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Parents' Perspectives on Community Integration and Social Inclusion of Children with Autism

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Children with Autism

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CERTIFICATE OF APPROVAL

This is to certify that the Action Research Project of

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Abstract

The purpose of this qualitative action research study was to examine parents' perspectives on community integration and social inclusion of their elementary and middle school age children with autism and developmental cognitive disabilities. The information obtained addresses the research question: How can I as a teacher help parents with community integration and social inclusion of their children? The data was collected through four face-to-face interviews. All of the participants' children have developmental disabilities of Autism Spectrum Disorder (ASD) as well as cognitive delays and communication disabilities. Four themes emerged from the data; (a) what is working, (b) what is challenging, (c) hopes and dreams, and (d) how to get there. The findings reflected that the participants' belief that their children need to develop skills targeted to increase their success in social inclusion and integration into the community. The data further indicated that community outings would be less stressful for the parents if there were more community awareness of autism and more tolerance of the behaviors associated with the disability. There is a great need for assistance for the parents while out in the community. These conclusions led to recommendations in the areas of establishing routines, increased autism awareness, and more assistance provided to the families.

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Parents' Perspectives on Community Integration and Social Inclusion of

Children with Autism

Introduction

One of the great things that any community can do is not teach tolerance,

but live tolerance, not talk respect, but live inclusivity.

- Michael Pritchard, 2006

As a young girl I lived in a small rural town in Iowa where everyone knew

each other. My best friend that lived next door had a younger sister, Cindy, who

was significantly challenged with a developmental disability. Cindy seemed like

part of our family. She particularly loved my dad and liked to be around him as

much as she could. She would walk right into our house without knocking. This

just seemed natural to me, like it was something everyone did. When Cindy was

probably five or six years old our family moved away. This was difficult for

Cindy; we heard that after we moved that she walked into our old house expecting

us to be there. As expected this was very surprising to the new owner. This

memory always stuck with me.

Hobson (2001) spoke of "triple telling" as a way of reflecting and using

your autobiography as a learning tool. As I reflect upon this experience with

Cindy I was able to use this approach of past, present, and future and connect it to

my study on community integration and social inclusion of children with autism.

In this example when a new family came into the community, it was unexpected

for a little girl they didn't know to walk into their home unannounced. In the past

it was acceptable for Cindy to come into our home unannounced, but not when a

stranger was presently living there. The action for the future would have been to help Cindy learn the community and the social skills necessary for successful community living.

Now that I'm teaching students with a similar disability to Cindy's, I realize that there are so many skills that our students need that we don't think of as teachers. These are skills that will assist them and their family with successful integration into their communities. Community skills need to be taught to children at much younger ages and not just when they are older or transition aged.

Purpose of the Study

The purpose of this study was to examine parents' perspectives on community integration and social inclusion of their elementary and middle school age children with autism in order to give the parents a voice and gain a better understanding of the difficulties they face. The findings will assist teachers determine how to help parents with the community integration and social inclusion of their children. Through interviews conducted with the parents I have gained insight into the experiences, difficulties, and frustrations they have in the community with their children.

The information obtained addresses the research question: How can I as a teacher help parents with the community integration and social inclusion of their children? The knowledge gained from this research can be used to develop strategies for instruction of functional skills necessary for more successful community integration of younger children.

Importance of the Study

Many parents of children with significant developmental disabilities struggle when taking their child out into the community. Some children lack the skills necessary for social inclusion in their communities, neighborhoods, retail businesses, and/or places of worship. Most schools work on providing skill instruction for inclusion in the general education/school environment beginning in early childhood. Lacking for elementary/middle school age students are social community inclusion skills training.

Conversations I have had with colleagues about this subject revealed that they concur; there is a deficit in instruction in the area community integration. One colleague accompanied a parent of one of her students to doctor visits and retail store outings to provide assistance with behavior management. This colleague stated that parents sometimes feel that others are viewing them as bad parents when their child had a meltdown in the store. Others' view that it is not age appropriate for children of elementary and middle school age to be having temper tantrums and melt downs only increase parents' feelings of stress.

Community integration skills are typically taught as students move into high school and transition programs. This implies that these aren't skills that are necessary when students are younger, but that is certainly not the case. I feel parents need and want their children to have successful outings in the community throughout their lives.

Through my research I discovered that there are very few studies that have been conducted about community integration and social inclusion of younger

children in elementary and middle school. As stated previously, high school and transition students are the typical population given community integration instruction. The limited existing base of current literature reflects schools lack of community based social skill focused education for younger students.

The data I gathered may be used to develop curriculum that teachers can use to build the skills necessary for successful integration and social inclusion of students with significant developmental disabilities. This will then enable teachers to give the parents the tools they need for successful outings in the community.

Definition of Terms

This was a qualitative study in which four participants were interviewed about the community integration and social inclusion of their children. Community integration and social inclusion in this study is defined as meaning, full participation in community. As Cummins and Lau (2003) stated integration and inclusion in the community does not only mean that the person with a disability is physically present in the community; it also means there is social acceptance by the community. This study pursues how the participants feel their children are integrated and socially included in their community, what they hope for, and how they can achieve community integration for their children with autism.

Literature Review

This literature review will examine some of the available literature related to community integration and social inclusion of children with developmental disabilities including their parents' perspectives. The chapter will be divided into sections addressing the following questions:

1. What are developmental disabilities?

2. What is community integration/social inclusion?

3. What interventions have been studied to address community participation?

4. How do parents feel about community integration and/or social inclusion?

Most of the literature found in a search of peer-reviewed journals was related to high school, transition age, or adult individuals with developmental disabilities. Nevertheless, the information presented in this literature review is relevant to students of any age.

What are developmental disabilities?

In defining developmental disabilities, it can be understood as a spectrum of impairments or disabilities that can appear at any point in a person's development up to the age of 22 years old (Reynolds & Fletcher-Janzen, 2007, p. 699). Summers (1981, p. 259) referenced the 1970 Public Law (PL) 91-517 verbatim when giving the definition of developmental disabilities:

> a disability attributable to mental retardation, cerebral palsy,
>
> epilepsy, or other neurological handicapping conditions of an

individual found to be closely related to mental retardation or to

require treatment similar to that required by mentally retarded

individuals, and the disability originates before such an individual

attains age 18 and has continued, or is expected to continue

indefinitely and constitutes a substantial handicap of such

individuals (42 USC 2670 emphasis added), (p. 259).

Following this legislation, in 1975, revisions were made to the

Developmental Disabilities (D. D.) definition to include Autism Spectrum

Disorder (ASD) and some Specific Learning Disabilities (SLD) (PL 94-103). In

theory these definitions and labeling of conditions lost the original intent of the

term, which was to reflect the functional problems they all mutually share

(Reynolds and Fletcher-Janzen, 2007). The 1978 Act gave a functional definition

to the term and the effects rather than labeling the specific conditions.

As Summers (1981) stated in her conclusion, the definition left openings

for further revisions that address the problems with exclusion, thus increasing

individualization and inclusion (p. 263). This was realized with the

Developmental Disabilities Assistance and Bill of Rights Act of 2000, or PL 106-

402. This legislation ensures supports and services for individuals and their

families: e.g. community inclusion, self-advocacy, quality of life issues, etc.

(Reynolds & Fletcher-Janzen, 2007, p. 700). Reynolds and Fletcher-Janzen

summarized the current definition as "…emphasizes considerable functional

limitations and identifies individuals whose disabilities will create needs in

particular activities" (p.700).

Reynolds and Fletcher-Janzen (2007) further reflected on the functional limitations of developmental disabilities that affect key areas of an individual's life as is indicated in PL 106-402: "self care, receptive and expressive language, learning, mobility, self direction, capacity for independent living, and economic self-sufficiency" (p. 699); all of which can affect one's ability to successfully be included in a community setting.

What is community integration/social inclusion?

Many studies have been conducted regarding inclusion of students with disabilities in the general education settings in schools; however, few have been conducted regarding social inclusion and integration in the community. Cummins and Lau (2003) noted that following deinstitutionalization the physical presence of individuals with disabilities has greatly increased, although this does not mean that social inclusion has done the same. Inclusion of persons with developmental disabilities in the community setting results in not only visibility, but also in increased acceptance. Others added that quality of life of individuals with developmental disabilities would be enhanced with inclusion (as cited in Ouellette-Kuntz, Burge, Brown, and Arsenault, 2009).

The history of community integration began with deinstitutionalization of individuals with disabilities. In his book from the early 1970's, "Normalization," W. Wolfensberger (as cited in Bradley, 2000) criticized the services and settings available to individuals with developmental disabilities. Views changed with the Education of All Handicapped Children Act of 1975. The language in this act ruled, "all children are educable," (p. 731) allowing for placement of children in

the Least Restrictive Environment (Grossberg, 2011). As noted by Taylor (2001),

the Least Restrictive Environment (LRE) gave direction for services in education,

residential living, and employment.

In their article on community-based services, Ticha, Hewitt, Nord, and

Larson (2013), spoke of the deinstitutionalization movement in the late 1970's to

the early 1990's as being steered by efforts in advocacy as well as in policy. The

shift from institutions has facilitated funds that are made available through

Medicaid Home and Community Based Services which became available in the

1990's.

The US Supreme Court ruled in 1999, in Olmstead v. L.C., the State of

Georgia, that it was illegal to separate individual with disabilities (Hesla,

Kennedy, & Poll, 2015). In Olmstead v. L.C., the state of Georgia found that two

women with developmental disabilities were misdiagnosed as having mental

illness and placed in a psychiatric unit of a hospital. Following the determination

by treatment professionals that it was appropriate for the women to be placed in

the community, the Georgia Commissioner of Human Resources (Olmstead) was

sued for unnecessary segregation and discrimination. Therefore, the women

needed to be integrated in the most appropriate community setting (Milne, 2012).

Zubritsky, Mullahy, Allen, and Alfano (2006) pronounced the act as being "one

of the most significant civil rights decisions of the 20th century" (p. 132). This

ruling, known as the Olmstead Decision, requires states to uphold the Americans

with Disabilities Act (ADA) and provide services that enable individuals to be

integrated in the community in a way that most appropriately meets their needs

(Hesla, Kennedy, & Poll, 2015). In her article on the Olmstead decision, Hargrove (2003) wrote that all states are developing a plan for providing support for appropriate community integration for all people with disabilities. In Minnesota, the Olmstead Plan more recently established an Olmstead Sub-Cabinet by an Executive Order (13-01) given by Governor Mark Dayton on January 28, 2013. Throughout 2013 and 2014 this sub-cabinet has been drafting and modifying their plan to provide and promote support for integration within the areas of housing, employment, school and other learning environments, as well as within transportation, health services, and all aspects of community living. On March 20, 2015 the proposed plan modifications were given to the court for approval. ("Minnesota's Olmstead Plan", 2015).

In her viewpoint article, Bradley (2000) wrote of community integration as the movement of individuals with disabilities from institution to membership in the community. She defined membership as, participation, choice, the accommodation of supports and relationships. Knoll and Peterson described inclusive communities as shifting from agency only provided services to working in partnership with the community in supporting individuals with disabilities (as cited in Bradley, 2000).

Andrews and Lupart, along with Ferguson defined community integration and inclusion as social interaction intended to increase active roles in the community. In order for inclusion to be successful, supports must be in place or the opposite results will occur, (as cited in Irvine & Lupart, 2006). Irving and Lupart (2006) expanded the Ferguson definition to "signify a unified community

that incorporates all individuals as fully participating members of the community; that ensures high quality service by providing the necessary supports to meet the specific needs of all persons over the lifespan" (p. 108). In Irvine and Lupart's (2006) study on the need for social supports in an inclusive setting such as in the community, they found that these supports are an essential component for success.

Many inferences have been made to the fact that even though individuals with Developmental Disabilities were physically living in communities, there was little evidence of belonging and membership in that community. Hence, social inclusion was lacking. Schools have proven that physical inclusion and structured interaction could be a successful method. To extend this to the community environment, community member perspectives need to be considered and assessed (Amado, Stancliffe, McCarron, & McCallion, 2013).

Fennick and Royle (2003) noted that as we include students with developmental disabilities in educational settings, we must remember that it was as equally important to include them outside of the school environment. They wrote of the importance of community recreation and leisure activities to be inclusive as opposed to separate. In their study, they concluded that both families of non-disabled and families of children with disabilities need to become more comfortable with inclusive recreation programs and more options for participation must be available. Moreover, they found that inclusive activities provided opportunities for children with developmental disabilities to interact with their typical developing peers (Fennick and Royal, 2003).

What interventions have been studied to address community participation?

In researching community participation interventions, the most prominent method found was Community-Based Instruction. Browder, Bamabara, and Belfiore (1997) wrote of the importance teaching functional skills in the actual community environment dating back to the 1970's. Equally as important was considering the social integration in the community and combining it with functional community skills development.

Community-Based Instruction (CBI) was instruction that was delivered in actual community settings. Many studies have been conducted to show its effectiveness for children and youth with developmental disabilities. This method was used to promote generalization of community skill development in areas such as, safety, shopping, money management, work, and independent living (Tekin-Iftar, 2008).

In Takin-Iftar's (2008) research of parent-delivered CBI, she found that many studies concurred that parental involvement was beneficial to the learning outcomes of their children with Developmental Disabilities. Spann, Kohler, and Soenksen (2003) found that generalization and maintenance of skills were greater when the children's parents were involved in their education (as cited by Tekin-Iftar, 2008). In Tekin-Iftar's (2008) study, four parents and their children with Developmental Disabilities participated in parent delivered CBI training. Prior to delivering CBI, the parents were given training by Tekin-Iftar. Parents delivered the CBI training in the actual settings. These settings included a grocery store, a pastry store and a dry cleaner. The results of the study indicated that the children

demonstrated a high percentage (100%) of accuracy in generalizing the skills taught and being able to maintain them. The results also showed that parents could effectively deliver the CBI intervention to their children (Tekin-Iftar, 2008).

Branham, Collins, and Schuster (1999) conducted a study on the effectiveness of three different community skill development interventions (classroom simulation, videotape modeling, and community-based instruction). Interestingly, they found in previous studies that CBI's benefits were abundant and also included using age-appropriate environments for instruction. Results from their study found that combining classroom simulation with CBI produced the most effective and efficient intervention results. They noted that with the current tendency for more full inclusion of students in the general education settings, the use of CBI might be limited (Branham, Collins, & Schuster, 2009). Billingsley and Albertson's (1999) study found that functional skills instruction decreases as full inclusion increases. This was confirmed in their research that Individual Education Plans (IEP's) have seen a greater percentage increase in social skills and a decreased percentage of functional skill objectives (Billingsley & Albertson, 1999). Therefore, due to its proven efficiency the intervention of combining classroom simulation with CBI, was of greater value even with the reduced opportunities available resulting from increased inclusion in general education settings (Branham, Collins, & Schuster, 2009).

Being fully integrated in the community, developing relationships and social networks, and fully participating in activities was important (Hendricks & Wehman, 2009). Social inclusion in the community was a component of Browder,

Bambara, and Belfiore's (1997) study on person-centered approach to CBI. They found that if CBI focused only on instruction in accessing and using the community without social support as well, it would not increase an individual's integration into the community.

Individuals with Autism Spectrum Disorder (ASD) were increasingly likely to have difficulties with the social aspect of integration into the community. Communication and social deficits are prevalent for persons with this developmental disability. Although children with autism had few social connections or relationships, it was important to remember that this does not mean they don't want them. It only means that they do not have the skills that are necessary to develop those relationships (Hendricks & Wehman, 2009). These difficulties were an excellent example of the need for building social supports into the structure of community integration instruction.

How do parents feel about community integration and/or social inclusion?

Community integration was often limited when children with moderate to severe disabilities also exhibit aggressive behaviors. Furthermore, family members, caregivers, and teachers experience increased stress (Carr, Ladd, & Schulte, 2008). In researching the parents of children with developmental disabilities perspectives on community integration and social inclusion, many found studies centered their focus on individuals that were in segregated settings.

In their article on the status of research about community participation and social inclusion, Amando, Stancliffe, McCarron, and McCallion (2013) found that the majority of children and adults with developmental disabilities were living

with their families. Their research also revealed that the families facilitated the most of their social relationships. They concluded that it was more challenging too in these incidences to find support and services for social inclusion and it's impact on the individuals and their families.

In their research, Siklow and Kerns (2006) found that there had not been any studies done on parents needs in the area of social and community supports. Considered supports, included recreational programs as well as respite care and babysitting. Parents deemed that it was important that they have suitable supports in order for their families to adapt successfully. They felt these supports would reduce the stress felt and aid in allowing them to cope with ongoing stresses. In addition, the study brought up the need for early intervention. The research concluded that more interventions were available for children with Down Syndrome (DS) than for children with Autism Spectrum Disorder (ASD). The study examined the parents self-identified most important needs and determined if those needs were being met. In addition the researchers compared experiences between the parents of children with Downs Syndrome and parents of children with Autism. The needs examined included services available, and both social and community activities. The study concluded that the available services were not providing sufficient supports in the area of social needs. The parents of children with Autism were least satisfied, and it was determined that the greater the behavioral difficulties the greater the needs of the parents.

Carr and Carlson's (1993) study examined the interventions that would enable individuals with developmental disabilities impacted by severe behavioral

difficulties, to successfully shop in supermarkets by evaluating the effects of the intervention that took place in the community. Their prior research had found that problem behaviors were not tolerated when intervention was practiced in a public setting (supermarket). Caregivers also experienced embarrassment. The criterion for an individual to be included in the study was they needed to have had a history of severe behavior problems while in the community. These behaviors could have included self-injurious behavior, aggression, tantrums, and property damage. They also had to have been previously excluded from participating in community activities. Some of the interventions included one-to-one support, positive feedback when the steps were followed correctly, or corrective feedback in the form of cues (verbal, verbal plus gestural, verbal plus physical). Each individual problem behavior was functionally hypothesized followed by an intervention that resulted in a desired or replacement behavior. The results of the study found that following intervention, the caregivers and supermarket staff felt that any behavior difficulties could be dealt with and the child with the disability could be fully accepted into the community setting.

Bevan-Brown (2010) conducted a study in New Zealand of what parents of children with Autism said should be included in a video about autism. The study was conducted via an online questionnaire and the findings aided in the development of a draft script of the video. The questionnaire included a section on community, inquiring about everyday scenarios that were difficult, and what may have made the situation easier (i.e. haircuts, dentist, neighbors, etc.). It addressed which strategies and helpful hints they found useful when interacting in the

community. The researchers found that there were many challenges in community settings, as new situations were difficult to adjust to. Parents felt that advance preparation was very important in order to avoid situations that would include long wait times. They also felt that shopping was an especially stressful activity and that it should be attempted during less busy times. Safety was another major concern for parents because elopement is a common characteristic of Autism. The key results were that parents wanted other people to know the characteristics of Autism and realized that was is not an illness that can be cured. They also wanted others to treat their child with respect and inclusion, as well as accommodate and accept their differences. Finally, they wanted others to "never underestimate their ability no matter what anyone else says" (p. 20).

Mayer and Anderson (2014) conducted a study to examine the perceptions of individuals with disabilities and their families regarding inclusive and segregated recreational activities. Through interviews conducted with the individuals with disabilities and their families, four categories emerged, structure, supports, social, and benefits to the participants. The study indicated that the structure of the segregated recreational programs provided more skill building opportunities and equality of access, but lacked social connections to people without disabilities. Having a support network influenced whether the individual with disabilities was involved in a segregated or inclusive program. Finally, the benefits of participating in either program included increased physical activity as well as a growth in self-confidence. Participation in the inclusive program provided the individual with social expectations and exposure to social norms.

Gallagher, Floyd, and Stafford (2000) found that a very limited number of studies focused on community inclusion of children with moderate to severe disabilities. While researching for their study regarding the parent and sibling perceptions on inclusion in the community setting, they found that the major focus of inclusion research pertained to general education settings. They also felt that one way of examining the effects of inclusion of children with disabilities in the community would be to examine the perceptions of the families of these children. They surmised that it was probable that the perceptions of parents and siblings would affect the inclusion of the child. They interviewed twelve families of elementary and middle school age children with moderate disabilities, which included Down Syndrome, Mental Retardation, and Autism for their study. The findings showed that on average the child with a disability participated in one school or community activity, while their typical sibling on average participated in 1.33 activities. It also found that if the child with disabilities was in an inclusive school environment the families also participated in community activities. They hypothesized that the parents who supported inclusion had knowledge and access to community resources and had the means of accessing inclusion. If siblings were involved in community activities, the child with disabilities also wanted to do what their siblings were doing.

Karst, and Vanghan Van Hecke (2012) researched the role parents and families of children with autism spectrum disorder took in interventions that could benefit children with autism, and the effects those interventions had on the family. They found that parents of children with autism had higher stress levels than

parents of children of with other types of developmental disabilities or typical development. Some of the contributing factors to the parental stress included deficits in language, in self-care skills, in adaptive functioning, in social skills, and the likelihood of being dependent on family. Interestingly, they found that the mothers were most impacted and had the highest stress levels when compared to the fathers. The level of parental involvement also affected stress levels too. They concluded that the impact Autism had on the family impacted the effectiveness of the intervention.

Summary

This literature review discussed that the shift away from institutionalizing individuals with disabilities, accompanied the start of community integration. Since this movement started in the 1970's the physical presence of individuals with disabilities has increased but not necessarily the acceptance or social inclusion of individuals with developmental disabilities. Since deinstitutionalization, a high percentage of individuals with developmental disabilities are living with their families. Family perceptions of the reality of community integration and social inclusion were essential in determining needs for successful experiences in the community. These needs illustrated the importance of providing social supports and interventions to improve the acceptance and social inclusion that is a core element of community integration.

Methodology

Qualitative research was a new concept to me, but the idea of an action research project was very appealing because of the usefulness in my teaching practice. Reflecting back on the decision making for the topic of my project, I realized in order to learn the parent's perspective on community integration I would need to conduct interviews as my form of data collection. Initially, it seemed overwhelming as to how to go about analyzing information contained in an interview and pull it all together in a meaningful fashion.

Action research was the foundation of the collection and analysis of the qualitative data gathered for this project. Geoffrey E. Mills defined action research as,

> Any systematic inquiry by teacher researchers, principals, school counselors, or other stakeholders in the teaching/learning environment to gather information…This information is gathered with the goals of gaining insight, developing reflective practice, effecting positive changes in the school environment…and improving student outcomes and the lives of those involved (Mills, 2014, p. 8).

It's a process of identifying a focus area, collecting the data, analyzing the data and from the findings developing a plan of action.

Qualitative Data

The qualitative data in this research project used a descriptive narrative method of data collection through the face-to-face interviews conducted. Meaning was derived from the participants' perspectives by organizing the data into

categories as patterns form. By using qualitative methods the researcher can describe what is happening and develop understanding so to incite change in an educational practice (Mill, 2014). For the purposes of this research project in the investigation of parents' perceptions on community integration and social inclusion of their children with developmental disabilities, qualitative research was used to investigate their needs and the difficulties they encounter. The findings may lead to a better understanding of skill deficits the students have and subsequently inform our instruction as we address those needs.

Interview Process and Participants

Four face-to-face interviews were conducted in a private setting within the school where the participants' children attend. The classrooms are located in a wing of the middle school section of a building that connects both an elementary school and middle school. The Federal Setting three program houses two classrooms of middle school age students and four classrooms of elementary age students. Each classroom has a maximum of six students with a high staff to student ratio, which is one-to-one in five of the six classrooms.

All of the participants' children have Autism Spectrum Disorder as well as cognitive delays and communication disabilities. All names of the participants have been changed to protect their anonymity. The participants included two mothers of middle school age students (one boy and one girl) and two mothers of elementary school age students (one boy and one girl).

Lynn. Lynn is a white married mother of two children and does not work outside the home. Her origin is from Central America. She is a very loving and caring mother, who only wants the best for her children. One of her children is a 10 year-old boy with Autism Spectrum Disorder. Her son is non-verbal with significant cognitive delays as well as behavior challenges. Lynn's son requires a structured visual approach for learning with one-on-one adult support throughout his day. He has difficulties in group activities as well as new or overly stimulating situations, all of which cause him to experience increased levels of stress. When stressed he cries, becomes aggressive (scratching, pinching, and biting), and/or over stimulation (running off, dropping to the floor, and/or throwing objects). Lynn believes that her son learns best using Applied Behavior Analysis (ABA). ABA is an evidence-based intervention used with individuals with Autism. The intervention is a process to modify behaviors using immediate positive reinforcement. At a younger age Lynn had her son involved in intense ABA therapy. She still follows this type of training with him to a small degree. Lynn is very appreciative for the love and support of all the staff at school. The family has some assistance at home from a personal care assistant.

Mary. Mary is a white married mother of two children and does not work outside the home. Both of her children are on the Autism Spectrum Disorder to some degree. Her 12-year-old daughter is more severely impacted with autism and is in the federal setting III program. Her son spends the majority of his day in the general education classroom but does have some pull out services for social skills and in a special education research room. Mary's daughter is in a highly

structured setting with one-to-one support throughout her day. She has attended the public school program for the last three and a half years. Prior to beginning public school in third grade, Mary's daughter received intense therapy at an ABA facility. Mary's daughter communicates using gestures, words, and short phrases that are often repetitive and echolalic in nature. She is extremely routine bound and has difficulty with change that may cause her to scream, throw things and hit. Mary's family has assistance at home from a personal care assistant.

Nancy. Nancy is a married Asian mother with three children and does not work outside the home. All of her children met criteria for Autism Spectrum Disorder at approximately the age of two. Her two younger children (five year old girl and two year old boy) are not in elementary school yet, but are receiving Early Childhood Special Education services. Nancy's oldest daughter is an eight year old second grader that is attending the elementary federal setting III program and receives one-to-one support throughout her day. Prior to kindergarten, this daughter received ABA services at a private therapy facility six hours per day, five days per week. Nancy's daughter has erratic sleep patterns, which affect her behavior. When upset or fatigued she will cry for an extended period of time. She uses simple gestures (reach, take hands), vocalization, facial expressions, eye contact and adult assisted use of visual symbols on a voice output device to communicate basic wants and needs, and to respond to others. Nancy has assistance at home from her mother who lives with the family.

Lori. Lori is a single white mother with one child and works as a paraprofessional in the same school district where her child attends. Her son is a 12 year-old sixth grader that has Autism Spectrum Disorder and is attending the middle school federal setting III program with high staff-to-student ratios. Lori's son is verbal but does have apraxia and has problems saying sounds, syllables, and words. Other autism characteristics include, wandering, need for routine and repetition, communication difficulties and cognitive delays. Lori is a very driven woman who likes to organize events for her son and other children with special needs. She currently organizes reoccurring bowling outings. Lori has some assistance at home from Personal Care Assistants.

All the participants were verbally asked their willingness to participate in the research project. Upon verbal consent, a formal written consent form was given to each participant. Interviews began following the receipt of their signed consent form.

The participants were asked a series of questions using an informal ethnographic interview format (Mills, 2014). This included a set of predetermined structured questions but allowed for a more casual conversation that led to additional inquiries that fluctuated with each interview. The structured questions were open ended to elicit the conversational style that was desired.

One participant requested flexibility in recording to pause if she became emotional and began to cry. This request was honored, and was used once when the participant felt she was off topic. The pause was brief and at the end of the interview.

Data Collection and Analysis

The method of data collection for this research project involved in-depth qualitative interviews. Taylor and Bogdan (1984) defined qualitative interviewing as a face-to-face encounter that is modeled as a conversation between the researcher and the informant. It is a method of understanding the informant's perspective of situations or experiences in their life. The interviews were 25 to 35 minutes in length and were audio recorded with the participant's written consent. By recording the information gathered in the interview it could then be accurately transcribed. The recording also provided data in the form of the participant's tone of voice when responding. Field notes were written following each interview to document the researcher's observations from the interview.

The method for interpreting the data collected from the interviews was based on grounded theory. Theory helps make sense of the data and pulls it together cohesively. Grounded theory "consists of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories from the data themselves" (Charmaz, 2014, pg. 1). Therefore, the theory is developed or constructed from the data, or in other words, grounded in the data. Grounded theory emerges from the data. It is ever changing and developing, it is an interconnecting process of data collection, coding, and analyzing (Glaser & Strauss, 1967).

To begin analyzing data, segments of the interview (data) were coded or assigned labels. Mills (2014) defined coding as "the process of trying to find patterns and meaning in data collected" (pg. 135). The coding refined the

qualitative data into manageable and organized terms. Themes began to emerge in the data collected, revealing relevant patterns. As they were categorized, these themes extended the understanding of the research (Mills, 2014).

Findings

The purpose of this study was to examine parents' perspectives on community integration and social inclusion of their elementary and middle school age children with autism in order to gain a better understanding of the difficulties the parents face. I also wanted to know, how could teachers help parents with the community integration and social inclusion of their children? The research findings are discussed in this chapter. Four main themes surrounding community integration and social inclusion emerged from the data: what is working; what is challenging; hopes and dreams; and how to get there.

What is Working

There was range of places in the community the four parent participants could successfully take their children. Although all the participants' children fall into the more severe and profound range of autism, there exists much variation regarding how autism impacts their four children. These varying degrees of behavior impact their ability to be successful while out in the community. When examining where the parents go with their children and how they make the experience successful, sub-categories emerged: routines and preplanning, preferred activities, and coping and distraction strategies.

Routines and Preplanning

When participants spoke of what makes their child's community outings more successful, most talked about repetition and routine. Examples included: always doing activities the same way, making events predictable in order to

reduce the stress for their children, or practicing over and over until the activity becomes familiar or learned. Lori described it as,

> I think by going out and constantly doing it. There's no right answer every child is different. It's trial and error, and with him [her son] it's repetitive, repetitive, repetitive. It's doing the same thing maybe thousands of times. Um, and he does get it! But it's just doing the same things thousands of times. And I switch things up, because I know with autism, they love the things to be the same, exact, but if something happens where something is tweaked or cancelled or something like that, it can lead to a meltdown. So I always try to change things up just slightly a bit. You know, it's ok, you know, but I don't want him to get into his meltdowns. Although those occasionally do [happen], but I want him to learn that hey, this is life. You know sometimes things change. And I think that right there is one of my little challenges right there. You know, but eventually he will get it, he'll understand that you know sometimes there are roadblocks in life. Ok we just take a detour around, and then we do something else or we wait.

Nancy and Lori have successfully included their children in most of their outings in the community. As Nancy shared, "The three kids can run errands with me now." She later continued, "We can do all the errands. We go to various parks." The main social outing the family does together is attending parties at friends' homes. As she explained, "We pretty much go places that we're comfortable with. I think [for instance] house parities." These are outings that Nancy feels her children, herself, and husband can do to maintain social

connections, "Our kids are socializing in a way." Nancy's interview was the week before spring break and she was thinking ahead about things to do with her children, "I'm already for spring break, I'm thinking of taking the kids to the Mall of America, to the Minnesota Zoo again, and maybe explore a different water park." Of the four parents I interviewed, Nancy was the only one who takes her children to the mall with her. The others felt the mall environment was overwhelming for their children. Nancy's philosophy on where she goes with her children is, "if I can't [go out with her children] we'd be stuck at home all the time."

Lori spoke of similar outings with her son in the community. She shared of going to grocery stores and other errands with her son. In the summer she gets a season pass to Valley Fair amusement park, "it's amazing, it's a magical place." She spoke of all the rides her son loves to go on. She does not go on the rides so they have learned to go with a group. As her son has gotten older he is able to do some of the familiar rides by himself. It was a place that both mother and son looked forward to going to every year. Lori shared that not all amusement parks held the same magic. They have tried the indoor amusement park at the Mall of America, but did not have the same success as being outdoors. Since Lori is a single mother, "he's always been doing this with me," she said.

Mary researches various places that have sensory friendly events. For instance, "For two years in a row on Super Bowl Sunday we've gone to the Mall of America and gone on rides, because the sports nuts have gone home." This helps provide a much more sensory friendly environment with less noise and

crowds. Other places they visit include an indoor giant inflatables entertainment center, which has sensory friendly nights for children with autism.

Preferred Activities

When it comes to the activities the participants do with their children there is much they have in common no matter how significantly their children are impacted by their disability. Swimming was mentioned by all of the participants. As Nancy shared, "I feel really confident that I can take them [her children] to the swimming pool at the gym on my own." She was very proud of this accomplishment considering that all three of her children are impacted by autism. Mary has a membership at the YMCA that provides her daughter with a pool to go to all year-round. This has been especially important to her this year as her daughter has moved on to middle school and the school setting no longer has a swimming program. Although Lynn has a pool at her home, she shared "In the summer we go to Bush Lake." Swimming is such a preferred activity that she takes her son to the beaches in the area, as well as the community pool.

Other outdoor activities such as walks are successful outings for all of the parents. As Mary shared "Like my husband and her [her daughter], they've done it twice, it's called a Cupcake Walk. The go from our house to [the grocery store] to get a cupcake." She also added, the majority of activities they do are outdoors because as she puts it, "But if you notice I do a lot of stuff, it's outdoor stuff, because if she screams, you're just scaring the bears." Lori also says that her son loves walks, "We go walking at the creek. He loves picking up sticks and carries bundles of sticks with him." This is an activity that Lynn can do with her son as

well, "I take him for walks too around the neighborhood because he likes to go for walk[s], especially on the railroad train [tracks]. He picks sticks."

Finally, movement activities are important for Lynn and Lori's children. Lynn shared "Movement, that's what I do a lot of activities with him, you know snow tubing." She continued that they go to an indoor roller skating rink, "We do roller blading every, almost every Saturday, because he likes that. You know it's music and lights and he can do his own skating next to me. So he can pretty much do his own thing." He also likes sliding in his boots at the neighborhood outdoor ice-skating rink. Special Olympics swimming was an activity that Lynn would like to involve her son in because of his love of swimming. She would also like to get him involved with their soccer program as another movement activity.

Lori has her son very active in adaptive sports, "We do adaptive swimming, and we do adaptive theater dance." She also has organized bowling for students with special needs in the area, "Yep, we called it the Sunshine Bowling League." Along with the adaptive sports, Lori's son has participated in autism walks and Special Olympics basketball.

All four of the participants enjoy taking their children to parks. They all agree that smaller, less crowded parks are better options. These parks allow more freedom for their children and a more relaxed time for parents. Another commonplace to go is to a zoo. It's a place that they can go year round, Mary shared, "The tropical gardens, we'd go there because [in the] winter it is nice."

Coping and Distracting Strategies

Lynn and Mary's children are more significantly impacted by autism than Nancy and Lori's children. The places they were able to take their children successfully was limited. When Mary spoke about going to stores such as Target or grocery stores, she spoke of these being difficult places to navigate but occasionally will attempt it, "If I'm going for quite a few items I really don't like to take [her] because there's a line." Lynn shared her view on those types of places and said she takes her son to "just go grab three or four things." Mary and Lynn both agree that the only way to have the outing be somewhat successful it has to be for a very short period of time. Lynn occasionally takes her son to church, but they are only able to stay for a short time and only when there is music playing; "We do to go to church too every Sunday. And at church it's hard because he likes the music and he will be in the music with me and sitting by me." She has taken him to wedding receptions, but again for a short amount of time.

The parents carry items with them that will keep their children occupied when they go to various community settings. These items serve as distractors or coping strategies. Several commonalities between the participants were found. All of the participants mentioned some form of portable technology or electronic device as an intervention to make their community outings more successful. When Mary was talking about taking her daughter to places like the grocery store or Target her response was, "Standing in line is not good for her. Sometimes the iPad, excuse me the iTouch or iPhone will help." Mary went on to explain that she takes a backpack with them containing things to occupy her daughter and how

electronics have helped; "But with the electronics it's been helpful. Um, and now with even better technology because sometimes it would work without the WiFi, or wouldn't work without the WiFi sometimes, the technology is better."

When the participants' spoke about what makes community outings easier both Nancy and Lori spoke of iPads and technology as a distractor. Lori described when she uses it:

> I know what would make everything more manageable, but I hold it back because he [her son] loves technology! So when we're out and I really need to focus on something like paying for groceries, I really need to focus on that. I'll hand my cell phone to him. And he will not budge. He will stand there and be really focused on that. So that's one technique that I use.

Lynn's son is significantly impacted by his autism; she said that technology does help. She spoke about taking her son to church with her; "When the pastor starts preaching then he [her son] wants to go out. So I have to go out with him and he won't sit still. A little bit maybe, outside with his tablet in the cafeteria."

Another common strategy that the parents use for making outings manageable is food. Nancy shared about things she has with her when she's out in the community with her children, "Snacks work really well, and they know I will have snacks, candy and things like that." Lynn had a similar response, "You know he [her son] likes to eat. So whenever we go, we will buy food for him because he likes to eat. He likes to drink. You know food comforts him a lot."

Fidgets are small hand held sensory toys or objects that are helpful with self-regulation, focus/concentration, stress reduction, and can be used for either calming or alerting. Lori described what she carries along in a backpack:

We have like squishy balls. He [her son] has it in his backpack too. But he does chewies. So we have chewies, but there are all types of different things. Sometimes coloring books and crayons. Although with crayons, um, he tends to chew them sometimes, so I have to be careful, whatever I put in my little bag of tricks that he can also chew. Or else I stick a chewy in his mouth and say, this is for your hands. Or maybe something he can make sounds with, maybe bubble pops and stuff like that.

What is Challenging

All the parents were forthcoming when talking about the challenges they face while out in the community. Reviewing the data from the interviews, five common categories emerged from the theme: behaviors, sensory issues, crowds, wandering/eloping, and child's age. Each of these categories was mentioned by at least two of the participants.

Behaviors

The first category of challenges experienced by the participants was behaviors. Lynn's son exhibits aggressive behaviors that she believes are due to his not being able to communicate his needs; he is non-verbal. She also believes that it's his way of expressing himself. It is difficult when they are at parks, church, as well as community and family events because of his aggressive behaviors of scratching and grabbing others. She shared that her son can also be

loud which causes difficulty at events where that kind of behavior is not appropriate. As Lynn put it,

> I don't want him to just come and grab the person. You know, that's not the right way to do it. That's one of my fears that when people get around him [her son]. You know he's not aware, he just wants to say hi or approach them, but he pushes them, or grabs them. The kids cry, you know. Some moms just freak so, you know. You know, going down the slides with other kids, I don't want him pushing them or scratching them or pinching them.

Mary's daughter's behaviors can range from screaming to occasional aggression that include hitting and biting. She described it as, "It's just hard because sometimes she's screaming and stuff like that." Mary later added, "Well, if somebody is screaming, you know, people are going to look."

Dealing with meltdowns while out in the community can be difficult at times. Lori shared about needing to leave places when her son has had a meltdown:

> He [her son], in the past has had a meltdown and I've said ok we're done. And we've just left the store because I also agree, hearing a kid scream, scream, and scream is not fair to everyone else. So I always try to walk that fine line, is this going to end in two minutes, because if it is we're just going to keep going. If it's not then we're going to leave because that's not fair to everybody else to have to listen to what we're dealing with.

Sensory Issues

The second challenge category to emerge from the interviews was sensory issues that affect the children. Being over-stimulated sensory wise can trigger behaviors. Stimming is a self-stimulating behavior that may be seen in individuals with autism. The individual may make a repetitive sound, physical movement, or movement of an object. Lori shared, "One of my struggles there is his [her son's] stimming. So we're working with that. Certain grocery stores he stims less at and I don't quite understand."

Mary discussed how too much noise and crowds can overload her daughter's sensory system and lead to meltdowns. It's also a reason the family does not attempt to take their daughter certain places, "Reasons we wouldn't take her, it could be crowded. It could be noisy." Nancy expressed the same thoughts about causes of overstimulation, "Because when it's just too crowded, it's just too over stimulating and too many people."

Crowds and Waiting

The third challenge category related to crowds and waiting. Lynn chooses times when it is less crowded to go places. "I like to do it when there is less people there because he [her son] sometimes gets kind of loud or try [tries] to grab somebody." Lynn commented on what occurs when she takes her son to the ice skating rink; "I think about, right now it won't be many people or at night. Or like in the ice rink where it's hardly any people." Lynn's example illustrates the need for preplanning.

Mary experienced similar difficulties with crowds and waiting. She shared, "Am I going to go to Target by myself on the weekends or am I going to go during the week? Am I going to go during the weekend, because everyone else goes to Target at that time?" Waiting in lines can be difficult, she stated, "I don't go to the grocery store, it has to be something important for me to go to the grocery store with her [her daughter]."

Wandering off

Children with autism may wander or run off. As Nancy described, "she [her younger daughter] was a runner and she would dart off." She gave an example that happened at a grocery store:

> Like I just brought her to Aldi yesterday and I said, [oldest daughter] hold on to your sister [younger daughter], I gave her a bag of candy and she held onto her sister. Before you know it the bag of candy was more interesting than holding on to her sister. Sure enough [younger sister] would run off into an aisle and I'm yelling stop. So I'm thinking it's definitely that age between three and five, where their finding their independence, I can run, I can move, I can go on my own.

Lynn shared a story about being in line at a store when her son ran off:

> Last year in Sam's Club I was paying and he [her son] just took off, you know. This lady was sitting across the street [across the store] at the table; she noticed he was special needs. So she just run and grabbed him and bring [brought] him to me. She asked me if I needed any help. And I just told her, sure, if you can just keep him holding while I pay then I take him.

Lori talked about why she felt her son wanders off, "He's just so curious. I love that about him. He's just curious about anything, to the fact that he wanders away." She went on to share a frightening experience:

> There was one time I was in the bathroom, he [her son] was in the bathroom and he just left. You know this happen in Walmart and I couldn't find him and I went nuts. But I went to management and they did a store lockdown. It was, oh my God, it gives me chills just talking about it. And they did find him. They surrounded him, but nobody touched him. Oh, it's just so scary. And he had just wandered, wandered around the store! You know, it must have been…I thought toys, videos, but he must have gone around a circle and I must have gone before or after him. Going round and round. It's like oh [Lori stopped and teared up], that was a scary moment.

Child's Age

Parents had differing opinions on what age their child was or is most difficult. Mary and Lynn felt that it is becoming harder for them to go out in the community, as their child gets older. As Mary described, "It seems like when she was a little bit younger we were able to do more." She stated now her daughter prefers, "Playing on the big computer or her small i Touch, that it's harder to get her out." She went on to say,

> It's just kinda hard. Just some of her behaviors, because what was ok when you're three verse when you're twelve. You know, it's hard. Plus

some of the things that she's interested in like the wading pools before,

she's still kinda interested in them, but he's [her son] like no.

Lynn elaborated that her concerns were greater as her son becomes older and

bigger, "But like with his behaviors, you know like the grabbing, and pinching,

that kinda goes up and down. That kinda really concerns me, cause I don't want

really him to deal with little kids, you know."

Nancy and Lori had opposing opinions regarding the age when it becomes

more difficult. Nancy felt that it has taken a lot of work but the practice and

routines they have established have helped the children handle situations better.

She stated, "Both girls can stand in a line pretty well, and he'll [her two year old

son] eventually [be able to]." Lori's was in agreement, "Now when I take him out

in the community, he's good, he's really good. As far as like the meltdowns go,

you know, it's few and far between. I mean, occasionally yes, but few and far

between."

Hopes and Dreams

As all parents do, the participants interviewed had hopes and dreams for

their children. Although for parents of children with autism, their hopes and

dreams looked somewhat different and can include things that parents of typically

developing children take for granted. The hopes and dreams that emerged from

the data included family activities, as well as community acceptance and

tolerance.

Family Activities

Family activities were a common theme of things the participants would like to be able to do. Mary gave an example of a family event that her son was involved with that she has had to miss:

There's a Cub Scout event, Pinewood Derby, and my husband just takes him [her son] and he films it because that's going to be too much for her [her daughter]. If I knew for sure his car is going to be at ten o'clock maybe I could take her for ten minutes.

Another example she gave had to do with a family Boy Scout event:

One time we went to a campfire thing and she was with, and because the nature center wasn't open and she's used to the Richardson Nature Center being open, she had a fit, and we didn't take two cars that time. So somebody else drove [her son] and I home. Um, because we thought, oh no, but it wasn't open, so she [her daughter] wasn't happy just walking around. I think we had snacks and all this other stuff, but nothing was working.

Lynn shared about the family events that are hard to attend with her son:

We don't do that much, like birthdays or weddings because he won't sit still, you know, through the ceremony. We'll stay for the reception. Once he finishes eating, you know, he's done, he's gotta go, so I gotta go.

Nancy spoke of her husband always wanting to go to restaurants, but "We often do like takeout. We'll do anything that is a little bit faster." She also said, "the kids can't sit still."

Finally, Mary spoke about how their family would like to do more traveling. They took a short family vacation two years ago that went very well; Mary described it as, "turned out better than we thought." They have since tried two other similar trips that have not been as successful. She sounded disappointed when saying, "my whole idea of walking down Canal Avenue, going to the coffee store, different family, not our family."

Community Acceptance and Tolerance

Mary also talked about a trip they took, travelling by air. This required more preplanning by arranging the seating on the airplane so as to not bother other passengers. Mary purposely sat in the seat in front of her daughter in anticipation that she would be kicking the seat in front of her. She continued, "The person behind [daughter] said something to my husband about, can you have her not move so much in her chair or something like that." Even the best laid plans, sometimes do not work out, she said "There's times where [I should be] wearing my autism awareness t-shirt and sunglasses because it's like, get a grip, I'm dealing with this for the rest of my life, you only need to deal with it for four hours."

The participants felt that lack of understanding was an obstacle in community integration. Lynn shared an experience at a restaurant that involved lack of understanding by others:

> One time we were in the Wisconsin Dells, I remember we were sitting eating breakfast. He [her son] started playing with the knife, you know. Not that loud but we're used to that, he plays with the knife. This middle

age couple comes [and] sits by us. He immediately says to me loud, can you tell him to stop. I told him [her son], you know, don't do that, but he kept doing that, you know. What they did is, well, he stopped for a little bit, then he came back doing that. They just moved from us. They told the waitress, you know, we don't want to be right next to these people they are noisy. They just moved. We just felt so bad.

Nancy described the lack of understanding as, "I just maybe feel like people want to talk to my kids and I just don't want to have to go into too much detail explaining, but you know they are just a little bit different from everybody else."

The difficult obstacles parents of children with autism and other developmental disabilities face can leave them with the feeling of isolation due to the lack of acceptance in the community. As Lynn shared, "I don't want to get in trouble with people. So I have to leave early. He's done, he gotta go, so I gotta go." Later in the interview Lynn went on to say, "Wherever you are, there is people like that. They won't say anything to you. Maybe sometimes they will, but most of the time they won't. But you can see in their face. Makes you uncomfortable, yeah."

How to Get There

Participants spoke of what they feel would help make it easier and more manageable to go out in the community with their child and what they think the school could do to help. Lori shared an idea she thought the school could work on:

I think getting the kids out in the community more, would help especially.

I think in general, getting out in the community more. Go grocery

shopping; make them pay for their groceries. Having them bag their

groceries. But I think integrating them into what society does.

Nancy suggested teaching some useful skills, "Walking along independently and

follow along with the group. I think that would be really great." Finally, Mary

added, "It would be nice to know little things that she [her daughter] likes to do.

Because when we're in line, she's doing so much screaming, I'm like geez!" I

don't know if I had my shirt [autism awareness] and sunglasses on, I'm like oh

well." She later continued, "If you practiced some of the things. Like if you told

me what things worked, what tricks that worked here [at school] that might work

at home."

During the discussion of things that would help make it easier and more

manageable for the parents, both Mary and Lynn brought up the topic of Personal

Care Assistants (PCA). Lynn discussed how she has a hard time finding a PCA

and how she was worried that the PCA she has may be leaving. Mary echoed

Lynn's difficulties:

You can't do this, but it would be lovely to know out of all these paras,

some of them may want some extra hours. But if there was somebody in

middle [school] that wanted to work some extra hours, because I know the

paras aren't paid well, it's a shame. And PCA's are not paid well either.

But if they wanted extra hours, I know it's a weird thing, I don't think the

school would back that or anything but it would be nice if I could post it or

something. Or something that would give us support to find somebody that

would be willing, because they already have experience, even if it's not

with her [her daughter], they have experience. You know what I mean.

Because it's hard, I tried para.com and it's expensive and I've gotten

flakes, people who don't show up for interviews. They haven't even seen

my house; they haven't even met my daughter yet. How you talk to them

on the phone and they don't even show up!

The participants' biggest concern was about the amount of autism awareness

people in the community had, as well as wishing there was greater understanding

of autism and its characteristics. Lori expressed her views:

That's a big problem too, society in general doesn't understand. You know

I can see being naughty, but there are a lot of kids out there that are on the

autism spectrum, they are not naughty. It's the lights that are affecting

them, whatever happened prior to being there, you know, they haven't let

go. Um, it could be their clothing that's giving them a problem. It's just

like a whirlwind of problems.

Lynn's view was more personal:

I would just like to have more awareness in the public, general public.

Like about kids with special needs have, the way that they act and why

and just accept them, you know, the way they are and the parents in the

community. It's hard when the people [are] looking at you and they don't

want anything to do with you because of your child. You know that is

rude, when somebody moves right next to you from the table and they

move somewhere else. You know, it makes you feel bad. So I don't know, probably, yeah being more awareness of, you know, accepting, just to love, you know, and be accepting of just people. Because it's not just kids, it's adults, it's old people. I mean it's all range. You know when I see people with CP and wheelchairs or whatever, I just go out of my way to say hi to make them feel comfortable. Nobody pays attention to them over in their corner. It's hard, I mean they have feeling too. Yeah, you know, just awareness of disabilities, they're everywhere you go. You find people that need something.

Findings in this chapter presented the important viewpoints of four parents on community integration and social inclusion regarding their children with autism. These shared experiences provided examples of accomplishments and difficulties. The findings gave us a better understanding of parents' perceptions and experiences, as well as a vision of how to move forward.

Discussion

This action research study examined parents' perspectives on community integration and social inclusion of their children that are significantly impacted by autism. Many of these parents struggle when taking their children out into the community. Some children lack the necessary skills for social inclusion in their community. Most elementary and middle schools provide skill instruction for inclusion into the general education classrooms. What are lacking for this age group of students are social community inclusion skills instruction. The purpose of this study was to examine parents' perspectives on community integration and social inclusion of their elementary and middle school age children with autism in order to give the parents a voice and gain a better understanding of the difficulties they face. Furthermore, the findings can assist teachers to help parents with the community integration and social inclusion of their children.

The four participants in the study were all mothers of children that were significantly impacted with autism and developmental cognitive disabilities. All the children were impacted to varying degrees that affects how they currently were able to successfully participate in community outings. Each participant was interviewed about their current experiences of taking their child out into the community, what had been successful for them, what obstacles they had encountered, things they feel would have made the experience more manageable and what they felt the school could do to help.

Summary of Findings

In analyzing the community integration and social inclusion data, four themes emerged: (a) what is working, (b) what is challenging, (c) hopes and dreams, and (d) how to get there. All the participants' experiences in the community included both accomplishments and difficulties. Half of the parents felt that they could be successful in taking their children to a variety of places in the community; however, doing this involved a great amount of practice and hard work. Two of the parents had significantly less success participating in community activities with their children. They felt that they were very limited in the activities they could do and the amount of time that could be spent at out in the community with their child. The participants felt that preplanning helped increase the likelihood of attaining a successful experience. The parents all felt that having community integration and social skills training in school would be beneficial for their children. Finally, they were all in agreement that better community awareness of autism and its characteristics would make their experiences easier and more manageable.

Conclusions and Recommendations

Conclusions included, parents felt there was a need for their children to develop skills to increase their success with social inclusion and integration into the community. The children's disabilities impacted their ability to generalize skills learned in different environments. The findings indicated getting children out in the community, practicing skills and establishing routines will increase parents' success when participating in community outings with their child. The

more children are out in the community and practicing these skills the more confident and comfortable they will become in these situations. The findings also indicated that community outings would be less stressful for the parents if there were more community awareness of autism and more tolerance of the behaviors associated with the disability. Finally, there was a great need for assistance for the parents so that they can receive respite, additional aid while out in the community, and available time for activities with other members of their family. These conclusions led to recommendations in the areas of establishing routines, increased autism awareness, and assistance provided for the families.

1. Establishing Routines

The participants indicated that when they had successful experiences in the community it was usually during activities that had become routine for their children. One way of helping the parents would be for community activities to be part of the school curriculum and having the actual learning experiences out in the community. Individuals with autism need direct instruction across all settings to acquire the skills. Therefore, community based learning is essential to generalizing the necessary skills in the actual setting and for developing the routine. Providing the children with these experiences not only as school activities but with their families could increase the likelihood of a successful experience.

2. Autism Awareness

The findings indicated that even for the participants that were able to successfully take their children with autism to most places, they still faced intolerance by some people in the community. They felt this is an obstacle that

they continually face. It created feelings of isolation and anxiety when in the community with their children. While control of how others in the community treat individuals with autism and their families is an impossible feat, bringing awareness to a smaller group of people is a good beginning. Providing autism awareness/education to students and teachers in the schools is that starting place. Gearing age appropriate lessons for general education students, especially those classes where students with autism are included will increase the awareness and acceptance in the community.

3. Family Assistance

The findings in the study showed that parents are having a difficult time finding the support and assistance they need. One recommendation would be establishing parent-networking groups within the district that would provide the parents with resources they may not have otherwise known about. These groups would also provide them with emotional support as well as camaraderie. The participants indicated that a shortage of personal care assistants was another need. The network of people interested in fulfilling this position could be expanded if all school district staff were made aware of this need.

Limitations of the Study

The findings in this study were enlightening regarding parents perspectives: what they felt was successful, what they felt challenging, and what they hoped for in order to move forward. Nevertheless, the study was not without limitations. First, the participants were all mothers of children with autism. One of the participants shared that if I had been interviewing her husband, his thoughts

may have been different. Also, if the parents had been interviewed together, there may have been different or additional thoughts shared.

Another limitation is the cohesiveness and validity of the parents' responses may be a limitation of the study. Everyone had differing levels of tolerances regarding how they handled difficult situations. What one parent considers successful; another parent may not. The parents may not want to fully expose their vulnerability; therefore, they may not give full account of their experiences.

Possible Future Research

When thinking about future research that would be related to this project, a natural extension would be the research and implementation of direct instruction in the community setting. One idea would be to research interventions currently being used for older students that could also be adapted for elementary and middle school age students. This would be a way of using action research to develop the curriculum for community integration and social inclusion skills. The development of this type of curriculum for this population of students is an area of need in my school district.

Self-Reflection

When I reflect on the beginning of my journey with this project, I recall feeling overwhelmed with how I could possibly write a paper of this length. Each step of this process caused these feelings to arise again. So as I begin this last chapter focusing on self-reflection, the chapter that I remember feeling this would be the easiest, once again that feeling of anxiety comes over me. I've reminded myself over and over again during this project, I need to take it one step at a time and keep moving forward.

The idea for the focus of this project arose as a result of a conversation with my colleagues about a year ago. We were discussing ideas for our Professional Learning Community (PLC) focus for the year, and one of my colleagues' shared a story about going to a doctor appointment with one of her students and his mother. She said that the mother struggled taking her child places. My colleague agreed to go with her and provide assistance and guidance. The story she shared led to an idea for our group to use as a future focus on community instruction. We discussed how it might be easier or less stressful for us as teachers to wait out meltdowns in a store during community outings because we wouldn't feel the same embarrassment parents of children with autism sometimes feel. Although we have not implemented the plan yet it was something that stuck in my mind.

Thoughts about the difficulty parents encounter while taking their children out into the community resurfaced immediately during the first night of our Action Research class. My area of focus began to emerge and I had the general

topic idea of my project. I started doubting my decision and the feeling of being overwhelmed started again the next week. I wrote in my first blog post about wanting to change my focus, because in the back of my mind I kept thinking that my original idea was just too broad and big of area and I was unsure of how to narrow it down. Mills (2014) stated that what we start out with might not be what we really want to focus on; it may lead to what the real focus of what our research should be. Upon reflecting on Mills statement I changed my broad focus to inclusion of federal setting three students in an elementary school and more acceptance in the school. After making the change I was given some good advice that I should reflect on what I'm most passionate about before changing my focus. I am glad I was given that advice and continued with my first general idea of parents' perspectives on community inclusion and integration.

As I listened to the parents' stories of experiences they have had in the community, there were things that I found encouraging and things that were heartbreaking. I loved how one parent started a bowling league for other children with special needs. While it provides a community outing for the families it also helps the parents build a network to share resources, experiences, and camaraderie. Hearing how the parents have experienced intolerance from other people in the community is so discouraging. As one parent shared, she feels she needs to wear an autism awareness shirt when she is out with her child in an attempt to gain better understanding and acceptance.

This past week we took our students on a field trip to the zoo. Lynn, one of the parent's I interviewed came along with us. The experience for both the

parent and myself was mutually enlightening. As I've stated in the findings, Lynn's son is significantly impacted by his autism. When he is in unfamiliar situations it is stressful for Lynn's son and he displays his anxiety with aggression. The zoo was a very busy place the day of our field trip. There was a line of busses waiting to drop off students from several schools. As we got off our bus, there was a steady stream of people. Lynn's son reacted by trying to flee the area. As Lynn and I attempted to keep him with us he bit her. From the corner of my eye I could see others stopping for a moment to watch. What should have been a fun day with her son's class was not starting out well. Because of the crowds, Lynn's son was frantically searching for a way to escape. He relaxed later when we found a spot in the zoo that was less crowded. It was good for me to experience what she goes through but it was also a good experience for her as well. As I demonstrated them in this situation she was able to see some of the strategies we use at school for coping and self care skills that she could use at home.

I feel that inclusion is always a top priority for me when I reflect on the Olmstead decision as a special education teacher. I want to prepare my students to be as successful as possible during inclusion in their general education classrooms and while out in the community. My philosophy extends to the community as well. My students and their families have the right to be fully engaged in the community. They need the services and supports necessary for successful participation.

I plan to pass along my findings and conclusions to my colleagues. Concluding this project is bittersweet for me; next school year I will be moving on from this population of students. I will be teaching students with special needs that are receiving less restrictive services. I have learned so much from the participants' and appreciate their willingness to share their experiences. I am honored to have given this special group of parents a voice.

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