding of those in our midst that are often marginalized by society. I am truly privileged to have been under the tutelage of these wise women.

I also want to thank the adolescents, parents and teachers who participated in this research study. Their willingness to share their experiences will benefit many in the years ahead.

My friends and extended family have been a tremendous source of support. I would not have undertaken this task without the encouragement of my sweet friend, Lisa Bickel, who so wisely told me years ago that I was bound to persevere on something so it might as well be productive! My mom, Connie Graves, has been my greatest fan, constantly providing both emotional and practical support (e.g., babysitting, grocery shopping, and dinner!). My sojourners, Debbie Richardson and Julie Rutledge, have also been a precious resource. Debbie served as my sounding board on several key decisions and Julie is the best editor I know!

Finally, I want to thank my husband, Tim, and children, Garrett, Maggie, and Porter, who have sacrificed so much for me to pursue this degree. Tim is the kindest, most selfless man I know; he continually puts the needs and desires of others above his own. I am so grateful that nearly thirteen years ago we naively embraced the task of parenting together...having no idea how much our lives would be forever impacted. Garrett, without you, this project never would have occurred. Thank you for enriching our lives and giving me a new and better lens through which to see the world. Maggie, "we" did it! Thank you for endless hours of putting together packets and alphabetizing exams; I know this degree will pale in comparison to all you will accomplish in life. You are a brilliant and beautiful woman. And last, but not least, Porter, your interest and pride in my work has been inspiring. Thank you bringing me such joy.

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Adolescence is the developmental period when most children begin to assert their independence and desire for autonomy (Erikson, 1950). For individuals with intellectual disabilities (ID), the developmental tasks associated with adolescence—extracurricular activities, sexuality, vocational preparation, and independent living—are compounded by their disability (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). While environmental events are known to influence the development of self-concept in both typically developing individuals and persons with ID, the context and content associated with such environmental events are likely to differ (Zigler, 1971). Accordingly, personal characteristics associated with the vulnerability of an individual's disabling condition can create stressors which disrupt positive family interactions patterns; which in turn, negatively affect child outcomes (Guralnick, 2005). Thus, the experiences of adolescents with ID, along with their families, are embedded within the context of disability.

For many persons with ID, it is during their adolescent years when they begin to recognize the differences between themselves and their typically developing peers. This recognition may lead to feelings of inadequacy, frustration, and isolation (Evans, 1998; Rowitz, 1988; Zetlin & Turner, 1985). Persons with ID are more likely to experience repeated failure; these experiences often lead to feelings of uncertainty and learned helplessness (Evans, 1998). Weisz (1990) argues that the culmination of these

experiences and learned helplessness are critical components in the expression of depression in children and adolescents with ID. Furthermore, depression has been significantly negatively correlated with aspects of social comparison (e.g., peer social belonging) and global self-worth in both adolescents and adults with ID (Dagnan & Sandhu, 1999; Glick, Bybee, & Zigler, 1997).

Stigmatization and the Intellectual Disability Label

Some have argued that the psychological risks for persons with ID may be due in part to the stigmatization of the intellectual disability label (Edgerton, 1993). Beart, Hardy, and Buchan (2005) argue that the label of intellectual disability is a powerful and stigmatizing social identity having a profound impact on peoples' lives; once bestowed, it can remain the dominant identity through which persons with ID are viewed by society. So influential is the label of ID that it may supersede other social identities (Hughes, 1945) including gender (Burns, 2000), ethnic origin, sexuality, and religion (Walmsley & Downer, 1997). Therefore, it is through this stigmatized lens that persons with ID are frequently viewed by others. As such, their self-perception may be filtered through these daily experiences and social interactions.

Self-Concept and Global Self-Worth

It is widely accepted that how one views oneself is critical to one's long-term personal development (Harter, 1986/1993; James 1892). An individual's self-concept is constructed from "organized interpretations of one's daily life experiences as they pertain to the self" (Caselman & Self, 2007, p. 353). Therefore, an individual's thoughts, feelings, and actions are influenced by their self-perception. Early research on the self-perceptions of children focused on self-esteem or self-worth as a global construct.

However, more recent literature has established the multidimensional nature of self-concept (Harter, 1999; Marsh, Tracy, & Craven, 2006) including domain specific self-perceptions while maintaining global self-esteem in their models (Harter, 1999; Rosenberg, 1979). Harter (1990) further asserts that self-worth and global self-esteem are comparable constructs which can be described as “the overall value that one places on the self as a person” (p. 67).

In comparison to the plethora of research on the study of self in the normative population, relatively little is known about the self-concept of individuals with intellectual disabilities (Evans, 1998; Widaman, MacMillan, Hemsley, Little, & Balow, 1992; Zigler & Hodapp, 1986). This void of knowledge is somewhat surprising given that this area of study has been a primary focus in the field of developmental psychology for many years (Evans, 1998). Professionals within the fields of special education, counseling, human development, and psychology have referred to self-concept as “the cornerstone of both social and emotional development” (Kagen, Moore, & Bredekamp, 1995, p. 18). As such, positive self-esteem is associated with desirable outcomes, while negative self-esteem is associated with detrimental outcomes.

Social Support

Symbolic interactionists such as Baldwin (1897), Cooley (1902), and Mead (1934) have long proposed that the development of self is primarily socially constructed. In more recent years, several researchers (e.g., Caselman & Self, 2007; Cicchetti, 1990; Harter, 1999; Sroufe, 1990) have highlighted the powerful influence of social interaction processes with peers and caregivers on self-esteem. Furthermore, research in both

normative and ID populations elucidate the influence of social support on global self-worth (e.g., Felson, 1993; Harter, 1999; Marsh, Tracey, & Craven, 2006).

Social support has been conceptualized as the demonstration of emotional support along with the perception of positive regard from others (Harter, 1989). Research indicates that higher levels of social support are associated with greater self-esteem in typically developing adolescents (Felson, 1993). Moreover, depression in adults with mild ID is associated with low levels of social support and high levels of perceived stigmatization (Reiss & Benson, 1985). Harter (1985b) identified four sources of support for children and adolescents: parents, teachers, classmates, and close friends. Interestingly in Harter's research (1999), parent and classmate support contributed more to individual's global self-worth than did teacher or close friend support. Given these findings and the understanding that the self is socially constructed, it seems necessary to explore adolescents' perception of support from others as a significant influence on their global self-worth.

Parents as a Source of Support. The majority of the research regarding parents and children with ID has explored the parent-child relationship from the perspective of the parent (e.g., Blacher & Baker, 2007; Blacher & Hatton, 2007; Parish, 2006; Ray, 2003; Sobsey, 2004). This body of research has been crucial to understanding the complexity of family relationships. While, feelings of isolation and difference are a common theme among parents of young children with disabilities (Kerr & McIntosh, 1999), a "resilient disruption" model for families has been proposed (Costigan, Floyd, Harter, & McClintock, 1997). When a child has a lifelong disability, parenting often assumes the role of a career which adapts as the child grows (Seltzer & Heller, 1997).

Therefore, one would expect that as the child ages, parents adapt; yet they may encounter new challenges during adolescence.

Despite such challenges, many families report that having a child with ID has resulted in a positive impact on their family. Blacher and Baker (2007) found that parent perception of their preschool age child with ID as having a positive impact on the family moderated the relationship between child behavior problems and parenting stress. Furthermore, positive and negative impact have been established as unique constructs, with several studies reporting parental perceptions of both positive and negative impact on the family (e.g., Blacher & Baker, 2007; Scorgie & Sobsey, 2000; Stainton & Besser, 1998). Hastings and Taunt (2002) conclude that the “the presence of positive perceptions and experiences seem to occur in concert with negative or stressful experiences...and positive and negative perceptions seem to be predicted by different factors and can be considered as different dimensions” (p. 124).

Classmates as a Source of Support. One would also expect classmates to serve as a source of support for adolescents. The research concerning adolescent perception of classmate support is largely from the perspective of the other; meaning the informant is the typically developing peer, teacher, or parent rather than the individual with ID. Those studies which do include individuals with ID as informants tend to focus on the peer relationship between children with ID and their typically developing peers in a mainstream setting, rather than the relationship between two children both with disabilities (Kasari & Bauminger, 1998). There is some evidence that mainstreamed settings are more beneficial to younger children with ID because the developmental discrepancies between children with and without ID are less (Kasari & Bauminger,

1998). This may also be true since younger children are more likely to accept adult direction in their social interaction than older children or adolescents.

Student-Teacher Relationship

Beyond parents and classmates as sources of support, the student-teacher relationship is also likely to influence the adolescent's development of global self-worth. Eisenhower, Baker, and Blacher (2007) found that teachers reported significantly poorer relationships with young elementary age students with ID than their typically developing peers. However, the differences between the teacher relationships with ID students compared to typically developing students could not be entirely attributed to cognitive ability. Rather the relationship between ID and student-teacher relationship quality was mediated by the child's self-regulation and maternal and teacher report of child behavior problems. Murray and Greenberg (2001) also found that students (5th and 6th grade) with mild ID had significantly poorer affiliation with teachers and greater dissatisfaction with teachers than students without disabilities.

Self-Determination

Given the unique challenges (e.g., poor social support, limited social opportunities) encountered by persons with ID, researchers and clinicians have focused on promoting and enhancing the self-determination of young persons with ID in order better equip them to meet the developmental tasks of adolescence and adulthood. Wehmeyer and Garner (2003) suggest that there are two primary contributors to an individual's self-determination. The first is the individual's capacity for self-determination. In other words, what decision-making, goal-setting, and problem-solving skills does the individual possess? The second contributor is the extent to which the

environment (e.g., home, school, work, and recreation) allows an individual to make choices and exert control over his or her life. Thus, self-determination skills can be taught and the contextual environment and support from others (e.g., parents, classmate, and teachers) are likely to influence the individual's engagement in self-determined behaviors. Additionally, the benefits of self-determination for persons with ID have been well established in the research literature: self-determination is correlated with improved quality of life (Lachepelle et al., 2005), is a crucial component of successful transition to adulthood (Field, Martin, Miller, Ward, & Wehmeyer, 1998b), and is predictive of post-school success (Wehmeyer & Schwartz, 1997).

The Present Study

What remains to be understood is the relationship among these constructs and their impact on the global self-worth of adolescents with ID. The variables utilized in this study are listed in italics below:

<u>Adolescent Report</u>	<u>Parent Report</u>	<u>Teacher Report</u>
<i>Global Self-Worth</i>	Parent Perception of Child Impact:	Student-Teacher Relationship:
Adolescent Perception of Support:	<i>Positive Impact</i>	<i>Student-Teacher Conflict</i>
<i>Parent Support</i>	<i>Negative impact</i>	<i>Student-Teacher Closeness</i>
<i>Classmate Support</i>		<i>Student-Teacher Dependency</i>
		<i>Student-Teacher Total</i>
Self-Determination:		
<i>Autonomy</i>		
<i>Self-Regulation</i>		
<i>Psychological Empowerment</i>		
<i>Self-Realization</i>		
<i>Self-Determination Total</i>		

The present study provides a greater understanding by answering three specific research questions within the context of the subjective experiences of adolescents with ID. The

first research question asked if global self-worth, adolescent perception of support, adolescent self-determination, parent perception of child impact, and student-teacher relationship were related in this sample of adolescents. The second research question asked if the global self-worth of adolescents in this sample was predicted by their perception of support, their self-determination, parent perception of child impact and teacher report of the student-teacher relationship. And finally, did adolescents in this sample in resource rooms differ from adolescents in self-contained classrooms in their global self-worth, perception of support, self-determination, parent perception of child impact, and student-teacher relationship? A mixed-methods approach was utilized in order to obtain the depth of understanding needed to answer these questions.

Method

Participants

The sample included 51 adolescents with ID ($n = 38$ males, $n = 13$ females) ranging in age from 11.09 to 20.02 years ($M = 15.97$, $SD = 1.85$), their parents ($n = 50$), and teachers ($n = 12$). One parent chose not to complete the parent surveys, but did allow her child to participate in the study. Participants with a range of reported etiologies for their intellectual disabilities were included in this sample, with the greatest proportion ($n = 23$) being unknown etiology. Other reported etiologies included Autism Spectrum Disorder ($n = 5$); Down Syndrome ($n = 5$); Fetal Alcohol Syndrome ($n = 4$); Cerebral Palsy ($n = 2$); Spina Bifida ($n = 1$). and Other ($n = 11$). Those in the Other category included rare medical conditions such as Oral Facial Digital Syndrome and Chromosome 8Q deletion. The ethnic distribution of adolescent participants included 63% European American, 29% African American, 6% Native American, and 2% Arab. Verbal mental

age (VMA) was assessed using the Peabody Picture Vocabulary Test (PPVT-4: Dunn & Dunn, 2007) yielding a VMA mean of 8.37 ($SD = 2.49$) compared to the chronological age mean of 15.97 ($SD = 1.85$).

When asked to describe themselves in a face-to-face interview with the researcher, 61% ($n = 31$) of the adolescent participants mentioned activities they enjoyed. Many of the activities described by this sample were similar to those one would expect of typically developing adolescents (e.g., playing video games, listening to music on their iPods, playing sports, and watching television). Thirty-nine percent ($n = 20$) used positive personality characteristics such as being “nice” or “a good person” when giving a self-description. Interestingly, only one child mentioned her race (e.g., “I’m black.”) and while 32% ($n = 12$) of the males described themselves by gender (e.g., “I’m a boy” or “I’m a young man”), only one female used gender as a descriptor. While almost half of the sample (43%; $n = 22$) described their physical characteristics such as hair or eye color, height, or age in neutral or matter-of-fact terms, ten of these adolescents went on to state physical characteristics they would like to change about themselves (e.g., acne, hair, weight). Particularly notable comments were those from adolescent participants who articulated a desire to change their disabling condition: “I would be with no disabilities and actually get to be in regular classes and play football. Sometimes my disabilities just get old.” There was a profound sense of weariness and loss from some adolescents. For many, their desire to change their disability appeared to be linked to limited opportunities (e.g., not being able to attend college or participate in school athletic programs).

All of the adolescents were identified by their special education teacher as having intellectual disabilities which fell in the mild, mild-moderate, moderate, or moderate-

severe range. Students' classroom placements included self-contained ID classrooms ($n = 31$) and ID resource rooms ($n = 20$); decisions regarding classroom placement were made by the students' Individualized Education Plan team. Self-contained classrooms were characterized by isolation from the general school population both in their daily school routine and socialization. These classes focused on life skills such as cooking and job training more than core academics. For students in self-contained classrooms, interaction with typically developing peers during the school day was generally limited to a peer model who served as a teacher helper for approximately one hour each day. Resource rooms offered individualized or small group learning environments with the primary focus on academic curriculum. Students in resource rooms generally remained within the mainstream of the school environment and nearly one-third ($n = 6$) of these students participated in school sponsored extracurricular activities with typically developing peers (e.g., band or athletics). Students in self-contained classrooms typically have greater cognitive deficits than those in resource rooms and this was the case for this sample. Verbal mental age scores did indicate significantly lower age-equivalency ($p = .01$) for students in the self-contained classrooms ($M = 7.51$, $SD = 1.79$) compared to those in the resource rooms ($M = 9.71$, $SD = 2.86$). Further descriptive information for the sample is presented in Table 1.

It is important to note that all data are static and represent one particular point in time; however adolescent relationships with teachers, parents, and classmates are not. Rather, adolescents' relationships with their classmates, parents and teacher in this study were dynamic and likely to continue to evolve across time. Also, there were multiple factors which might influence the relationships between adolescents and their classmates,

parents, and teachers. For example, adolescent perception of classmate support is likely to be impacted by the extent of the relationship between adolescents and their classmates. Students in self-contained classrooms may have been together with the same classmates for extended periods throughout their academic career; whereas, this may be less true of adolescents in resource rooms. Likewise, it is probable that students in self-contained classrooms would have the same special education teacher for several consecutive years. Thus, the duration of the relationship between adolescents and their classmates and adolescents and their teachers may impact adolescent perception of support and teacher report of the student-teacher relationship.

Measures

Instrument selection was based on gathering information from all three stakeholder groups (adolescents, parents, and teachers), with particular emphasis placed on the subjective experiences of the adolescents with ID. Adolescents responded to items from three quantitative measures assessing their self-perception, social support, and self-determination along with a brief measure of verbal ability. A qualitative interview was also conducted with the adolescents to explore their knowledge of self and intellectual disability. Parents completed a demographic questionnaire regarding child characteristics and family structure along with a survey regarding their perception of child impact on the family. Teachers completed a quantitative measure of student-teacher relationship. A brief description of each instrument is presented below.

Self-Perception Profile for Children (SPPC; Harter, 1985a) is a 36-item self-report measure that taps Global Self-Worth and five specific domains: scholastic competence, athletic competence, social acceptance, physical appearance, and behavioral

conduct. Items are presented in a structured alternative format where the child is asked to decide which kind of *kid* is most like him or her, and then asked whether this is only *sort of true* or *really true* for him or her. Items are scored from 1 to 4 with 4 representing the most positive self-perception. Each subscale contains six items and produces an independent score ranging from 6 to 24. Subscale means are computed for the five specific domains and for Global Self-Worth. Only the Global Self-Worth scale was used as a variable in this study. Internal consistency reliabilities for each of the subscales were based on Cronbach's alpha and ranged from .71 to .85; factor analysis revealed that each of the subscales defines their own factor with cross loadings across factors negligible at .04 to .08 (Harter, 1985a).

Given the scarcity of self-perception measures designed specifically for persons with ID, the SPPC along with other measures developed by Harter (e.g., Pictorial Scale of Perceived Competence and Social Acceptance for Young Children, Harter & Pike, 1984; Self-Perception Profile for Learning Disabled Students, Renick & Harter, 1988) have been used frequently in research exploring the self-concepts of children and adolescents with ID (Bybee, Ennis, & Zigler, 1990; Cunningham & Glenn, 2004; Cuskally & de Jong, 1996; Glenn & Cunningham, 2001; Glick, Bybee, & Zigler, 1997; Levy-Shiff, Kedem, & Sevilla, 1990; Szivos-Bach, 1993). Glenn and Cunningham (2001) found the format and content of the SPPC items to be valid when used with young people with Down Syndrome who had verbal mental ages around seven years of age. Glick, Bybee, and Zigler (1997) also found the SPPC to be a valid measure of self-perception in their sample of adolescents (mean age 13 years, 3 months) with ID (mean IQ = 66).

Social Support Scale for Children and Adolescents (SSSCA) is a 24-item self report inventory also developed by Harter (1985b). This instrument taps perceived support and positive regard from four sources: parents, teachers, close friends, and classmates. Similar to the SPPC, the SSSCA items are presented in a structured alternative format where the child is asked to decide which kind of *kid* is most like him or her, and then asked whether this is only *sort of true* or *really true* for him or her. Items are scored from 1 to 4 with 4 representing the greatest sense of support and 1 representing the least. Each source of support comprises a subscale (Parent, Teacher, Close Friend, and Classmate) containing six items and produces an independent score ranging from 6 to 24. Internal consistency reliabilities for the subscales are in an acceptable range of .72 to .88 (Harter, 1985b).

The SSSCA was utilized in this study because of its previous ability to predict self-esteem in students ages 8 to 18 (Harter, 1986). Also, the SSSCA has been utilized in research with special populations including children and adolescents with intellectual disabilities (Saylor & Leach, 2009), craniofacial anomalies (Shute, McArthy, & Roberts, 2007), neurofibromatosis (Counterman, Saylor, & Pai, 1995), developmental coordination disorder (Piek, Dworcan, Barrett, & Coleman, 2000), cystic fibrosis (Christian & D’Auria, 2006), and learning disabilities (Martinez, 2006; Rothman & Cosden, 1995). It is important to note that Silon and Harter’s (1985) research has shown “children’s scores are directly influenced by the particular social reference groups they are employing” (Harter, 1985a, p. 22). Therefore, adolescent participants in this study were instructed to use their classmates (i.e., other students in the resource room or self-contained classroom) when making comparisons to others on both the SPPC and SSSCA.

Thus, adolescents in this study were comparing themselves to other students with similar cognitive abilities rather than to typically developing peers.

Arc's Self-Determination Scale (ASDS: Wehmeyer & Kelchner, 1995) is 72-item self-report measure of self-determination designed for use by adolescents with ID. The ASDS contains four subscales: Autonomy, Self-Regulation, Psychological Empowerment, and Self-Realization. Autonomy items assess independence and the extent to which the informant acts on the basis of personal beliefs, values, interests, and abilities. Sample items include “I make my own meals or snacks” or “I choose my own hair style” with a forced-choice format of 4 answers (I do not even if I have the chance; I do sometimes when I have the chance; I do most of the time when I have the chance; I do every time I have the chance). The adolescent is given the beginning and end to a story in the Self-Regulation items sections (e.g., beginning: “You hear a friend talking about a job opening at the local bookstore. You love books and want a job. You decide you would like to work at the bookstore.” end: “The story ends with you working at the bookstore.”) and then asked to tell what happened in the middle of the story. Items in the Psychological Empowerment subscale ask the adolescent to choose the answer which best describes them (e.g., “I can make my own decisions” OR “Other people make decisions for me.”). The Self-Realization domain asks the adolescent if they agree or disagree with a statement (e.g., “I know what I do best”). Scoring for the ASDS results in domain totals for each section, as well as, a Self-Determination Total score. Adequate construct validity, including factorial validity established by repeated factor analyses, and discriminative validity were reported by instrument authors along with internal

consistency reliabilities as follows: .90 Scale as a whole, .90 Autonomy, .73 Psychological Empowerment, .62 Self-Realization (Wehmeyer & Kelchner, 1995).

Peabody-Picture Vocabulary Test-4 (PPVT-4: Dunn & Dunn, 2007) is a widely used measure to assess receptive vocabulary and a screening test for verbal ability. The instrument consists of 228 picture plates with 4 pictures per plate. Test administration involves the examiner reading a word and asking the participant to select the picture that best describes that word. The score is computed by subtracting the number of errors from the ceiling score. Tables allow scores to be converted to a percentile rank, age-equivalent score, or standard score. Reliability analyses included internal consistency, alternate-form, and test-retest with results indicating PPVT-4 scores as highly precise and only minimally affected by measurement error (Dunn & Dunn, 2007). Construct and content validity were also established by the authors and the standardization sample included typically developing children, special populations (e.g., hearing impaired, speech impaired, ADHD), and children with ID ranging in chronological age from 6 to 17.

Knowledge of Self and Disability. Questions for this instrument were adapted from Cunningham and Glenn's (2004) interview used with young adults with Down Syndrome. Questions included asking adolescents (1) to describe themselves, (2) what, if anything, would they like to change about themselves, (3) have they heard of terms related to intellectual disability and what do those terms mean, (4) how do they know if someone has a disability, (5) do they have a disability, and (6) do any of their friends have a disability. The purpose of the interview was to assess adolescents' knowledge of intellectual disability terminology (e.g., learning disability, mental retardation, special needs) and their application of such terminology to themselves. Asking adolescents with

ID directly about their knowledge of intellectual disability and application of disability terminology to themselves gave a voice to this group of participants. The researcher believed it was imperative that adolescent participants have the opportunity to describe themselves and express their own thoughts, feelings, and opinions about the labels placed upon them and the categories into which they are placed by others.

Family Impact Questionnaire (FIQ: Donenberg & Baker, 1993) is a 50-item measure focused on the child's impact on the family compared to the impact of other children his/her age on their families. Parents are asked to endorse items on a 1 to 4 or 1 to 7 Likert-type scale ranging from *not at all* to *very much* by comparing their thoughts and feelings to children and parents with children the same age as their child with a disability. Sample items include "I participate less in community activities because of my child's behavior" and "I enjoy the time I spend with my child more". Child impact on the family is measured in six domains: (1) impact on social relationships, (2) negative feelings about parenting, (3) positive feelings about parenting, (4) financial impact, (5) impact on marriage, and (6) impact on siblings. Scales one and two (i.e., impact on social relationships and negative feelings about parenting) combine into a 20-item scale measuring Negative Impact; while scale three (i.e., positive feelings about parenting) measures Positive Impact. Only the parent perception of child Negative Impact and Positive Impact were used in this study. Reliability and validity of this measure are reported as acceptable in samples of parents of children with and without intellectual disabilities (Baker, Heller, & Henker, 2000; Blacher & Baker, 2007; Blacher & McIntyre, 2006).

Student-Teacher Relationship Scale (STRS: Pianta, 2001) is a 28-item teacher-report instrument that utilizes a 5-point Likert-type rating scale. The STRS was designed to measure student-teacher relationship patterns in terms of conflict, closeness, and dependency, as well as the overall quality of the relationship. As such, scores can be derived for these three subscales (Conflict, Closeness, and Dependency), as well as a Total score derived from the three subscale raw scores. Items from the Conflict domain measure the extent to which the teacher perceives his or her relationship with a student as negative and conflictual (e.g., “This child and I always seem to be struggling with each other”). Conflict scores that are high reflect teacher-student struggles and a teacher perspective of the student as angry or unpredictable. Items from the Closeness domain measure the degree to which the teacher views his or her relationship with a student as warm, affectionate, and reflective of open communication (e.g., “If upset, this child will seek comfort from me). High Closeness scores indicate teacher perception that the student can effectively access the teacher as a source of support. Items from the Dependency domain measure the extent to which a teacher perceives a student as overly dependent on him/her (e.g., “This child asks for my help when he really does not need it”). As such, high scores on the Dependency domain imply a strong student reaction to separation from the teacher, student requests for help that is not needed, and a concern that the student is over-reliant on the teacher. The STRS Total scale measures teacher perception of his or her relationship with a student as generally positive and effective. Higher Total scale scores tend to indicate lower levels of Conflict and Dependency and higher levels of Closeness. Test-retest reliability correlations were significant ($p < .05$) and internal consistency reliabilities along with construct, concurrent, and predictive

validity are acceptable (Pianta, 2001). The STRS has been used in research with students with ID ranging in age from preschool through 6th grade (Eisenhower, Blacher, & Baker, 2005; McIntyre, Blacher, & Baker, 2006; Murray & Greenberg, 2001).

Procedure

The participating school district provided a list of special education teachers whose students were categorized as having ID. Written consent was then obtained from school principals, teachers, and parents. Due to the limited reading skills of some adolescent participants, verbal assent was obtained from adolescents prior to data collection. Individual interviews and administration of the instruments with adolescent participants took place at their school in a quiet area close to their classroom. Detailed interview notes were recorded and then transcribed by the researcher; the decision not to audiotape the interviews was made in order to remove any distractions or barriers for the adolescent participant. Parents and teachers completed their questionnaires independently and returned the sealed packet to the researcher.

Results

Preliminary analyses were conducted before moving forward with statistical tests to answer the three research questions. The purpose of the qualitative data in this study was to elucidate the subjective experiences of the adolescent participants. Thus, the qualitative findings are presented along with the quantitative results throughout this section.

Preliminary Analyses

Reliability of measures was addressed through evaluation of internal consistency using Cronbach's alpha. Coefficient alphas were acceptable for all measures and are

presented along the diagonal in Table 2. Also, as expected, each of the SPPC competency subscales was significantly positively correlated ($p < .01$) with Global Self Worth (scholastic competence: $r = .482$; social acceptance: $r = .516$; athletic competence: $r = .407$; physical competence: $r = .652$; behavioral conduct: $r = .399$) indicating convergent validity of this measure.

Given that this sample was drawn from a special population, there was the expectation of variability in the sample characteristics. Even so, review of the scatterplots indicated that the data did meet the linearity assumption needed for multiple regression analysis. Furthermore, a non-parametric test, the Mann-Whitney U, was used to explore differences in adolescent and family characteristics between participants in self-contained classrooms and those in resource rooms. Results indicated significant group differences in only two of the descriptive variables: verbal mental age ($z = -2.57, p = .010$) and maternal education ($z = -2.07, p = .038$).

Preliminary analyses also included evaluation of intercorrelations for multicollinearity. Of specific concern was the relationship between parent perception of their child as having a Positive Impact or Negative Impact as reported on the FIQ. Similar to previous literature (Blacher & Baker, 2007) Positive Impact and Negative Impact were significantly negatively correlated ($r = -.453, p < .001$); however, multicollinearity was not indicated.

Correlations among the Variables

Examination of Pearson's correlation coefficients (see Table 2), revealed several significant correlations among the variables of interest. Adolescent perception of Parent Support was positively correlated with Global Self-Worth ($r = .352, p < .05$) and

Psychological Empowerment ($r = .284, p < .05$). Adolescent perception of Classmate Support was positively correlated with parent perception of child Positive Impact ($r = .329, p < .05$). There was also a positive correlation between Self-Realization and parent perception of child Negative Impact ($r = .305, p < .05$). Lastly, teacher report of student Dependency was significantly negatively correlated with Self-Regulation ($r = -.325, p < .05$) and Psychological Empowerment ($r = -.357, p < .05$).

As stated previously, there was a significant negative correlation ($r = -.453, p < .001$) between parent perception of Positive Impact and parent perception of Negative Impact. This concurrent expression of both Positive Impact and Negative Impact is further evidenced in the qualitative data from parents. Parents in this sample often described their child as a “blessing” or “special” while simultaneously indicating that having a child with a disability does create some unique challenges. One parent wrote,

We have truly been blessed with this exceedingly happy, independent, affectionate, and motivated child and we believe that God indeed has a much higher purpose for our family. As every parent of a special needs child knows every day is a challenge – and you have to believe that God will show you the way. But, it is still an incredibly difficult task that comes with many highs and many lows, but always an honor to have been “chosen.”

The parent’s choice of words such as “higher purpose”, “honor”, and “chosen” reflect an association of their child’s disabling condition and their own spirituality. Several parents echoed this sentiment with statements about “God making their child special.”

Parents also appeared to have put a great deal of effort into minimizing their child's disability. Comments such as, "I try hard to make her life as normal as possible" and "We don't treat John any different from his siblings; we have the same rules and expectations of him as his sisters," were prevalent. It appeared as if parents were doing a great deal of psychological work to validate that they treated their child the same as other children. This theme of minimizing *disability* appeared frequently when parents were asked "Do you think your child believes he or she has a disability?" Parents often stated they did not use the term *disability* or they tried hard to "downplay the disability" and did not "allow" their child to apply that term to him- or herself.

Predictors of Global Self-Worth

Standard multiple regression was used to determine if adolescent perception of Parent Support and Classmate Support, Self-Determination, parent perception of child Positive Impact and Negative Impact, and teacher report of Student-Teacher Relationship Total predicted Global Self-Worth. The full model (see Table 3) was not significant ($R^2 = .161$, $F(6, 43) = 1.378$, $p = .245$); thus, a hierarchical linear regression was conducted with three steps. The steps were ordered by informant report: step one included adolescent report, step two included parent report, and step three included teacher report. Adolescent perception of classmate support was not included in the hierarchical regression based on lack of significance as a predictor in the full model. As Table 4 illustrates, only Step 1, which included adolescent perception of Parent Support and Self-Determination, was significant ($R^2 = .153$, $F(2, 47) = 4.242$, $p = .020$).

As one would expect, adolescents' perceptions were the strongest predictors of Global Self-Worth. Thus, the qualitative data were very useful in exploring how this

sample of adolescents viewed intellectual disability and themselves. Adolescent participants were asked about their understanding of disability terminology (e.g., disability, learning disability, mental retardation, special needs) as well as whether they or their friends had a disability. Their responses were illuminating.

Participants reacted very strongly to the term *mental retardation*, often stating that it was a “mean” thing to say or a “bad” word that meant “stupid.” One student said, “I don’t like the ‘R’ word. A teacher called me that once and I was about to punch her.” After one participant stated that she “was MR” she was asked to express her feelings about the MR label; her response was quite telling:

I hate being MR because people make fun of me. They call me names and laugh and talk behind my back. I also hate being MR because I have to ride a special bus and I do not function in the right classroom like others. I also hate being MR because you can’t do what others do. You function at a different level.

This young woman’s feelings of social isolation due to “being MR” were heartbreaking. It was interesting that she identified herself as “being MR” not “having MR” and that “being MR” prevented her from inclusion in the “right classroom.”

While parents tended to emphasize the similarities of their child with typically developing children, adolescents were more likely to acknowledge feelings of difference and social isolation. In response to how do you know if someone has a disability, one young man replied,

The way they look – if they’re in a chair [wheelchair]. That’s what gets to me the most. I don’t like the way I walk. That’s why I don’t like to look in

the mirror or go dancing. People try to convince me that I'm just like everyone else and get my confidence up, but I tell them I'm not and that I do have disabilities. That's probably why I don't make very much friends, but I'm used to it.

This adolescent's experiences of having others tell him he is "like everyone else" in order to improve his self-esteem were seemingly ineffective. He recognized and articulated a feeling of difference between himself and others without disabilities and internalized this as a possible reason for social isolation. Thus, parent report of minimizing their child's disability in order to improve their child's self-esteem (e.g., "We don't allow him to feel like he has a disability; we've always built up his self-esteem so that he would at least try hard to do what others do.") appears to be an unsuccessful strategy.

Classroom Placement

Another objective of this study was to include adolescents with a broad range of intellectual disabilities. Thus, the sample included participants from both resource rooms and self-contained classrooms. Due to the reduction in sample size when separating participants by classroom type, a non-parametric test, the Mann-Whitney U, was used to assess the difference between participants in resource rooms and those in self-contained classrooms. Table 5 illustrates the comparison of means by classroom, with significant differences indicated between students in resource rooms and those in self-contained classrooms. Students in resource rooms had significantly higher Self-Determination Total scores ($z = 2.82, p = .005$) and on three of the Self-Determination subscale scores [Autonomy ($z = 2.06, p = .043$); Self-Regulation ($z = 2.19, p = .033$); and Psychological Empowerment ($z = 3.05, p = .002$)] than students in self-contained classrooms. However,

students in self-contained classrooms reported significantly greater perceptions of Classmate Support than students in resource rooms ($z = 2.85, p = .004$). Also, teachers of students in self-contained classrooms reported greater Dependency than teachers of students in resource rooms ($z = 3.04, p = .002$).

The subjective experiences (i.e., qualitative data) of the adolescents are again very helpful when examining differences among students by classrooms. Referring to his class, one participant in a resource room stated, “Special ed classes are just another class. I’m still in special ed, it helps you out. I couldn’t learn nothing if I wasn’t in special ed. I couldn’t read or do times or spell, but now I do.” This particular student appeared appreciative of the services he received and felt that the supports available to him in the resource room had contributed to his academic success. Interestingly, students in self-contained classrooms were more likely to state they did not belong in special education and should be in “normal” classes. One young man felt very strongly that he did not belong in a self-contained classroom, “A couple of us down here don’t have a disability; they put us down here for no reason. They put me down here because my foster mom thinks I’m mentally disabled.” Another student echoed these same concerns, “It’s a mistake. I should be in regular classes. I love them—the regular classes. It feels bad to be in special ed classes because I feel bad about these people. They don’t learn to walk, talk, or feed their self.” Interestingly, this student’s teacher and parent reported that he had been in special education classes, primarily self-contained classrooms, his entire academic career.

The comment from this student relating limited physical capacity and disability terminology were echoed by several other students when asked if any of their friends or

classmates had a disability. Thirty-nine percent ($n = 20$) of the total sample made reference solely to students who were in wheelchairs as those who had a disability. A few others ($n = 6$) referred to classmates who had seizures or severe communication disorders. Interestingly, this understanding of disability as a purely physical limitation was primarily from the perspective of students without physical limitations. In other words, able-bodied students with ID were more likely to define disability purely in terms of physical limitation than students who experienced profound physical restrictions along with their intellectual limitations.

Discussion

The goal of this study was to examine the self-concept of adolescents with ID through exploration of variables believed to contribute to adolescent global self-worth. The study expands existing research by including multiple informants (adolescents, parents, and teachers) with particular emphasis on the perceptions and subjective experiences of the adolescent with ID. Individual interviews were conducted with each adolescent in hopes of giving a voice to this population's thoughts and feelings. Certainly, interviews can only provide a snapshot from a particular day and time; even so, the inclusion of the adolescent perspective was foundational to this study.

Significant relationships among the variables of interest: adolescent global self-worth, adolescent perception of support, parent perception of child impact, and the student-teacher relationship were found. Additionally, it was hypothesized that adolescent perception of parent support and classmate support, along with parent perception of child positive impact and child negative impact, and teacher report of the student-teacher relationship would predict adolescent global self-worth. Finally, group

differences between students in resource rooms and students in self-contained classrooms were explored.

The results revealed that adolescents who reported higher levels of parent support also reported greater global self-worth. This finding is similar to those reported in studies with typically developing populations (e.g., Harter, 1999) and preadolescents with developmental coordination disorder (Piek, Dworcan, Barrett, & Coleman, 2000). Adolescent perception of positive parental support was also associated with greater psychological empowerment. These findings suggest that adolescents who perceive their parents as supportive are more likely to act in a psychologically empowered manner and express feelings of greater self-competence. Also, parents who perceived their child as having a positive impact on the family had adolescents who perceived their classmates as more supportive.

While these findings are correlational and causation cannot be inferred, the favorable associations of global self-worth, psychological empowerment, and classmate support with parent perception of child positive impact and adolescent perception of parent support are encouraging. It appears that not only are there benefits to families when parents perceive their child with ID as having a positive impact on the family as reported in previous literature (e.g., Blacher & Baker, 2007; Hastings & Taunt, 2002; Scorgie & Sobsey, 2000; Stainton & Besser, 1998) but these findings indicate that parent perception of child positive impact is also related to adolescents' relationships with peers.

The analysis of correlates also revealed a significant relationship between teacher perception of high student dependency and low levels of adolescent self-regulation and psychological empowerment. This finding is similar to those of Eisenhower, Baker, and

Blacher (2007) who found that self-regulation in young children with ID mediated the relationship between ID and the quality of the student-teacher relationship. Eisenhower and colleagues (2007) concluded that this finding is particularly interesting since previous research (Fabes et al., 1999; Wilson, 1999) has indicated a negative pattern of deficits in self-regulation contributing to later social problems which in turn may contribute to the increased risk for long-term behavioral problems and higher prevalence rates of psychopathology in persons with ID (Borthwick-Duffy & Eyman, 1990; Dykens, 2000; Einfeld & Tonge, 1996; Emerson, 2003).

Regarding predictors of adolescent global self-worth, the full model was not significant; however, hierarchical linear regression did reveal that adolescent perception of parent support and self-determination are predictors of global self-worth. This finding expands upon previous literature emphasizing the role of family support to positive child outcomes in early childhood (Guralnick, 2005). The contribution of self-determination to global self-worth also corroborates previous research which found self-determination and quality of life to be significantly positively correlated (Lechepelle et al., 2005).

While students in self-contained classrooms reported slightly higher global self-worth ($M = 19.41$, $SD = 4.17$) than students in resource rooms ($M = 18.95$, $SD = 4.63$) the difference was not significant. However, significant differences were found between the two groups of students regarding adolescent perception of classmate support, teacher perception of student dependency, and self-determination. It is not surprising that students in self-contained classrooms would perceive their classmates as more supportive since the structure of the self-contained classrooms often includes keeping the same students together with the same teacher for the duration of middle school and again for

the duration of high school. It appears that classmate support is a benefit of this arrangement. In fact, Kasari and Bauminger (1998) suggested that children who have similar disabling conditions are likely to have greater familiarity with each other leading to relationships which are more reciprocal and stable. Likewise, Marsh, Tracey, and Craven (2006) found that preadolescents with mild ID who were in self-contained classrooms reported more positive peer relationships and higher global self-worth than students in more mainstream settings.

Students in resource rooms did fare better than those in self-contained classrooms in three of the four self-determination subscales (autonomy, self-regulation, and psychological empowerment) and the self-determination total. While this may be explained in part by cognitive ability, other factors are likely to contribute to this difference. Wehmeyer and Garner (2003) suggest that there are two primary contributors to an individual's self-determination: (1) the individual's capacity for self-determination, and (2) the extent to which the environment allows an individual to make choices and exert control over his or her life. Thus, the disparity between students by classroom may be due in part to differences in the opportunities available to students in resource rooms which appeared not to be accessible to students in self-contained classrooms. Further exploration of differences among students by classroom placement is warranted.

Similar to Davies and Jenkins (1997) study, application or lack of application of the intellectual disability label did not alter feelings of frustration regarding limited social opportunities. Adolescents in this sample (particularly those in self-contained classrooms) expressed frustration with not being able to obtain a driver's license, go to college, participate in mainstream school athletics; whereas, the young adults in Davies and

Jenkins (1997) study mentioned limited opportunities in activities or events normative to young adulthood (e.g., marriage and the prospect of parenthood).

The understanding of disability terminology and identification with the intellectual disability label by adolescents in this study expands on previous research with adults (Cunningham & Glenn, 2004; Davies & Jenkins, 1997; Finlay & Lyons, 2005). An intriguing pattern to note in the qualitative data is the self-description of adolescents in this study in terms of race, gender, and disability. Only one participant used race (“I’m Black”) as a self-descriptor. Only one female used gender as a descriptor in comparison to twelve male adolescent participants. These results could be interpreted in a number of ways, including young male adolescents’ need to assert their masculinity. While previous research has indicated that the label of intellectual disability may supersede other social identities (Burns, 2000; Hughes, 1945; Walmsley & Downer, 1997), further analyses of the data is warranted to explore the influence of imposed identity (i.e., the intellectual disability label) in comparison to an understanding of self as a member of a gender group, racial or ethnic culture, and one’s identification with the disability community.

The individual interviews with adolescents allowed for a depth of understanding regarding the subjective experiences of this sample which could not be measured solely with questionnaires. However, a questionnaire format was used in data collection from parents and teachers. Thus, a limitation of this study may be that some of the parent and teacher responses lack the intensity and depth seen in the adolescent data. Also, further research is needed to explore the sources of information that adolescents utilize in their understanding of disability and how the label applies to them. Accordingly, the

development of resources regarding disability awareness specifically designed for adolescents with ID is warranted.

In summary, the global self-worth of adolescents in this sample was predicted by their perception of parent support and self-determination. Parents expressed that having an adolescent with ID had both positively and negatively impacted their family and these variables approached significance as predictors of adolescent global self-worth.

Differences in adolescents by classroom placement revealed that students in resource rooms have more favorable relationships with teachers and are more self-determined than their peers in self-contained classrooms. These findings indicate the need to teach self-determination skills to adolescents in self-contained classrooms and provide optimal opportunities for those students to practice such skills.

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Table 1

Descriptive Statistics for Adolescents and Families

Adolescent Variables	Mean (SD), or Percent	<i>n</i>	Family Variables	Mean (SD), or Percent	<i>n</i>
Chronological Age	15.97 (1.85)	51	Persons in household	4.36 (1.39)	50
Verbal Mental Age	8.37 (2.49)	51	Total household income	\$30-40K	45
Gender			Informant		
Male	75%	38	Mother Report	86%	44
Female	25%	13	Father Report	8%	4
			Other	4%	2
Child Disabling Condition			Parents Relationship Status		
Etiology unknown	44%	23	Married	37%	19
Autism Spectrum Disorder	10%	5	Divorced	37%	19
Down Syndrome	10%	5	Not Living Together	18%	9
Fetal Alcohol Syndrome	8%	4	Other	6%	3
Cerebral Palsy	4%	2			
Spina Bifida	2%	1	Maternal Education		
Other	22%	11	Less than 12th grade	8%	4
Classroom Placement			High school diploma/GED	45%	23
Self-contained	60%	31	Vo-Tech training	12%	6
Resource room	40%	20	College graduate	25%	13
			Completed Graduate School	6%	3
Ethnicity			Paternal Education		
European American	63%	32	Less than 12th grade	6%	3
African American	29%	15	High school diploma/GED	37%	19
Native American	6%	3	Vo-Tech training	8%	4
Arab	2%	1	College graduate	18%	9
Family Structure			Completed Graduate School	8%	4
Biological Child	78%	40			
Adopted Child	18%	9			
Foster Child	2%	1			

Note: Not all percentages sum to 100% as participants may have elected not to report some information.

Table 2

Intercorrelations, Means, SDs, and Reliability

Measured Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Global Self-Worth	.760													
2. Parent Support	.352*	.811												
3. Classmate Support	.072	.104	.641											
4. Autonomy	-.202	.027	-.150	.784										
5. Self-Regulation	-.137	-.054	-.153	.327*	.756									
6. Psychological Empowerment	.269	.284*	-.047	.088	.334*	.629								
7. Self-Realization	.200	.111	.081	.078	.167	.131	.659							
8. Self-Determination Total	-.133	.065	-.160	.915**	.612**	.335*	.300*	.813						
9 Positive Impact	-.032	-.111	.329*	-.124	-.152	-.247	-.153	-.202	.739					
10. Negative Impact	-.031	.005	-.165	-.182	-.105	-.058	.305*	-.126	-.453***	.741				
11. Student-Teacher Conflict	-.048	-.120	-.206	.032	.033	-.108	.052	.027	-.149	.037	.927			
12. Student-Teacher Closeness	-.128	-.111	-.101	.207	.082	-.136	-.258	.123	-.052	-.138	-.316*	.776		
13. Student-Teacher Dependency	-.048	.018	-.207	-.020	-.335*	-.357*	-.274	-.208	-.194	.144	.524**	.061	.765	
14. Student-Teacher Total	-.009	.030	.146	.068	.093	.104	.073	.083	.125	-.116	-.923**	.604**	-.568**	.824
Means	19.23	19.92	19.47	60.97	12.64	12.70	10.35	96.67	14.26	8.23	23.23	41.64	11.25	109.15
Standard Deviations	4.32	4.29	3.60	12.38	4.22	2.36	2.67	15.55	4.94	4.66	11.06	6.76	4.03	16.58

Note: $n = 50-51$. Adolescent Report (variables 1-8), Parent Report (variables 9-10), Teacher Report (variables 11-14).* $p < .05$ ** $p < .01$

Cronbach's alpha reported on the diagonal

Table 3

Summary of Regression Analysis for Predictors of Global Self-Worth

Predictor Variable	<i>B</i>	<i>SE B</i>	β
Parent Support	.346	.142	.346
Classmate Support	-.022	.181	-.000
Self-Determination Total	-.061	.042	-.218
Positive Impact	-.071	.150	-.081
Negative Impact	-.091	.150	-.099
Student-Teacher Total	-.003	.037	-.012

$R^2 = .161, F(6, 43) = 1.378, p = .245$

Table 4

Summary of Hierarchical Regression Analysis for Predictors of Global Self-Worth

Model/Predictor Variable	B	SE B	β	R ²	ΔR^2	<i>p</i>
1				.153	.153	.020
Parent Support	.352	.134	.353			
Self-Determination Total	-.053	.037	-.190			
2				.161	.008	.803
Positive Impact	-.072	.141	-.083			
Negative Impact	-.091	.146	-.098			
3				.161	.000	.932
Student-Teacher Total	-.003	.036	-.012			

Table 5

Comparison of Means for Variables by Classroom

Measured Variable	Self-Contained Classrooms		Resource Rooms		U
	Mean (<i>SD</i>)	<i>n</i>	Mean (<i>SD</i>)	<i>n</i>	
Global Self-Worth	19.41(4.17)	31	18.95(4.63)	20	298.0
Parent Support	19.77(4.37)	31	20.15(4.28)	20	296.0
Classmate Support	20.54(2.99)	31	17.80(3.88)	20	163.5**
Autonomy	58.18(12.06)	31	65.30(12.01)	20	205.0*
Self-Regulation	11.67(4.43)	31	14.15(3.48)	20	200.0*
Psychological Empowerment	11.90(2.38)	31	13.95(1.73)	20	153.0**
Self-Realization	10.06(2.94)	31	10.80(2.19)	20	264.0
Self-Determination Total	91.82(15.08)	31	104.20(13.39)	20	163.5**
Positive Impact	14.78(5.19)	30	13.47(4.55)	20	254.5
Negative Impact	8.39(4.62)	30	8.00(4.82)	20	290.5
Student-Teacher Conflict	24.58(11.90)	31	21.15(9.52)	20	258.0
Student-Teacher Closeness	40.96(7.73)	31	42.70(4.88)	20	279.5
Student-Teacher Dependency	12.58(3.82)	31	9.20(3.51)	20	153.0**
Student-Teacher Total	105.80(18.26)	31	114.35(12.24)	20	236.5

p* < .05 *p* < .01

APPENDICES

APPENDIX A

REVIEW OF LITERATURE

The following literature review examines the developmental period of adolescence for persons with intellectual disabilities (ID). More specifically, it focuses on the development of self-concept for adolescents with ID. The review begins with a brief overview of Zigler's (1971) developmental approach to intellectual disabilities. Next, a summary of the tasks associated with adolescence are explored, including the importance of promoting self-determination. The remainder of the chapter reviews literature regarding the self-esteem of persons with ID with a particular emphasis on possible contributing factors to the global self-worth of adolescents with ID.

Theoretical Framework

Zigler and his colleagues (Hodapp & Zigler, 1995; Zigler, 1971) helped transform the understanding of persons with ID from individuals who are defined primarily by their cognitive deficits to the appreciation for the contextual influences that engender personality development. Zigler's developmental approach (Zigler, 1971) built on the works of Werner, Piaget, and Vygotsky by combining and reinterpreting the developmental work of these previous theorists and adding the personality and motivational factors which affect individuals with ID along with etiological considerations (Hodapp & Zigler, 1995). While originally applied to persons with non-organic (i.e., cultural-familial) intellectual disabilities, more recent research has suggested that the developmental framework is applicable to persons with ID of organic etiologies (Cicchetti & Pogge-Hasse, 1982; Cunningham & Glenn, 2004; Hodapp & Zigler, 1995; Zigler, 1999).

The three original tenets of Zigler's (1971) approach were that children with ID follow a similar sequence, similar structure, and have similar reactions to life experiences as their typically developing peers. The similar sequence tenet states that children with ID follow a comparable developmental trajectory as children without ID. In other words, while rate of progression is expected to differ, children with ID progress through the same developmental stages and generally the same order as their normative peers. The sequence of development hypothesis has been examined in several domains (e.g., symbolic play, pragmatics, and language categorization) within the ID population with findings supporting Zigler's similar sequence hypothesis (Hodapp & Zigler, 1995). It is noteworthy that exceptions to the similar sequence hypothesis have been found in young children with autism (Prizant & Wetherby, 1987; Wetherby, 1986); children with severe, uncontrolled seizures (Weisz & Zigler, 1979); and in the moral development of children with ID (see Hodapp & Zigler, 1995, for a review).

The similar structure tenet states that children with ID should perform similarly on linguistic and specific cognitive tasks as typically developing children when matched on overall mental age. Research in populations with both organic and nonorganic ID (Weisz & Yeates, 1981) has been less supportive of the similar structure hypothesis (Hodapp & Zigler, 1995). Recent empirical studies in the field of intellectual disabilities have moved away from the similar structure tenet and instead focused on the structure of development specific to particular disabling conditions, such as Down Syndrome, Autism, and Williams Syndrome (Hodapp & Zigler, 1995).

The hypothesis of greatest interest and most applicable to this literature review is that of similar reactions. Zigler (1971) referred to this tenet as personality-motivational

factors. Zigler understood persons with ID as a *whole person*, and thus was unwilling to attribute personality characteristics solely to cognitive deficiency in the ID population and subsequently ignore the environmental events known to be influential to the personality development of persons with normal intellect (Zigler, 1999).

When we deal with children with mental retardation, we often seem to assume that the cognitive deficiency from which they suffer is such a pervasive determinant of their total functioning as to make them impervious to the effects of influences known to affect the behavior of everyone else (Zigler, 1999, p. 5).

The literature presented throughout this chapter will elucidate the value of this statement; although, it should be understood that the context and content associated with such environmental events does differ between individuals with and without ID. Adolescents with ID are likely to have life experiences that are unique to them because of their disabling condition. For example, persons with ID do experience greater amounts of failure; yet the patterns of behavior which results from failure are assumed to be the same among persons with ID and persons without ID whose life history includes an inordinate amount of failure (Zigler, 1999). Likewise, if one could guarantee equivalent experiences of success among the two populations, one would expect the patterns of behavior to be similar, regardless of intellect (Zigler, 1999).

Furthermore, Guralnick (2005) states children's characteristics associated with the vulnerability of their disabling condition can create stressors which disrupt positive family interactions patterns. Consequently, these stressors negatively affect child outcomes. Limited peer social networks are also problematic for persons with ID.

Guralnick (1997) found children with developmental delays as young as preschool were at a distinct disadvantage regarding social competence, due largely to a lack of opportunity. Such limited social opportunity is likely to be a result of multiple factors including negative societal attitudes and less time for social play due to therapeutic services (Guralnick, 1999). Unfortunately, this pattern of poor social networks continues into adolescence manifested by compromised social intelligence (Greenspan & Granfield, 1992) which often leads to peer rejection and loneliness (Ladd & Troop-Gordon, 2003).

Developmental Period of Adolescence

While the majority of intellectual and developmental disability research continues to focus a great deal on early childhood or old age (Blacher, 2001), adolescence remains a formative and distinct time period (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). The need for research and programs to address the socio-emotional needs of adolescents with intellectual and developmental disabilities has been universally established. For example, the United Nations General Assembly 27th Special Session stated “the greatest problems faced by individuals with disabilities are social, economic, and cultural--not medical--in nature” (2001, p. 104). While the United Nations makes explicit that all children with disabilities should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child’s active participation in the community; adolescents with disabilities around the globe are often bypassed by both the programs and policies designed for children with disabilities and left out of the advocacy initiatives for adults with disabilities (Groce, 2004).

Adolescence is the developmental period when most children begin to assert their independence and desire for autonomy (Erikson, 1950). While the majority of

adolescents with ID follow a typical trajectory of physical development, they are likely to be at a much younger psychological developmental stage (Parmenter, Harman, Yazbeck, & Riches, 2007). Navigating the road towards independence is a challenging endeavor for all adolescents; however, for adolescents with ID these tasks are increasingly complex. For individuals with ID, the developmental tasks associated with adolescence—autonomy, extracurricular activities, sexuality, vocational preparation, and independent living—are compounded by their disability (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). Over the past twenty years, researchers and clinicians have focused on the promoting and enhancing the self-determination of young persons with ID in order better equip them to meet the developmental tasks of adolescence and adulthood.

Self-Determination

Self-determination is rooted in the study of motivational psychology. Deci and Ryan's (1985) theory of self-determination focuses on the extent to which people engage in actions with a full sense of choice, thus assuming that people are active agents in their own development (Deci & Ryan, 2002). The construct of self-determination specific to the disability field can be traced back to the normalization movement (Nirje, 1969). In his chapter titled *The Right to Self-Determination*, Nirje (1972) argued that self-determination is a right of all persons with disabilities. However, as this right gained attention in the disability field, the lack of opportunity extended to persons with ID to exercise control over their own lives became evident (Wehmeyer, Bersani, & Gagne, 2000).

In response to this, the self-determination movement within the field of special education has grown exponentially in the past 20 years (Karvonen, Test, Wood, Browder,

& Algozzine, 2004). So much so that “self-determination” became the buzzword in special education (Wehmeyer, 2004) and was even identified as “the ultimate goal of education” (Halloran, 1993). Within the context of special education, the construct of self-determination is defined as:

a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding on one’s strengths and limitations, together with the belief of oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society (Field, Martin, Miller, Ward, & Wehmeyer, 1998a, p. 2).

The self-determination construct has been operationalized by Wehmeyer and Kelchner (1995). Wehmeyer and Kelchner propose four essential characteristics of self-determined behavior: (1) behavioral autonomy, (2) self-regulated behavior, (3) acting in a psychologically empowered manner, and (4) self-realization. Furthermore, the development of component elements (e.g., choice-making; decision-making; problem-solving; goal-setting and attainment; self-observation, evaluation, and reinforcement; internal locus of control; positive attributes of efficacy and outcome expectancy; self-awareness; and self-knowledge) are vital to the expression of self-determined behavior (Doll, Sands, Wehmeyer, and Palmer, 1996).

Wehmeyer and Garner (2003) suggest that there are two primary contributors to an individual’s self-determination. The first is the individual’s capacity for self-

determination. In other words, what decision-making, goal-setting, and problem-solving skills does the individual possess? The second contributor is the extent to which the environment (home, school, work, and recreation) allows an individual to make choices and exert control over his or her life. Thus, one could conclude that self-determination skills can be taught and that one's contextual environment and support from others (i.e., teachers, parents, peers) are likely to influence the level of self-determined behaviors in which an individual with ID might engage. Ward's (1996) personal experiences provide an excellent example of the necessity of both capacity and environmental opportunity as contributors to an individual's self-determination. [see Ward, 1996, for an excellent review of the self-determination movement within the context of other related social movements (e.g., self-advocacy, disability rights, empowerment) and from both a historical and personal perspective].

The benefits of self-determination for persons with ID have been well established in the research literature. Moreover, within the ID population, self-determination is correlated with improved quality of life (Lachepelle et al., 2005), is a crucial component of successful transition to adulthood (Field, Martin, Miller, Ward, & Wehmeyer, 1998b), and is predictive of post school success (Wehmeyer & Schwartz, 1997). For example, students with ID who were more self-determined at the time of high school graduation were 50% more likely to be employed one year later and earning higher wages than their peers with disabilities who were less self-determined (Wehmeyer & Palmer, 2003).

It is important to note that previous research has found that intellectual capacity is not a significant predictor of self-determination in the ID population (Wehmeyer & Bolding, 1999; Wehmeyer & Garner, 2003); rather it is the opportunity to make choices

about one's own life that contributes significantly and positively to self-determination. Having the opportunity to exert control over one's own life is important across contexts and environments, including the classroom and family home (Field & Hoffman, 1999; Shogren & Turnbull, 2006; Zhang, 2001; Zhang, 2005). The need for self-determination is underscored by the risks associated with adolescents who have ID.

Adolescents with Intellectual Disabilities: A Population at Risk

Unfortunately, children and adolescents with ID suffer many social disadvantages as compared to their non-disabled peers. In Goldson's (2001) review of maltreatment among children with disabilities, he found evidence that children with disabilities suffer from neglect and abuse at significantly higher rates than other children. Possible contributing factors to the higher prevalence of abuse in this population include child characteristics (e.g., difficulty of care, behavior problems, demanding physical needs), societal attitudes towards children with disabilities (e.g., a communal understanding as "less-than"), and caretaker/parental characteristics (e.g., unmet expectations for parenthood, stress, disrupted attachment; Goldson, 2001). An additional child characteristic present in many children with ID is compromised social intelligence, (Greenspan & Granfield, 1992). As with the normative population, compromised social intelligence is evidenced by an inability to accurately interpret the social cues of others which often leads to peer rejection, thereby increasing the likelihood of children experiencing loneliness and developing internalizing or externalizing problems (Ladd & Troop-Gordon, 2003). Ghaziuddin, Alessi, and Greden (1995) also found significant life events, chiefly those with a negative impact, to contribute to depression in children with ID, specifically those children diagnosed with pervasive developmental disorders.

For many persons with ID, it is during their adolescent years when they begin to recognize the differences between themselves and their typically developing peers. This recognition may lead to feelings of inadequacy, frustration, and isolation (Evans, 1998; Rowitz, 1988; Zetlin & Turner, 1985). Persons with ID are more likely to experience repeated failure and these experiences often lead to feelings of uncertainty and “learned helplessness” (Evans, 1998). Weisz (1990) argues that the culmination of these experiences and learned helplessness are a critical component in the expression of depression in children and adolescents with ID. Persons with ID are at an increased risk for psychopathology (Borthwick-Duffy & Eyman, 1990; Dykens, 2000; Einfeld & Tonge, 1996; Emerson, 2003; Heiman, 2001; Reiss, 1990; White, Chant, Edwards, Townsend, & Waghorn, 2005) with prevalence rates three to four times higher than that of typically developing children (Einfield et al., 2006). Furthermore, depression has been significantly negatively correlated with aspects of social comparison (e.g., peer social belonging) and global self-worth in both adolescents and adults with ID (Dagnan & Sandhu, 1999; Glick, Bybee, & Ennis, 1997).

Intellectual Disability: A Stigmatizing Label

Some have argued that the psychological risks for those with ID may be due in part to the stigmatization of the disability label (Edgerton, 1993). As such, denial of the label may be a protective mechanism to maintain one’s self-esteem. In their review of the social identity of adults with ID, Beart and colleagues argue that the label of disability is indeed a powerful and stigmatizing identity resulting in a profound impact on peoples’ lives (Beart, Hardy, & Buchan, 2005); once bestowed it is likely to remain the dominant identity for the rest of the individual’s life. So influential is the label of ID that it

supersedes other identities (Hughes, 1945) including gender (Burns, 2000), ethnic origin, sexuality, and religion (Walmsley & Downer, 1997). Therefore, it is argued that it is through this stigmatized lens which persons with ID are frequently viewed by others. As compared to typically developing peers who might be described by their gender, race, or interests (i.e., “She is a Native American,” “He enjoys playing the clarinet”), adolescents with ID are often described primarily in terms of their medical diagnosis or educational placement (i.e., “She has Down Syndrome” “He is in the moderate-severe class”). As such, their social identity may be filtered through these daily experiences and social interactions.

Children and Young Adolescents Experiences of Disability

Connors and Stalker (2007) proposed that children and adolescents with disabilities view themselves as similar to their non-disabled peers due to a lack of positive language through which to discuss their differences. Contrary to previous research (e.g., Baldwin & Carlisle, 1994) based on parental or professional report which tended to elucidate the negative, Connors and Stalker (2007) found child and adolescent participants reported mostly positive accounts of their lives. These findings were based on semi-structured interviews with informants ranging in age from 7 to 15. Of the fifteen participants with some degree of learning disabilities, only one made reference to her impairment stating that it made her feel different. These authors suggest that parental and teacher response and management of participants’ differences was crucial to their internalization of disability. It was further concluded that the majority of children were discouraged from discussing their disability both at home and school, and for those who did, it was primarily in terms of a medical model. The authors concluded that one

plausible reason children are not encouraged to acknowledge their impairments during childhood and early adolescence is the lack of appropriate positive language and adult role models with similar disabilities.

Young Adults and the Label of Disability

Interestingly, a number of studies have found that persons with ID deny the applicability of the label or do not use the label when describing themselves (Davies & Jenkins, 1997; Edgerton, 1993; Finlay & Lyons, 1998; Jahoda, Markova, & Cattermole, 1988; Todd & Shearn, 1997). Finlay and Lyons (2005) distinguish between the participants' acknowledgment of particular limitations related to practical or cognitive tasks and the acknowledgment of a general label of disability. They further conclude that even when persons with ID deny the label, they are not reluctant to discuss specific challenges and needs they have along with oppressive situations they have experienced seemingly related to their disability. In other words, denial of the label does not indicate a lack of difficulty related to one's disability or the experience of prejudice or oppression from others. In this way disability is more than a diagnostic category or identity, rather it can be understood as a socially constructed category. Therefore, lack of knowledge or identification with a disability label does not appear to shield an individual from feelings of isolation (Davies & Jenkins, 1997; Finlay & Lyons, 2005). It is interesting to note that individuals with ID expressed frustration with denial of opportunities (e.g., driving a car, dating, having a baby) that are perceived as inherent rights of individuals without disabilities (Davies & Jenkins, 1997). Parents often pointed to conversations surrounding these denied opportunities as the catalyst for a definitive conversation in which the parent

would explain to the child that he or she had a disabling condition (Davies & Jenkins, 1997; Finlay & Lyons, 2005).

Cunningham and Glenn (2004) interviewed young adults with Down Syndrome seeking to understand when and how they became aware of Down Syndrome and disability, the impact of their awareness, and what factors influenced their understanding. Only those participants who had a mean verbal mental age (VMA) around 8 years or older demonstrated social relational awareness; meaning they not only knew the terms related to Down Syndrome and disability but also made social comparisons to others and commented about the effects on their own social interactions. Once VMA was statistically controlled for, other factors related to awareness (i.e., chronological age, gender, parent telling, self-evaluation, and mainstream experience) were no longer significant. This finding supports a developmental approach (Hodapp, 1990; Zigler, 1971) to levels of awareness and understanding of Down Syndrome and disability. The authors propose that this sequential development approach be utilized in future research with less emphasis on age or specific diagnosis and instead focusing on what is occurring among individuals with ID at differing places in the sequence of self-concept development. Cunningham and Glenn (2004) conclude there is much work to be done to identify when and how parents and caregivers should explain disability to the individual with ID.

Plesa-Skwerer, Sullivan, Joffre, & Tager-Flusberg (2004) utilized a structured interview (Damon & Hart, 1988) to explore the self-concepts of adolescents and adults with Williams Syndrome and Prader-Willi Syndrome in hopes of examining how these individuals reflect on their own lives and view themselves, as well as, examine changes

in self-concept from adolescence to adulthood. They also found support for the developmental approach to ID (Hodapp, 1990) in that participants appeared to follow the typical developmental trajectory of self-understanding, but were significantly delayed in comparison to typically developing individuals. This was evidenced by the adolescent participants' use of more physical and active self-descriptors rather than more social qualities or the social implications of self-concept utilized by the adult participants. This pattern of self description is characteristic of typically developing young children, and according to this study, indicates that self-understanding is inhibited by an individual's cognition and language, thus mediating their interpretation of their experiences. Plesa-Skwerer and colleagues conclude "these age-related changes in self-description revealed that self concepts undergo a process of elaboration, suggesting development over time in the ways people with Williams Syndrome and Prader-Willi Syndrome engage in self reflection" (p. 136).

Self-Esteem

It is widely accepted that how one views self is critical to one's long-term personal development (Harter, 1986/1993; James 1892). An individual's self-concept is constructed from "organized interpretations of one's daily life experiences as they pertain to the self" (Caselman & Self, 2007, p. 353). Therefore, an individual's thoughts, feelings, and actions are influenced by their self-perception. Early research on the self-perceptions of children focused on self-esteem or self-worth as a global construct. However, more recent literature has established the multidimensional nature of self-concept (Harter, 1999; Marsh, Tracy, & Craven, 2006) including domain specific self-perceptions while maintaining global self-esteem in their models (Harter, 1999;

Rosenberg, 1979). Harter's (1999) argument for the multidimensional nature of self-worth follows the theoretical framework of James (1892) with a central tenet being that feelings of self-worth are related to perceived competence. Harter (1990) further asserts that self-worth and global self-esteem are comparable constructs which can be described as "the overall value that one places on the self as a person" (p. 67).

Harter (1999) has developed multiple measures (Harter, 1982; Harter, 1985a; Harter & Pike, 1984) of self-competence and global self-worth based on the argument of a multidimensional nature of self-worth including five specific domains: scholastic competence, social acceptance, athletic competence, physical appearance, and behavioral conduct along with a sixth dimension of global self-worth. Note that global self-worth is not the summation of an individual's self-competency in these five domains, rather it is a separate and unique construct. Differentiating global self-worth from specific self-competency domains allows the researcher to examine the relationship among the constructs (Caselman & Self, 2007).

In comparison to the plethora of research on the study of self in the normative population, relatively little is known about the self-concept of individuals with intellectual disabilities (Evans, 1998; Widaman, MacMillan, Hemsley, Little, & Balow, 1992; Zigler & Hodapp, 1986). In his review of self-concept literature in the ID population, Evans (1998) considers this void of knowledge as somewhat surprising given that this area of study has been a primary focus in the field of developmental psychology for many years. Professionals within the fields of special education, counseling, human development, and psychology have even referred to self-concept as "the cornerstone of both social and emotional development" (Kagen, Moore, & Bredekamp, 1995, p. 18). As

such, positive self-esteem is associated with desirable outcomes, while negative self-esteem is associated with detrimental outcomes. Given the centrality of positive self-esteem to beneficial outcomes, one would hope that this area of study would be widely studied in the ID population; however, that has not been the case. One reason for this may be the inherent limitations in cognition and language which make data collection in this population particularly challenging. However, in his review of the development of self-concept, Evans (1998) reports that adolescents with ID “appear to possess a fairly realistic self-appraisal that is tied to actual competency” (p. 476).

Research does indicate that children and adolescents with ID have several “senses of self,” meaning they conceptualize themselves in reference to their functioning in multiple domains (Harter, 1983). Children’s ability to view themselves in a greater number of domains (e.g., scholastic, athletic, social acceptance, physical appearance) increases with development (Hodapp & Zigler, 1995). Thus, one can expect that the “more developmentally advanced individual tends to employ more categories and finer distinctions within each category than a person functioning at a lower developmental level” (Glick, 1999, p. 50). Congruent with this developmental understanding, is the expectation that persons of similar mental age, regardless of intellect, would exhibit self-images that are at similar cognitive developmental levels (Glick, 1999). This is not to say that persons matched for mental age have like self-images, rather that their cognitive developmental understanding and manifestation of self-image would be similar. Furthermore, the life experiences of all persons make a significant contribution to self-concept. In fact, those experiences, or environmental events, are of primary interest to the understanding of self-esteem in adolescents with ID. The following paragraphs will

provide a brief summary of the research on self-competency and global self-worth in the ID population with a particular emphasis on those studies which utilized Harter's measures (Harter, 1982; Harter, 1985a; Harter & Pike, 1984).

Glenn and Cunningham (2001) examined the utility of three self-evaluation measures and concluded that in their sample of young people with Down Syndrome, Harter's Self-Perception Profile (Harter, 1985a) had more validity support than did the other two measures. Their findings support Harter's cognitive-developmental model of self-evaluation (Harter, 1983) in that those participants with a developmental level around 7 or 8 years of age were able to engage in discriminatory social comparisons. Whereas, those participants below 6 to 7 years tended to think they were competent in all areas and did not appear to be comparing themselves to others.

Cuskelly and de Jong's (1996) study used the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Pike 1984) to compare self-concept in adolescents with Down Syndrome to typically developing children ages four to six. They found evidence of similar cognitive processes related to self-perception between the adolescents with Down Syndrome and the typically developing young children. Significant positive correlations between the subscales in the ID group included: peer acceptance with both cognitive and physical competence and maternal acceptance with both physical competence and peer acceptance.

Glick, Bybee, and Zigler (1997) found consistent responses across domains of Harter's Self-Perception Profile (1985a) in their sample of 20 adolescents; thus, supporting the construct validity of the measure with this population. Their findings

revealed a significant positive correlation between global self-worth and behavioral conduct and between global self-worth and real self-image.

Using the Perceived Competency Scale for Children (Harter, 1982), Bybee, Ennis, and Zigler (1990) investigated the self-concept of institutionalized adolescents and non-institutionalized adolescents attending the same educational program. Results indicated no significant differences between the groups. However, concerning the competency scales, both groups of adolescents rated themselves significantly more positively on the global self-worth and cognitive subscales than on the social and physical abilities subscales. The higher self-rating on global self-worth was reported as plausible evidence that adolescents with ID were able to maintain positive regard for themselves as worthwhile persons despite acknowledgment of limitations in particular areas.

In reviewing the ID self-image literature, Glick (1999) explains that the positive ratings in the cognitive domain are likely a function of comparison group, suggesting that the adolescents in Bybee, Ennis, and Zigler's sample (1990) compared themselves to other adolescents with ID rather than typically developing peers. Because Harter's measures employ a comparative process in determining competence (i.e., the child is asked to decide which kind of *kid* is most like him or her, and then asked whether this is only *sort of true* or *really true* for him or her), it is crucial that the comparison group is well defined; the researcher must ascertain if the participant is comparing him- or herself to other students with ID or to typically developing peers (Silon & Harter, 1985). One would expect the standard of comparison used by the participants to lead to greater or lesser feelings of competence dependent upon the skill level of the comparison group (Marsh, Tracey, & Craven, 2006).

One would also expect to see a growing disparity between an individual's real self-image (one's current view of self) and the ideal self-image (the ideal person one would like to be) as the individual progresses through development (Achenbach & Zigler, 1963). In other words, as cognition advances so does the complexity of self-concept; the more an individual understands the multidimensional nature of self, the greater the disparity between one's real self and one's ideal self. Likewise, as individuals progress developmentally, they are challenged by more complex social demands and expectations (Glick, 1999). The subsequent guilt associated with the failure to meet these increasing demands contributes to a greater self-image disparity (Bybee & Zigler, 1991).

Sources of Support

Symbolic interactionists such as Baldwin (1897), Cooley (1902), and Mead (1934) have long proposed that the development of self is primarily socially constructed. In more recent years, several researchers (Caselman & Self, 2007; Cicchetti, 1990; Harter, 1999; Sroufe, 1990) have highlighted the powerful influence of social interaction processes with peers and caregivers on self-esteem. Furthermore, research in both normative and ID populations elucidate the importance of social support. For example, Felson (1993) concluded that higher levels of social support are associated with greater self-esteem; while Reiss and Benson (1985) found that depression in adults with mild ID was associated with low levels of social support and high levels of perceived stigmatization. Given these findings and the understanding that the self is socially constructed, it is necessary to explore adolescents' perception of support from significant others.

Social support has been conceptualized as the demonstration of emotional support along with the perception of positive regard from others (Harter, 1989). In her measure of social support (Social Support Scale for Children and Adolescents), Harter (1985b) identified four sources of support for children and adolescents: parents, teachers, classmates, and close friends. Harter (1999) found that perception of support was predictive of global self-worth. Interestingly, parent and classmate support contributed more to individual's global self-worth than did teacher or close friend support. Unfortunately, research has indicated that students with ID lack social support from their parents (e.g., Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Carminati, 2008) and peers (e.g., Zic & Igric', 2001). Nonetheless, due to the limited social opportunities of many adolescents with ID, the primary sources of support are still likely to be from parents and classmates. Thus, the literature reviewed next will focus on the interactions of adolescents with ID with their parents, classmates, and teachers.

Adolescent Perception of Parents as a Source of Support

To state that the literature exploring adolescents with ID perception of parental support is dearth would be an understatement. Parental support has been explored in special populations of children and adolescents with craniofacial anomalies (Shute, McArthy, & Roberts, 2007), neurofibromatosis (Counterman, Saylor, & Pai, 1995), developmental coordination disorder (Piek, Dworcan, Barrett, & Coleman, 2000), cystic fibrosis (Christian & D'Auria, 2006), and learning disabilities (Heiman, Zinck, Heath, 2008; Martinez, 2006; Pavri & Monda-Amaya, 2001; Rothman & Cosden, 1995), yet little research has explored the perceptions of parental support from adolescents with ID.

While adolescent participants' perception of parent support was measured in Saylor and Leach's (2009) study, it was not the focus of their study and reported findings are limited to descriptive statistics. Saylor and Leach found no significant difference in adolescents' perception of parental support between typically developing adolescents and those with ID. One other study was found that explored how adults with ID perceived their family context and the social capital that they as an individual family member provide (Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Galli Carminati, 2008). Sadly, the individuals in this particular sample perceived themselves as less central in their own family.

It appears that most of the research regarding parents and adolescents with ID is focused on the parent, with little attention given to the subjective experience of the individual with ID. Certainly, Goldson's (2001) research literature has emphasized the maltreatment of children with disabilities and it is plausible that the higher prevalence of abuse and neglect in this population may be reflected in adolescent perception of parent support. Alternatively, some parents of children with ID are strong advocates for their children, as suggested by the career role of parenting in this population (Seltzer & Heller, 1997), which may result in higher than expected reports of parental support by adolescents with ID. In contrast to the lack of research that explores parental support from the perspective of the adolescent with ID, research on the families of persons with intellectual and developmental disabilities has been a primary focus of those in the ID field (Blacher & Hatton, 2007). It is hypothesized that parents perception of their child with ID, may impact adolescent perception of parental support. Thus, the literature exploring parenting a child with ID will be examined here.

Parenting a Child with Intellectual Disabilities. Feelings of isolation and difference are a common theme among parents of young children with disabilities (Kerr & McIntosh, 1999). However, a “resilient disruption” model for families has been proposed (Costigan, Floyd, Harter, & McClintock, 1997), recognizing the birth of a child with disabilities as a disruption to family patterns, routines, and expectations but stating that most families do return to previous patterns of family relationships and well-being. Thus, it is important to remember that while the birth or adoption of a child with disabilities does forever change the family, research has not shown a causal relationship between children with disabilities and family dysfunction (Blacher & Baker, 2007; Sobsey, 2004). Quite to the contrary, parent perception of their child with ID as having a *positive impact* was shown to moderate the relationship between child behavior problems and parenting stress (Blacher & Baker, 2007).

When a child has a lifelong disability, parenting often assumes the role of a career which adapts as the child grows (Seltzer & Heller, 1997). “Over time, accommodations are made in family routines, expertise in managing the unique and common demands of parenting children with disabilities is developed, and coping strategies and social supports are utilized that can enhance the family’s capacities” (Hauser-Cram et al., 2001, p. 15). Therefore, one would expect that as the child ages, parents adapt; yet they are likely to encounter new challenges with the onset of adolescence. As children enter adolescence parents seek opportunities that will foster their child’s autonomy and identity formation. Parents are charged with the tasks of encouraging independence while being mindful of the need to protect; all of this at a time when their children begin to “age out” of many services (Parish, 2006; Ray, 2003).

Despite the challenges encountered by parents of children with disabilities, many families report that having a child with ID has resulted in a positive impact on their family. In their review of the literature, Hastings and Taunt (2002) identified fourteen themes indicating positive perception and experiences in parenting a child with disabilities. These themes included: (1) pleasure/satisfaction in providing care for the child; (2) child as a source of joy/happiness, (3) sense of accomplishment in having done one's best for the child; (4) sharing love with the child; (5) child provides a challenge or opportunity to learn and develop; (6) strengthened family and/or marriage; (7) gives a new or increased sense of purpose in life; (8) has led to the development of new skills, abilities, or new career opportunities; (9) become a better person (more compassionate, less selfish, more tolerant; (10) increased personal strength or confidence; (11) expanded social and community networks; (12) increased spirituality; (13) changed perspective on life; and (14) making the most of each day, living life at a slower pace. Thus, despite the difficulty associated with their child's disabling condition, parents appear to maintain that their child has positively impacted the family. It is significant to note that positive and negative impact are not dichotomous as several studies report parental accounts of both positive and negative impact on the family (e.g., Blacher & Baker, 2007; Scorgie & Sobsey, 2000; Stainton & Besser, 1998).

Adolescent Perception of Classmates as a Source of Support

The research concerning adolescent perception of classmate support is largely from the perspective of the other—meaning the informant is the typically developing peer, teacher, or parent rather than the individual with ID. Those studies which do include the individual with ID as an informant tend to focus on the peer relationship between

children with ID and their typically developing peers in a mainstream setting, rather than the relationship between two children both with disabilities (Kasari & Bauminger, 1998). Results from these studies indicate that students with ID were frequently rejected by their typically developing peers (Guralnick, 1990; Zic & Igric, 2001), but that focused intervention through methods such as cooperative learning or a peer buddy did increase social interaction and led to higher sociometric ratings of social acceptance by non-disabled peers (Carter, Hughes, Guth, & Copeland, 2005; Jacques, Wilton, & Townsend, 1998). There is some evidence that mainstreamed settings are more beneficial to younger children with ID because the developmental discrepancies between children with and without ID are less (Kasari & Bauminger, 1998). This may also be true since younger children are more likely to accept adult directiveness in their social interaction than older children or adolescents.

It is presumed that the social reference group (typically developing peers or peers with disabilities) would influence the perception of peer social support reported by adolescents with ID in a similar fashion as was proposed in areas of self-competence. In fact, Kasari and Bauminger (1998) suggested that children who have similar disabling conditions or are both in self-contained classrooms are likely to have greater familiarity with each other leading to relationships which are more reciprocal and stable. However, this proposal has not been examined.

Marsh, Tracey, and Craven's (2006) study is of particular interest to this review of the literature as they found that preadolescents with mild ID who were in self-contained classrooms had lower self-concepts related to academic domains (reading, math, and general school) than those in general education or mainstream classrooms.

However, those same students (i.e., in self-contained or segregated classrooms) reported higher self-concepts in non-academic domains (physical ability, appearance, and parent relationships) and in peer relationships and global self-worth. Marsh and colleagues concluded that this is not surprising given that students with ID often feel rejected or alienated in mainstreamed classrooms. The ability of adolescents with ID to discriminate between academic and nonacademic components of self-concept supports theory and previous research citing the multidimensional understanding of self in this population.

The Influence of Classroom Placement. While recognizing the enormous benefits of mainstreaming, it is unrealistic and irresponsible to ignore the possible negative effects that placement in general education classrooms (as opposed to self-contained special education classrooms) may have on the self-concept of students with ID, particularly those in middle school and high school. Similar to the studies reviewed earlier, Scheepstra, Nakken, and Pijl (1999) found that nearly one-half of the students with Down Syndrome in their study experienced rejection by their typically developing peers. These experiences of rejection may be why many individuals with ID do prefer more segregated social arenas (Philo & Metzel, 2005).

Furthermore, it is not only the individual with ID who may prefer a segregated environment. Clegg, Murphy, Almack, and Harvey (2008) explored the “tensions around inclusion” during adolescents transition from school to work and found that the parents in their study often made statements indicating an internal conflict about mainstreaming. While parents tended to endorse mainstreaming in principle, they were unsure as to the benefits or usefulness of mainstreaming for their child. This seems especially true for students with more severe intellectual disabilities.

Student-Teacher Relations

Beyond the adolescents' relationship with parents and classmates, teachers are also likely to be a source of support for adolescents with ID. According to Pianta and Steinberg (1992) research on the student-teacher relationship is founded on the common understanding of the importance of child's relationship with his or her teacher to the school experience and child adjustment, as well as, "research in social development, attachment theory, and teaching and learning that increasingly shows the importance of adult-child relationships as contexts for development" (p. 61). Pianta (1999) identified three separate domains related to student-teacher relationship quality: Conflict, Closeness, and Dependency. Conflict refers to teacher-student struggles and a teacher perspective of the student as angry or unpredictable. Closeness refers to the degree to which the teacher views his or her relationship with a student as warm, affectionate, and reflective of open communication. Dependency indicates the extent to which a teacher perceives a student as overly dependent on him/her. Thus, the most desirable student-teacher relationship quality would reflect lower levels of Conflict and Dependency and higher levels of Closeness. Research in the normative population has shown more favorable child outcomes (e.g., fewer behavioral problems, greater social competence, better school adjustment) when the student-teacher relationship is characterized by warmth and closeness, rather than conflict (Pianta, 1999; Pianta & Steinberg, 1992).

Eisenhower, Baker, and Blacher (2007) found that young elementary age students with ID did experience significantly poorer relationships with teachers than their typically developing peers. Teachers reported that their relationship with students with ID was characterized by less closeness and more conflict and dependency. However, the

differences between the teacher relationships with ID students compared to typically developing students could not be entirely attributed to cognitive ability. Rather the relationship between ID and student-teacher relationship quality was mediated by the child's self-regulation and maternal and teacher report of child behavior problems. In other words, child behavior and self-regulation were responsible for the differences in student-teacher relationship quality in this sample of children with and without ID.

McIntyre, Blacher, and Baker (2006) also found that children (ages 5 and 6) with ID had poorer overall student-teacher relationships than typically developing children.

Murray and Greenberg (2001) also found that students (5th and 6th grade) with mild ID had significantly poorer affiliation with teachers and greater dissatisfaction with teachers than students without disabilities. Furthermore, students with disabilities perceived their school as significantly more dangerous than their typically developing peers (Murray & Greenberg, 2001). This study corroborates the work of Fink (1990) and Morrison, Furlong, and Smith (1994). Fink's research (1990) reported that youth with learning disabilities and intellectual disabilities in grades 6 through 12 had poorer attachments to school and higher levels of fear and victimization than students without disabilities. Morrison, Furlong, and Smith (1994) found that high school students in special education settings experienced significantly higher levels of bullying than other students groups.

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APPENDIX B

Parent Information Letter

Dear Parent or Caregiver:

This letter provides information about a project I am working on for my graduate research. Please find attached a letter from your child's teacher indicating support for this study and willingness to help. The overall goal of this study is to better understand how teenagers with intellectual disabilities (i.e., mental retardation) understand themselves and their social development. I am interested in this topic because I am also the parent of an adolescent with intellectual disabilities. My son has been receiving special education services for the past 11 years.

The purpose of this project is to increase understanding of the social support, social opportunity, and self-determination of adolescents with intellectual disabilities. We know that both the school and the family influence children. We also know that children with disabilities have fewer social opportunities than children without disabilities. By gathering data from you, your child, and your child's teacher we will be able to provide valuable information to policymakers and educators who provide services to and allocate funds for persons with intellectual disabilities.

If you choose to participate in this project you will need to complete four surveys. These surveys include questions about your child's behavior, your relationship with your child, and how you think your child impacts your family. This project also involves interviewing your child and having your child's teacher complete three surveys. I will be the person interviewing all children and will be asking them questions about the activities they enjoy doing, their friends, and their understanding of disability. The teacher surveys are very similar to the parent surveys and include questions about the child's behavior, the teacher's relationship with your child, and the child's participation in school activities. Please contact me if you would like a complete list and description of the child and teacher surveys.

Participation in this project is voluntary and may end at any time. If you do not want information to be gathered about your child or do not want to provide information about your child, you can choose not to participate. For those parents who do agree to participate and to let information be gathered about their child, the attached consent letter clearly states what information will be gathered and how that information will be used.

I am conducting this research as part of my dissertation and as a requirement for my doctoral studies in Human Development. My academic advisor, Dr. Patricia Self, is helping to oversee this project. If you have any questions about the project or your participation you can contact me, Jennifer Jones, or Dr. Self at the Department of Human Development & Family Science, 233 HES, Oklahoma State University, Stillwater, Ok 74078, Jennifer Jones (405-974-1331; email jennifer.jones@okstate.edu) Patricia Self (405-744-8348; email patricia.a.self@okstate.edu).

If you agree to participate in this project, please complete the enclosed consent form and surveys and return them to your child's teacher in the envelope provided no later than _____. Please seal the envelope in order to ensure confidentiality. You will receive a check for \$35 for your participation via mail within approximately two weeks. If two parents complete the forms, you will receive a total of \$45. Your child will also receive an item for his/her participation. The items he/she will be able to choose from are valued at approximately \$15 each and include school t-shirts, gift cards, and games.

Sincerely,

Jennifer Jones

Principal Consent

Project Directors: Jennifer Jones, Doctoral Student at Oklahoma State University and **Dr. Patricia Self**, Professor.

Project Purpose and Procedures: The purpose of this project is to increase understanding of the social support, social opportunity, and self-determination of adolescents with intellectual disabilities. The researchers want to gather information that will be useful to policymakers and educators who provide services to persons with intellectual disabilities. **Your participation includes identifying teachers of students enrolled in special education classrooms which serve students with intellectual disabilities (i.e., mental retardation). Your consent will allow the researcher to recruit students, their parents and teachers to participate in this study.**

Teacher Participation will include:

- Sending home recruitment letters to parents and collecting consent forms and parent surveys. Also, completing a teacher consent form for their participation in the project.
- Completing the following surveys (estimated time=30minutes) for each child whose parent or legal guardian has given consent:
 - *Teacher's Report Form*
 - *Student-Teacher Relationship Scale*
 - *Student Participation—Teacher Report*
- Allowing each student (with parental consent and the child's assent) to be excused from class two or three times for interviews (approximately 45 minutes each). The primary researcher (Jennifer Jones) will be responsible for conducting the interviews. The interview includes completion of several student surveys (see Student Participation section below). A quiet room or space will be needed to conduct the interviews.

Student Participation will include:

Due to the intellectual disabilities of the participants and the potentially limited reading and writing skills, an assent script will be used and verbal assent obtained before conducting interviews. The assent script states to the adolescent that it is all right not to answer a question and they can stop the interview at any time. Student surveys include:

- *Arc's Self-Determination Scale*
- *Self-Perception Profile for Children*
- *Social Support Scale for Children and Adolescents*
- *Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children*
- *Knowledge of Self and Disability Interview*
- *Peabody Picture Vocabulary Test -4*

Parent Participation will include completion of the following surveys:

- *Background Information*
- *Family Impact Questionnaire-Revised*
- *Child Behavior Checklist/6-18*
- *Adult-Child Relationship Scale*

Risks: We do not anticipate any harm as a result of participation in this study. The survey questions will ask participants to reflect on everyday experiences and challenges they may or may not have in their lives. However, if a teacher or parent feels uncomfortable, has questions, or feels tired and wants to talk about it, they can contact one of the project directors (Jennifer Jones at 974-1331 or by email at jennifer.jones@okstate.edu). If a student becomes uncomfortable or upset during the interview, he or she will be given the opportunity to stop with absolutely no penalty.

Benefits: It is expected that the participating adolescents will engage in self-reflection. In turn, parents and teacher will likely gain insight into the social self development of adolescents with intellectual disabilities. The results of this study will be beneficial to the field by providing a greater understanding of social self development in adolescents with cognitive limitations. Specifically, it is expected that the data gained from this study will be useful in identifying factors which influence adolescents' self-determination, perceived social support, and social opportunities. Information will be disseminated in reports, articles, and/or conferences.

Additionally, participation in this study will aid students in meeting the PASS skills as identified in the Curriculum Access Resource Guide-Alternate (CARG-A).

Confidentiality: The records of this study will be kept private. Any written results will discuss group findings and will not include information that will identify participants. Research records will be stored securely and only researchers responsible for oversight of this study will have access to the records. It is possible that the consent process and data collection may be observed by research oversight staff responsible for safeguarding the rights and well being of people who participate in research. The surveys are confidential and will only be tracked with a code number. No names will be written anywhere on the survey materials. Participants may be contacted in the future for follow-up studies. However, names and identifying information will be kept separate from study data and securely stored. Once follow-up studies are complete, all identifying information will be destroyed.

Compensation: Each adolescent participant will be offered an item (e.g., school t-shirt, gift certificate, or game) valued at approximately \$15 each upon completion of their interview. Parents will be offered \$35 by check to be provided upon receipt of their completed parent packets. If a participant has two parents willing to complete the questionnaires, the second parent-informant will be offered an additional \$10 check. Teachers will be offered \$10.00/per student participant by check to be provided upon their completion of the teacher packet.

Contacts: Any questions you have about the project or your participation can be answered by Jennifer Jones at the Department of Human Development & Family

Science, 233 HES, Oklahoma State University, Stillwater, Ok 74074, 405-974-1331 or by email at jennifer.jones@okstate.edu. Feel free to ask any questions at any time during the project. You may request a copy of the results from this project. **If you have questions about the research and your rights as a research volunteer, you may contact Dr. Sheila Kennison, IRB Chair, 219 Cordell North, Stillwater, OK 74074, 1-405-744-1676 or irb@okstate.edu.**

All participation is voluntary and your school, the teachers, parents, or students may withdraw from this program at any time by notifying the Jennifer Jones. In order for us to proceed with this project, **we need the completed attached form from you. Please return it to Jennifer Jones.**

Thank you for your time and assistance with this project, and the opportunity to partner with Oklahoma State University.

PRINCIPAL CONSENT FORM

I give my consent:

____yes ____no For subject recruitment and data collection to take place at my school during the Fall of 2008.

____yes ____no For my school to be identified as participating in the project to other schools in the project, and local or state officials.

I understand that the study has been reviewed by Oklahoma State University's Institutional Review Board and that informed consent will be obtained from teachers and parents before students are allowed to participate. The researcher will be required to check in at the office upon entering and leaving the school and teachers' schedules will be honored.

Principal Signature

Date

Name of School

Please return to Jennifer Jones.

Signature of Researcher

Date

Teacher Consent

Project Directors: Jennifer Jones, Doctoral Student at Oklahoma State University and **Dr. Patricia Self**, Professor.

Project Purpose and Procedures: The purpose of this project is to increase understanding of the social support, social opportunity, and self-determination of adolescents with intellectual disabilities. The researchers want to gather information that will be useful to policymakers and educators who provide services to persons with intellectual disabilities.

Your Participation will include:

- Sending home recruitment letters to parents along with a cover letter indicating your support of the project. Collecting consent forms and parent surveys.
- Completing the following surveys (estimated time=30minutes) for each child whose parent or legal guardian has given consent:
 - *Student-Teacher Relationship Scale*
 - *Student Participation—Teacher Report*
 - *Teacher Rating Scale of Child Actual Behavior*
- Allowing each student (with parental consent and the child's assent) to be excused from class two or three times for interviews (approximately 45 minutes each). The primary researcher (Jennifer Jones) will be responsible for conducting the interviews. The interview includes completion of several student surveys (see Student Participation section below). A quiet room or space will be needed to conduct the interviews.

Student Participation will include:

Due to the intellectual disabilities of the participants and the potentially limited reading and writing skills, an assent script will be used and verbal assent obtained before conducting interviews. The assent script states to the adolescent that it is all right not to answer a question and they can stop the interview at any time. Student surveys include:

- *Arc's Self-Determination Scale*
- *Self-Perception Profile for Children*
- *Social Support Scale for Children and Adolescents*
- *Knowledge of Self and Disability Interview*
- *Peabody Picture Vocabulary Test -4*

Parent Participation will include completion of the following surveys:

- *Background Information*
- *Parent Questionnaire*
- *Family Impact Questionnaire*
- *Parent Rating Scale of Child Actual Behavior*

Risks: We do not anticipate any harm as a result of participation in this study. The survey questions will ask participants to reflect on everyday experiences and challenges they may or may not have in their lives. However, if you feel uncomfortable, have questions, or feel tired and want to talk about it, you may contact one of the project directors (Jennifer Jones at 974-1331 or by email at jennifer.jones@okstate.edu). If a

student becomes uncomfortable or upset during the interview, he or she will be given the opportunity to stop with absolutely no penalty.

Benefits: It is expected that the participating adolescents will engage in self-reflection. In turn, parents and teacher will likely gain insight into the social self development of adolescents with intellectual disabilities. The results of this study will be beneficial to the field by providing a greater understanding of social self development in adolescents with cognitive limitations. Specifically, it is expected that the data gained from this study will be useful in identifying factors which influence adolescents' self-determination, perceived social support, and social opportunities. Information will be disseminated in reports, articles, and/or conferences.

Additionally, participation in this study will aid students in meeting PASS skills as identified in the Curriculum Access Resource Guide-Alternate (CARG-A).

Confidentiality: The records of this study will be kept private. Any written results will discuss group findings and will not include information that will identify participants. Research records will be stored securely and only researchers responsible for oversight of this study will have access to the records. It is possible that the consent process and data collection may be observed by research oversight staff responsible for safeguarding the rights and well being of people who participate in research. The surveys are **confidential** and will only be tracked with a subject number. No names will be written anywhere on the survey materials. **You may be contacted in the future for follow-up studies. However, names and identifying information will be kept separate from your study data and securely stored. Once follow-up studies are complete, all identifying information will be destroyed.**
Compensation: You will receive \$10.00/per student participant by check to be provided upon completion of the teacher packet.

Contacts: Any questions you have about the project or your participation can be answered by **Jennifer Jones** at the Department of Human Development & Family Science, 233 HES, Oklahoma State University, Stillwater, Ok 74074, 405-974-1331 or by email at jennifer.jones@okstate.edu. Feel free to ask any questions at any time during the project. You may request a copy of the results from this project. **If you have questions about the research and your rights as a research volunteer, you may contact Dr. Sheila Kennison, IRB Chair, 219 Cordell North, Stillwater, OK 74074, 1-405-744-1676 or irb@okstate.edu.**

All participation is voluntary and you, your school, parents, or students may withdraw from this program at any time by notifying the Jennifer Jones. In order for us to proceed with this project, **we need the completed attached form from you. Please return it to Jennifer Jones.**

Thank you for your time and assistance with this project, and the opportunity to partner with Oklahoma State University.

Informed Consent for Parent and Child Participation

Project Directors: Jennifer Jones, Doctoral Student at Oklahoma State University and Dr. Patricia Self, Professor.

Project Purpose and Procedures: The purpose of this project is to increase understanding of the social support, social opportunity, and self-determination of adolescents with intellectual disabilities. The researchers want to gather information that will be useful to policymakers and educators who provide services to persons with intellectual disabilities. **Your participation will involve completing surveys.** The surveys will ask you about life as a parent of a child with disabilities and about your child's behavior. **The surveys will take approximately an hour to complete.**

Participation also involves allowing your child's teacher to complete surveys about your child's behavior, participation in school activities, and their relationship with your child; and giving the teacher permission to report your child's school records (e.g., attendance and assessment). The researcher will not have access to your child's school file.

Participation also involves allowing your child to be interviewed by the researcher. This interview will take place at your child's school during regular school hours. Your child will be asked questions about the activities they enjoy doing, their friends, and their understanding of disability. The interview with your child will take approximately 2 ½ hours and will be conducted over two or three 45 to 60 minute time periods. The interview will be audio recorded.

Risks: We do not anticipate any harm as a result of your participation or your child's participation in this study. The survey questions will ask you to reflect on everyday experiences and challenges you may or may not have in your life as a parent of a child with disabilities. However, if you feel uncomfortable, have questions, or feel tired and want to talk about it, you can contact one of the project directors (Jennifer Jones at 974-1331 or by email at jennifer.jones@okstate.edu). If your child becomes uncomfortable or upset during the interview, he or she will be given the opportunity to stop with absolutely no penalty.

Benefits: It is expected that the participating adolescents will engage in self-reflection. In turn, parents and teacher will likely gain insight into the social self development of adolescents with intellectual disabilities. The results of this study will be beneficial to the field by providing a greater understanding of social self development in adolescents with cognitive limitations. Specifically, it is expected that the data gained from this study will be useful in identifying factors which influence adolescents' self-determination, perceived social support, and social opportunities. Information will be disseminated in reports, articles, and/or conferences. Additionally, participation in this study will aid students in meeting PASS skills as identified in the Curriculum Access Resource Guide-Alternate (CARG-A) developed by the Oklahoma State Department of Education.

You grant permission for your child’s teacher to complete surveys on your child’s behavior and participation in school activities. You also grant permission for your child’s teacher to report information from school records such as attendance and assessment scores.

Parent/Caregiver Name (printed) Date

Parent/Caregiver Signature Date

Teacher’s Name Child’s Name

You grant permission for the researcher to interview your child about his/her the participation in activities, their friends, and their understanding of disability.

Parent/Caregiver Name (printed) Date

Parent/Caregiver Signature Date

Child’s Name

Signature of Researcher Date

Child Assent Script

The following script will be read to the student. If they agree, their name will be written, “child assented”, checked and the researcher will sign. If they do not agree, the interview will not continue.

Hello [child’s name].

Your parent said it would be ok for me to talk to you and ask you some questions about what you like to do and your friends. I ‘m also going to ask you some questions about school and the people in your life.

No one but people studying this information will see your answers, and your answers will be kept locked up. You can tell your parents what we talked about. We won’t show them your answers unless we are worried about you, and we will not tell anyone else about your answers.

If there are some questions you do not wish to answer, that is ok. If you want to stop answering questions at any time, that will be ok – just tell me and we will stop. We’re going to work on this for about an hour today and then I’ll come back another day and we’ll work on it some more.

If you want to answer these questions, please tell me it is ok.

_____ Child assented
Child Name

_____ Date
Interviewer Signature

Oklahoma State University Institutional Review Board

Date: Thursday, July 03, 2008
IRB Application No HE0839
Proposal Title: Development of the Social Self in Adolescents with Intellectual Disabilities

Reviewed and Processed as: Expedited (Spec Pop)

Status Recommended by Reviewer(s): Approved Protocol Expires: 7/2/2009

Principal Investigator(s):

Jennifer L. Jones Patricia Self
8020 NW 15th St. 321 HES
Oklahoma City, OK 73127 Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Beth McTernan in 219 Cordell North (phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely,



Shelia Kennison, Chair
Institutional Review Board

APPENDIX C

Knowledge of Self and Disability Interview-Adolescent Report

1. Can you tell me about yourself? (Can probe with other questions: What kind of person are you? What would you tell somebody about yourself (e.g., the name of somebody they knew)? What sort of things would you say? PROMPT. Well, for example, what's your name, are you a young man or a young woman, anything else?)
2. Now I'd like to ask you about some of the things you told me. (Utilizing the adolescent's responses from above, ask the following...Is that something you would like to keep the same or something you would like to change?)
3. If you could change something what would it be (e.g., if you had a magic wand)?
4. Have you heard of disability (NOTE: may substitute disability for mental retardation, Down syndrome, autism, etc.)?

Background Information

INSTRUCTIONS: Thank you for completing this background information about your family and your child. If there is a question that you do not want to answer, it is okay to skip that question and move on to the next one.

ABOUT YOUR CHILD:

1. Child's date of birth: _____

2. Child's gender: Male Female

3. What is your relationship to child?

Mother Father Grandparent Foster parent Other (please specify) _____

4. Is this child adopted?

no yes If yes, how old was the child when he/she joined your family? _____

5. Race of child:

White African-American Hispanic/Latino Asian Biracial
 Native American Other (please specify) _____

6. What categories or labels of disability has your child received from professionals? Please check all that apply.

Down Syndrome Prader-Willi Syndrome Fetal Alcohol Syndrome
 Behavior Disorder Autism Asperger Syndrome
 Mental Retardation Williams Syndrome ADHD
 Other: _____ Other: _____

7. What information would you like to tell us about your child's diagnoses:

8. Does your child have any serious medical problems?

no yes If yes, please explain:

ABOUT YOUR FAMILY:

9. List all people currently living in the child's home and their dates of birth (e.g., mom, 4/8/60)

Relation to child	Date of birth
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

10. Marital status of child's parents:

- Married Separated Divorced Estranged Widowed
 Never Married/Living Together Never Married/Not Living Together

11. Race of mother (or primary caregiver's):

- White African-American Hispanic/Latino Asian Biracial
 Native American Other (please specify) _____

12. What is the mother's (or primary caregiver's) highest level of education?

- 0-8th grade 9th-11th grade 12th grade/GED Vocational training
 Completed college Completed Graduate School

13. What is the mother's job/ occupation?

14. Race of father (or child's other caregiver/guardian):

- White African-American Hispanic/Latino Asian Biracial
 Native American Other (please specify) _____

15. What is the father's (or child's other caregiver/guardian's) highest level of education?

- 0-8th grade 9th-11th grade 12th grade/GED Vocational training
 Completed college Completed Graduate School

16. What is the father's job/occupation?

17. What is the total household income (before taxes) each year (excluding public assistance)?

- | | |
|---|--|
| <input type="checkbox"/> Under \$10,000 | <input type="checkbox"/> \$60-70,000 |
| <input type="checkbox"/> \$10-20,00 | <input type="checkbox"/> \$70-80,000 |
| <input type="checkbox"/> \$20-30,000 | <input type="checkbox"/> \$80-90,000 |
| <input type="checkbox"/> \$30-40,000 | <input type="checkbox"/> \$90-100,000 |
| <input type="checkbox"/> \$40-50,000 | <input type="checkbox"/> \$100-150,000 |
| <input type="checkbox"/> \$50-60,000 | <input type="checkbox"/> \$150-200,000 |
| | <input type="checkbox"/> \$200,000+ |

COMMENTS:

Is there any other information you would like to share about your child or family that you feel is important to this project?

PARENT QUESTIONNAIRE

INSTRUCTIONS: Part of the purpose of this project is to better understand how teenagers with disabilities understand themselves and their own disability. Please explain your answers as much as possible. As always, if there is a question you are not comfortable answering it is okay to skip it and move on.

Do you think your child believes that he or she is different in some way than kids? (Please explain your answer).

Does your child ever indicate that he or she feels different from other kids or feels left out? (Please explain your answer as much as possible).

Can you remember a time when you talked to your child about being different from other kids his or her age? (If so, please describe that conversation).

If you have talked with your child about being different from other kids his or her age, please describe how your child responded to your conversation.

Have you talked to your child's brothers or sisters about how their brother or sister is different from other kids? If so, how did you explain the difference to them?

What do you think your child understands about the word: disability?

Do you think your child believes he or she has a disability? (Please explain your answer).

Do you think your child believes that his or her classmates have a disability? (Please explain your answer).

Can you remember a time when you talked to your child about his or her disability? If so, please describe your conversation in detail.

If you have talked with your child about his or her disability, please describe how your child responded to your conversation.

Have you talked to your child's brothers or sisters about his or her disability? If so, how did you explain disability to them?

We would love to hear any other comments you would like to share:

Student Participation--Teacher Report

1. Does this student spend time with typically developing peers during his/her regular school day?

no yes If yes, for what subjects/activities?

If yes, what percentage of the student's day is spent with typically developing peers?

10% 20% 30% 40% 50% 60% 70% 80% 90% _____Other

2. Does this student participate in any extracurricular activities sponsored by the school (e.g., Special Olympics, Drama, Art Club, Band, School Dances)

no yes If yes, what activities and how often?

3. Did this child participate in his/her last IEP meeting?

no yes If yes, please describe in as much detail as you can his/her role as a participant.

4. Have you used self-determination curriculum (e.g., *Self-Directed IEP, Choicemaker Self-Determination Curriculum Series, Next S.T.E.P., Take Charge for the Future, Whose Future is it Anyway?*) in teaching this child?

no yes If yes, please provide the name of the curriculum and when you used it with this child?

5. Is there any other information you think is important for us to know about this student's participant in educational and extra-curricular activities?

VITA

Jennifer Lynn Jones

Candidate for the Degree of

Doctor of Philosophy

Dissertation: INFLUENCES ON THE SELF-CONCEPT OF ADOLESCENTS WITH
INTELLECTUAL DISABILITIES

Major Field: Human Environmental Sciences (option: Human Development)

Biographical:

Education: Received a Bachelor of Science degree in Family Relations and Child Development from Oklahoma State University in Stillwater, Oklahoma in July 1995; received a Master of Science in Human Development and Family Science from Oklahoma State University in Stillwater, Oklahoma in July, 2006; completed the requirements for the Doctor of Philosophy in Human Development at Oklahoma State University, Stillwater, Oklahoma in July, 2009.

Experience: Medical Social Worker at The Children's Center in Bethany, Oklahoma (1995-1996); Therapeutic Foster/Adoptive Parent for the Oklahoma Department of Human Services (1996-present); Executive Director of Deaconess Home Pregnancy and Adoption Services in Oklahoma City, Oklahoma (2002-2005); Graduate Research and Teaching Associate at Oklahoma State University in Stillwater, Oklahoma (2005-2009).

Professional Memberships: American Association on Intellectual and Developmental Disabilities

Name: Jennifer L. Jones

Date of Degree: July, 2009

Institution: Oklahoma State University

Location: Stillwater, Oklahoma

Title of Study: INFLUENCES ON THE SELF-CONCEPT OF ADOLESCENTS WITH
INTELLECTUAL DISABILITIES

Pages in Study: 114

Candidate for the Degree of Doctor of Philosophy

Major Field: Human Environmental Sciences (option: Human Development)

Scope and Method of Study: The purpose of this study was to examine the self-concept of adolescents with intellectual disabilities (ID). The sample included 51 adolescents with ID, their parents ($n = 50$), and teachers ($n = 12$). A mixed methods approach was utilized, with qualitative data used to enrich quantitative results. Individual interviews were conducted with each adolescent and particular emphasis was placed on the perceptions and subjective experiences of the adolescent participants. The relationship among adolescent perception of support, adolescent self-determination, parent perception of child impact, and student-teacher relationship was explored along with the contribution of each of these variables to adolescent global self-worth. Group differences between students in self-contained classrooms and students in resource rooms were also examined.

Findings and Conclusions: Significant correlations were found among this constellation of variables. Of primary interest were the favorable associations of global self-worth, psychological empowerment, and classmate support with parent perception of child positive impact and adolescent perception of parent support. Hierarchical linear regression revealed that adolescent perception of parent support and self-determination were significant predictors of global self-worth. These findings expand the literature by emphasizing the role of family support on positive child outcomes for adolescents with ID. When examining the impact of classroom placement, adolescents in self-contained classrooms perceived their classmates as more supportive; whereas, adolescents in resource rooms reported higher self-determination. The mixed methods approach resulted in a depth of understanding regarding the multiple influences on the self-concept of adolescents with ID.

ADVISER'S APPROVAL: Patricia A. Self, Ph.D.
