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Social Support Networks Among Children with Intellectual and Developmental Disabilities

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Abstract

Previous research using predominantly adult populations has found that social support is positively correlated with an individual's quality of overall health and wellbeing. Given the limited research investigating social support among children, especially children with special needs, the present study explored the social support networks of children with intellectual and developmental disabilities (IDD). Nine children enrolled in an after-school program were observed interacting with others and were interviewed in group discussions about the sources of support they tend to rely on in their daily activities. Preliminary findings suggest that children relied on each other's for help during the regular after-school activities and reported receiving different extent and types of support from family members, peers, teachers, and coaches. These findings suggest that children with IDD benefit from a strong social support network system which may have practical implications for middle childhood interventions in educational settings.

Social Support Networks Among Children with Intellectual and Developmental Disabilities

The present study investigated the social support networks preadolescents and adolescents with intellectual and developmental disabilities (IDD) rely on in their everyday lives. In particular, this study was aimed at identifying and describing specific sources and forms of social support these youth depended on in accomplishing their daily activities.

Research on social support has indicated that people with strong social support networks tend to report less psychological, physical, and social problems than those without such social support systems (Cohen & Willis, 1985; Gerich, 2013; Hupcey, 1998). Cohen and Willis (1985) suggest that people who hold few positive social relations with others have been found to report negative psychological experiences that may increase their risks for diseases and early mortality rates. Similarly, Fiorillo and Sabatini (2011) indicate that people who report having no to little positive social relationships with others are more likely to be in poor health. Park et al. (2012) also found that perceived social support is one of the top predictors of participants' interdependence and perceived stress levels.

The positive role of social support on individual's wellbeing has received a few explanations. The Buffering Model suggests that having a strong social support network acts as a buffer to potentially negative outcomes of a stressful event. There are two points at which support may play a role in the stress response: 1) a person may appraise the initial stressful situation differently knowing they have a strong social network to support them, and 2) a person may be less reactive to the perceived stress due to knowing they have a social support network to fall back on, and also due to their social support network facilitating healthy coping and response behaviors (Cohen & Willis, 1985; Gerich, 2013; Hupcey, 1998; Park et al. 2012; Shorey, & Lakey, 2011). The Buffering Model suggests that social support networks impact the

psychological, physical and social wellbeing of individuals by changing the way a person perceives and reacts to stress. Social support is thought to act as a buffer and facilitates positive and proactive reactions to stress.

The Main Effect Model is a competing hypothesis that claims social support doesn't act as a buffer to reduce reactions, but affects a persons' overall outlook (Cohen & Willis, 1985; Gerich, 2013; Hupcey, 1998; Park et al. 2012; Shorey, & Lakey, 2011). This model explains that when a person has a strong social support network they tend to have a more stable environment, they continuously have positive experiences with others, and develop a sense of community and self-worth (Cohen & Willis, 1985; Gerich, 2013; Hupcey, 1998; Park et al. 2012; Shorey, & Lakey, 2011). The Main Effect Model claims that having a strong social support network benefits a person in many ways, which in turn protects a person against the psychological, physical, and social problems that may arise when people don't have this type of support system (Cohen & Willis, 1985; Gerich, 2013; Hupcey, 1998; Park et al. 2012; Shorey, & Lakey, 2011).

The concept of social support has been examined since the 1970's, and the definition of the term has changed over time. Currently almost any social interaction can be classified as an act of social support (Cohen & Willis, 1985; Gerich, 2013; Hupcey, 1998). Hupcey (1998) analyzed social support literature and divided the definitions of social support researched into five categories. 1) Type of support provided; 2) recipients perception of support; 3) intentions or behavior of the provider; 4) reciprocal support; 5) social networks. In this study, two of the five categories as described by Hupcey (1998) are used, focusing on the participants first hand perceptions of social support as this is one of the most relevant indicators when relating social support to psychological and physical well being (Cohen & Willis, 1985; Gerich, 2013; Park et

al. 2012; Fiorillo & Sabatini, 2011) and exploring who the participants believe make up their personal social network.

Given its benefits to people's psychological and physical well-being, a strong and reliable social support network may be particularly critical during youth's transition from middle-childhood to early adolescence. During this transitional phase, youth undergo important cognitive, social, emotional, and biological changes that shape the ways they engage with family members, peers, friends, and teachers (del Valle, Bravo, & Lopez, 2010; Martínez, Aricak, Graves, Peters-Myszak, & Nellis, 2011). It is a time when parents expect youth to become more independent and responsible. In line with these expectations, youth are found to spend increasingly more time with their peers in activities outside their homes (del Valle et al., 2010; Zhang, Yan, Zhao, & Yuan, 2014). Zhang et al. (2014) found that when youth 13-16 years old are under increased stress those who report lower levels of social support from peers display more symptoms of depression, compared to those who report a high quality and quantity of peer support. While youth rely on their peers for emotional support, they continue to depend on their parents' advice, assistance, and support (del Valle et al., 2010). Youth often report less social support during periods of high stress, and it is during these times that parents and family members could increase support to help relieve the youth's stress levels (Zhang et al., 2014). In fact, Waters, Lester, and Cross (2013) found that support from parents is the only significant predictor of how well a child will adjust socially and emotionally to stressful situations, such as when a child transitions from a primary to secondary school.

Children with various disabilities develop differently than their typically developing peers and these variations in development can affect them in many direct and indirect ways. Nonis, and Jernice, (2014) found that children with mild learning disabilities tend to perform

below average on motor skill tasks such as object control and locomotor skills. The participants in this study tended to perform on average four years behind their typically developing peers of the same age (Nonis, & Jernice, 2014). Various disabilities can also affect a child's ability to understand emotion and interact socially. Ališauskaitė, and Butkienė (2013) found that children with intellectual disabilities often differ from typically developing children in being able to recognize and understand an emotion within a social situation; this may be due to a failure to recognize social signs or cues, or being able to recognize those cues, but interpreting them differently than typically developing children. This finding isn't surprising since characteristics of many disabilities make it difficult for people to engage in tasks such as communication, understanding social norms, and being able to read other's emotions or social cues the way that typically developing people do, which is the underpinning of most social interactions (Ališauskaitė, & Butkienė, 2013). There is a wide range of disabilities that can affect a person in many different developmental domains, physically, cognitively, socially and emotionally. Adding these difficulties on top of the major developmental changes that happen during early adolescence and puberty can make this time even more stressful and difficult.

The few studies in the social support literature involving children with learning disabilities and emotional and behavioral problems have found positive associations between children's perceived social support and their tendency to cope with the challenges they encounter in their daily lives (LaBarbera, 2008; Martinez et al. 2011; Popliger, Toste, & Heath, 2009). Wendelborg, and Kvello (2010) found that children with disabilities often have a harder time creating strong relationships with peers. This could be for many reasons, often children with disabilities run into more barriers when trying to participate in both school-related activities and after-school activities, these children report less participation in these activities overall, as well

as less involvement and satisfaction when they do participate (Coster et al. 2012; Wendelborg, & Kvello, 2010). These factors can have a large affect on children with IDD's perception of social support as children with learning disabilities often report as receiving different levels of social support from parents, classmates, friends, and teachers than peers in dealing with challenges (LaBarbera, 2008; Popliger et al., 2009).

Research indicates that parents and others often tailor their support to youth's competence and needs, which, in turn, contributes to shaping youth's development (Azmitia, 1996; Gauvain & Perez, 2005). Yet, despite this extensive empirical work, the ways youth with special needs perceive their own social support systems have been the focus of little research (Mundhenke, Hermansson, & Nätterlund, 2010; O'Rourke, & Houghton, 2008; Wendelborg, & Kvello, 2010). Migerode, Maes, Buysse, and Brondeel (2012) is one of the few studies which took into account both the parent's and the child with a disability's perspectives, they measured quality of life (QoL) on subjective and objective scales. The results showed that parents tend to be satisfied with their QoL (though their ratings are slightly under global ratings). But the children tend to report a much lower QoL compared to their peers and their parents' ratings (Migerode et al., 2012). This finding reinforces that is important to take into account not only the parents, teachers, and doctors perspective, but also the child's perspective when it comes to research and health care.

To expand the little available research, this study examined who youth with IDD perceived as their sources of social support and the forms of support these sources provided in their daily activities within and outside of their after-school recreational therapy program. Through focus group discussions and naturalistic observations, this study aimed to achieve a deeper understanding of these youth's perceptions of the roles members of their social support

system played in their everyday lives. By bringing youth's with IDD voices to the foreground, the findings of the present study were expected to inform efforts to build and foster more effective social support systems that contribute positively to their well-being and development.

Method

Participants

13 middle school students were invited to participate in the current study, participants were recruited through their participation in a therapeutic recreation based after school group. 9 students returned permission slips signed by legal guardians and gave verbal assent to participate in the study. Participants were in 6th – 8th grade, 5 males (mean age of 12.4), and 4 females (mean age 11.75). The participants all attended a public middle school in the northern New England region that reflects the demographic background of the area, and the parents of the participants all had at least a high school education. Participants had a wide range and varying degrees of IDD, participants spent 0-50% of their school day in special education classrooms, the rest of the time they were included into integrated classrooms, some of the participants did have aides who would accompany them throughout their school day as well. The participants had a wide range of disabilities including Attention Deficit/Hyperactivity Disorder, Oppositional Defiant Disorder, Autism/Asperger Syndrome, Mood Disorder, Sensory Processing Dysfunction, Anxiety, Seizures, speech language delays, developmental delays, and other learning disabilities.

All participants were involved in the same therapeutic recreation based after school group. This program focuses on helping students develop different social skills and life skills through engaging activities. Each week an activity is created with a specific goal in mind, for example one session may have the students playing various board and card games as a group, but the students may have to work in pairs, the purpose of this session would be to facilitate the

development of sportsmanship, cooperation, compromising in social situations, focus, and acting socially appropriate. To become part of this program teachers and school faculty identify students who would benefit from this type of program, then along with the student's parents and the therapeutic recreation specialist it is decided whether the student will attend this program. This specific program splits up the students into two groups based on gender, this is mostly for logistical reasons, but there are secondary benefits identified such as decreasing distractions of possible romantic interests and because often students of this age are more comfortable around those of the same gender.

Materials

This study used a short demographic background questionnaire filled out by the parents of the students to collect information that would provide context about the student's home life such as educational background and occupation of the parents; this questionnaire was estimated to have taken no more than 10 minutes to complete.

In addition to the questionnaire, coding sheets were used to collect observational data on the occurrences of social support among the students during their typical after school group activities. These coding sheets were used to capture different information such as the type of social interaction (e.g. emotional support, collaboration in problem solving, general conversation, etc.), who was involved (e.g. program staff, fellow peers, etc.), and the context of the interaction (e.g. part of the predetermined activity, group discussion, social conversations, etc.) as well as if the interaction included any sort of specific support whether it be offered by the student, requested by the student, etc. The coding sheets also required the inclusion of the activity and goals of the session at the day of the observation.

During the group discussion phase involving the researcher, staff members, and

participants an audio recording device was used to record their discussions on perceived social support. This recording was then transcribed for coding and analysis purposes.

Procedure

This study consisted of two phases that all participants were involved in, group discussions focused on themes of social support and observations where each participant was observed individually during the normal program activities.

Group Discussion. 2 group discussions per group (males and females) were held for about 20 minutes each over multiple sessions. The group discussion was broken up this way in order to keep the students attentive and focused, since this population tends to get distracted, and off topic easily. Each group discussion was led by the same researcher and facilitated by other adults present who were affiliated with either the therapeutic recreation program or the school that the students attended. The researcher guided the conversation using pre-written questions and prompts aimed to elicit the different forms of support the students receive from the people they interact with in their daily life. The researcher used the same questions and prompts for both groups.

Observation. A majority of the participants were observed 2-3 times, but due to participants being absent during some sessions 2 participants were only observed one time each. Observations occurred over six normal program sessions.

Prior to the sessions a random order was produced, and then accommodations were made if a child was not present or requested to not be observed that day. Each individual observation session consisted of a researcher focusing on one child for a total of 9 minutes, recording one minute spot observations using the coding sheet, every three minutes. In other words the researcher would observe the target child for 2 minutes, then for 1 minute record observations

using the coding sheet, after the 1 minute recording the researcher would again observe for 2 minutes and continue until they had 3 minutes of recorded observations, then move onto the next target participant. This 9 minute observation procedure was repeated during the duration of the program's daily activity. The researcher did not perform these formal observations during times of transportation in order to keep the context of the data consistent across observation periods.

Results

Group Discussion

Recordings of group discussions were transcribed into word documents and then reviewed by the researchers involved in the project. The researchers who reviewed the transcriptions identified major themes relating to sources of social support and types of support received from the participant's discussion. The major sources of social support identified by the participants were parents/families, friends, teachers, and coaches. Parents were identified as a source of both instrumental support (physical or tangible help, such as helping with homework or resolving issues at school) as well as emotional support (such as being a confidant for the child to express emotions about their day). Other family members such as siblings and grandparents were also mentioned as having similar roles, though they were not mentioned as often as parents. Friends were identified as a major source for emotional support. The participants almost exclusively said they looked to their friends to confide in, talk with, and to have fun with. The participants identified that teachers (including aides, one-on-ones, or other special education staff) provided students with instrumental support. The participants focused on the fact that teachers helped them with school work, even when prompted about other types of support they may provide the students only reported receiving school related instrumental support from

teachers. Participants who take part in sports and other after school activities also mentioned coaches and club/activity advisors as providing solely instrumental support within the specific sport or activity.

Observation

The data from the coding sheets recorded during observations were input into SPSS and were analyzed using descriptive statistics, focusing on frequency statistics that were converted into percentages. Data was collected for 55 observation points (of 1 minute each) during various activities. See the tables 1-7 in the appendix for frequency and percentage charts describing the observation data collected. During the 55 observed 1-minute periods, 76.4% of the time an instance of support occurred. Of that 76.4% of the time that support occurred 20% of the time support was offered by the target child to someone else, 14.5% of the time support was requested by the target child from someone else, 1.8% percent of the time the target child received support without requesting it, 1.8% of the time support was offered to the target child but the target child refused it, and 38.2% of the time the target child was in general conversation or another form of support occurred that did not fit into any of the previous categories. Out of that same 76.4% of the time that support occurred 12.7% of the time it was physical assistance, 9.1% of the time it was emotional support, 7.3% of the time the target child was making suggestions to others, 3.6% of the time the target child was collaborating in problem solving related to the predefined group activity, 3.6% the target child was mediating arguments with others, 30.9% the target child was having a general conversation with others, and 9.1% some other form of support occurred that did not fit into the previous categories.

Discussion

The current study examined multiple facets of social support focusing on observed

interactions and first hand perceptions of middle school students with IDD. During the group discussions many of the participants identified their parents as being major sources of social support, helping in both tangible, instrumental ways, as well as emotionally. Participants often turned to friends and peers both during school and in non-school activities for emotional support and to play with or have fun with. The participants reported teachers and coaches provide them with mostly tangible, or instrumental support. During the observation periods support did occur often (76.4% of the time), most often this support was in the form of general conversation with peers as well as adults (30.9% of the time), the second most often observed form of support was physical assistance either offered or received by the target participant. Second to being in general conversation (where the target participant is both receiving and providing support), the participants were most likely to offer their support to others (20% of the time) compared to receiving, requesting, or refusing support from others.

The current study was conducted to be person centered, this idea was central when creating this study because it is important for health care practitioners, teachers, and other professionals to be able to see situations from their client's perspectives. There is little research that focuses on obtaining children with IDD's personal perspectives on social support which means there is a major gap in the research because without hearing feedback from the client's themselves it is almost impossible to validate and improve practices (Migerode et al., 2012; Mundhenke et al., 2010; O'Rourke, & Houghton, 2008; Wendelborg, & Kvello, 2010). Much research, as well as many practitioners, rely heavily on information reported by the parent's of children with disabilities, and while it is important to take their perspective into account, we have to remember that their opinions and experiences don't always reflect their child's experiences. Migerode et al., (2012) found that subjective and objective measures of quality of life were

significantly lower for children with disabilities compared to their peers, but their parents' measured only slightly lower than global averages. This reiterates the fact that it is important to bring the clients into the conversation, especially if they are children.

Research shows that social support can have a significant effect on a child's self-esteem and that in adolescence teenagers rely more heavily on their peers for emotional support and begin to distance themselves from their parents (del Valle et al., 2010; LaBarbera, 2008; Martínez et al., 2011; Popliger et al., 2009; Zhang et al., 2014). Because of this being able to create strong relationships with peers is crucial for healthy development, but it often harder for children with disabilities to foster friendships compared to their typically developing peers for a variety of reasons (Ališauskaitė, & Butkienė, 2013; del Valle et al., 2010; LaBarbera, 2008; Martínez et al., 2011; Popliger et al., 2009; Wendelborg, & Kvello, 2010; Zhang et al., 2014). Wendelborg, and Kvello (2010) found that the more severe a disability or impairment is, the lower the child's perceptions of social acceptance and peer intimacy are, this may be due to many factors including isolation from typically developing peers during school, less participation in after school activities, and marginalization of children with disabilities due to their peers having negative stigmatism of disabilities (Bellanca, & Pote, 2013; Mpofu, 2003; Mundhenke et al., 2010; Putnam, Markovchick, Johnson, & Johnson, 1996). Practitioners, teachers, and parents who work with children with disabilities should particularly focus on helping the child foster positive relationships with peers and others in their community in order to strengthen their social support network and help buffer against some of the negative effects of perceiving a low amount of social support (Migerode et al., 2012; Mpofu, 2003; Wendelborg, & Kvello, 2010). LaBarbera (2008) suggested that private schools specialized for children with disabilities foster more inclusive communities within the school that can have many positive affects on a child including

higher perceived social support as well as an increased sense of self-worth and self-esteem. However it is often not possible for children to attend specialized schools due to costs and availability, and because of that it is important to offer programs such as the therapeutic recreational based program the participants of this study attended in order provide a safe, positive environment where children can learn and practice social skills, as well as foster friendships with their peers in a natural, but guided way, and receive extra sources of social support (LaBarbera, 2008; Migerode et al., 2012; Mpofu, 2003; Putnam, 1996).

Having a strong social support network can increase overall health and well-being and is especially important for children and adolescents to allow them to develop socially and emotionally. Children with disabilities, specifically with intellectual and developmental disabilities, often have difficulties fostering emotional bonds with peers and families and often perceive receiving less social support compared to their peers, though they arguably need more support. The current study looked at social support as perceived by preadolescents and adolescents with IDD and observed within a therapeutic recreation based after school program that they participated in. The participants reported relying heavily on parents and peers for social support, and identified teachers as sources of instrumental support.

Though it is important to take into account the child's perspective this does not always provide the full picture. When asked about how teachers help the participants they exclusively said that teachers help with classwork, though through observation, and through conversation with teachers and program staff the researcher found that teachers, specifically aides and special education staff, often provide the participants with emotional support. For example teachers, aides and special education staff often help the participants calm down when frustrated, and remind them about socially appropriate and inappropriate behaviors.

It is important to look at multiple views when working with clients, especially children, because by relying on just the child's, parents', or teachers' perspectives we can miss large amounts of information. The current study was created to address the fact that children with IDD's first hand perspectives are often overlooked in the social support literature and should become a focus for research in the future in order to improve our practices involving these children.

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Appendix

Group activity

	Frequency	Percent
Making Gak	6	10.9
Swimming	19	34.5
Collage	9	16.4
Making own obstacle course	6	10.9
Playing Quelf	12	21.8
Roller Skating	3	5.5
Total	55	100.0

Table 1. Frequency of observations during various group activities which were predefined to fit into therapeutic goals aligning with the purpose of the after school program.

Did target child participate in activity?

	Frequency	Percent
Yes	52	94.5
No	1	1.8
Observing	2	3.6
Total	55	100.0

Table 2. Whether target child was participating in the predefined group activity, not participating, or observing others participating.

Activity in which target child was physically involved in

	Frequency	Percent
Not involved	2	3.6
Group discussion	6	10.9
Predefined activity	22	40.0
Free-standing conversation	14	25.5
Play/other activity	11	20.0
Total	55	100.0

Table 3. Whether target child was participating in predefined group activity or in other types of activities during 1-minute observation period. Free-standing conversation and play/other refer to activities not directly related to predefined activity, group discussion refers to a discussion led by a program staff about the predefined group activity.

Did support occur?

	Frequency	Percent
Yes	42	76.4
No	13	23.6
Total	55	100.0

Table 4. Whether support occurred during 1-minute observation period.

Types of support offered, requested, received, and refused

	Frequency	Percent
No Support Occured	13	23.6
Support Offered	11	20.0
Support Requested	8	14.5
Support Received	1	1.8
Support Refused	1	1.8
Conversation / Other	21	38.2
Total	55	100.0

Table 5. How often support was offered by the target child, requested by the target child, received by the target child without asking, refused by the target child, or in general conversation

or some other type of support that did not fit into a previous category.

Partners interacting with target child

	Frequency	Percent
No Support Occured	13	23.6
Group Multiple Partners	24	43.6
Staff/Volunteer	7	12.7
Peer	10	18.2
Other	1	1.8
Total	55	100.0

Table 6. The partner(s) involved when support occurred.

Types of support that occurred

	Frequency	Percent
No Support Occured	13	23.6
Physical assistance	7	12.7
Emotional support	5	9.1
Making Suggestions	4	7.3
Collaborating in problem solving	2	3.6
Mediating arguments	2	3.6
General conversation	17	30.9
Other	5	9.1
Total	55	100.0

Table 7. Frequency of the types of support that occurred.