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The Frequency and Severity of Problem Behaviors Among Individuals with Autism, Traumatic Brain Injury, and Mental Retardation from the Utah DSPD Dataset

Melanie Kay Arp
Brigham Young University - Provo

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THE FREQUENCY AND SEVERITY OF PROBLEM BEHAVIORS AMONG INDIVIDUALS WITH AUTISM, TRAUMATIC BRAIN INJURY, AND MENTAL RETARDATION FROM THE UTAH DEPARTMENT OF SERVICES FOR PEOPLE WITH DISABILITIES DATASET

by

Melanie K. Arp

A thesis submitted to the faculty of
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in partial fulfillment of the requirements for the degree of

Master of Science

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BRIGHAM YOUNG UNIVERSITY

GRADUATE COMMITTEE APPROVAL

of a thesis submitted by

Melanie K. Arp

This thesis has been read by each member of the following graduate committee and by majority vote has been found to be satisfactory.

Date	Lynn K. Wilder, Chair
Date	Betty Ashbaker
Date	Richard Sudweeks
Date	Susanne Olsen

BRIGHAM YOUNG UNIVERSITY

As chair of the candidate's graduate committee, I have read the thesis of Melanie K. Arp in its final form and have found that (1) its format, citations, and bibliographical style are consistent and acceptable and fulfill university and department style requirements; (2) its illustrative materials including figures, tables, and charts are in place; and (3) the final manuscript is satisfactory to the graduate committee and is ready for submission to the university library.

Date

Lynn K. Wilder
Chair, Graduate Committee

Accepted for the Department

Tina T. Dyches
Graduate Coordinator

Accepted for the College

Barbara C. Culatta
Associate Dean, McKay School of
Education

ABSTRACT

THE FREQUENCY AND SEVERITY OF PROBLEM BEHAVIORS AMONG INDIVIDUALS WITH AUTISM, TRAUMATIC BRAIN INJURY, AND MENTAL RETARDATION FROM THE UTAH DEPARTMENT OF SERVICES FOR PEOPLE WITH DISABILITIES DATASET

Melanie K. Arp

Department of Counseling Psychology and Special Education

Master of Science

The study reports on analyses of data collected from the *Inventory for Client and Agency Planning* (ICAP) for 5,859 children with autism (*n* = 511), Traumatic Brain Injury (TBI, *n* = 522), or Mental Retardation (MR, *n* = 4826) whose legal guardians applied for support services through the Utah Department of Services for People with Disabilities (DSPD). Results indicate that the least to most frequent problem behaviors were (a) destructive to property, (b) hurtful to self, (c) hurtful to others, (d) socially offensive, (e) unusual habits, (f) withdrawal, (g) uncooperative, and (h) disruptive behaviors. The degree of severity varied from problem to problem, with uncooperative behaviors rated as most severe. Males displayed higher frequency and severity for all problem behaviors, except hurtful to self.

ACKNOWLEDGEMENTS

I believe in living the following statement by Marvin J. Ashton, "The best indicator that we are progressing spiritually and coming unto Christ is by the way we treat other people." This is the life road that I am pursuing and I hope that my works will ultimately lead others to choose this way of life.

I first would like to thank my Heavenly Father for the many gifts, blessings, and talents that He has bequeathed upon me. I am exceedingly thankful for the Gospel of Jesus Christ in my life with Christ's atonement and resurrection, the Gift of the Holy Ghost, and the scriptures. One of the many talents God has graciously bestowed upon me is the gift of administrations. This gift grants me the ability to juggle an exceeding number of tasks at once, among other things.

One of my many blessings is my family. I am so grateful to my husband Adam, and my four extraordinary and beautiful children. Our oldest Jared is conscientious of his choices and a skillful chess player for a nine year old. Amberlee our second child is our little angel with autism and the reason why I am in special education. Kylee is our brilliant six year old with witty manners, and Esther, our sweet and adorable little queen is four years old. They keep me going and they are the reason for the choices I make. I am also especially thankful for my parents and their spouses, George and Carol Bowser, and Keith and Jolene Adams. Thanks Mom and Dad for believing in me.

Next, I would like to express my appreciation to my committee chair Lynn K. Wilder, for her supportive, directive, and encouraging guidance through the past three years. Her Christ-like example and spirit was a lifesaver as I struggled to teach special education full-time, fulfill my calling as a Cub Scout den leader, and care for my four children. I could not have achieved this thesis without her. I would also like to acknowledge my committee members, Betty Ashbaker, Richard Sudweeks, and Susanne Olsen for their perspectives and suggestions through the prospectus and thesis processes. Their efforts contributed to my success.

In addition, I would like to express to Karolyn King-Peery; I deem it a privilege to have become her friend. I would also like to acknowledge her efforts to obtain a grant in order to originate and implement the Families Project, titled "Mom, Catch Me a Rainbow," at Brigham Young University. She has a child with disabilities and understands the complexity of dealing with problem behavior and the need for support services for families with children with disabilities.

One last reason why I have pursued a Masters of Science in Special Education, and am passionate about teaching children and youth is manifested by this concluding idea that I discovered about the way a child with autism learns, and changes behavior: autism means that you have to look me in the eyes and teach me!

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PREFACE

It had been a very hot summer, with already 20 days in a row over 100 degrees in Coppell, Texas. The Fourth of July was just two days away and I was pregnant still. My biggest annoyances were that I was three days late, huge as a whale, and frustrated by the prospects that my daughter Amberlee might be born on July 4, 1998. However, that evening, labor began, while my husband and mother-in-law enjoyed their meals at the Outback Steakhouse.

Amberlee was born the next morning at home in Coppell, Texas. She earned a nine on the Apgar scale, even though, in the middle of pushing, I had to stop and resist so that my midwife, Jenny Jesson, could loosen and pull the cord from around Amberlee’s neck. After Amberlee’s birth, my husband Adam, my son Jared, my mother-in-law Donna and I enjoyed that she was finally here, healthy and beautiful, and equipped with all body parts. At that time, we had no idea what would later appear in our little angel.

Although I thought it would be a nuisance to give birth on the Fourth of July, that notion was trivial to the health problems that Amberlee experienced during the first two years of life. During her first month, Amberlee showed problems with digesting milk. After nursing, she would vomit up almost everything she had just consumed. Unfortunately, I simply thought that she always overate and because of my ignorance, I never did anything about it. My husband and I believe now that she might have suffered from PKU. Then, just a month before her first birthday, she had two severe ear infections.

After she turned one-year-old, however, she seemed all right. She was never sick, she was learning to talk, she smiled at others, and she approached others on her own initiative, even responded to someone who called her name. However, that seemed to disappear when she turned 24 months.

An injury occurred when Amberlee was 15 months old, just one week before her sister Kylee was born. I had gone into the Palmer College of Chiropractic Clinic for an adjustment. I took Amberlee with me. The electrically powered table in the patient room that we went to allowed the doctor to raise and lower the table with a foot control. Amberlee was sitting on a chair at this time. I stood with my back against the table, while the table moved down. With enthusiasm, the doctor continued in his casual conversation, forgetting that Amberlee was in the room. Suddenly, the adjusting table stopped. The doctor profaned and I jumped off the table. Amberlee ran under the table and had stopped it from moving with her head. I picked her up and she remained silent for about 3 seconds. Then, she screamed as if something very painful had just happened to her.

We were living in Iowa at the time and my friends who occasionally babysat my three children, noticed that Amberlee rarely talked and never came to them when they called her name. They suggested that I take her in for a hearing test. I thought that odd because I always seemed to understand what she needed. As I reflected, I, too, realized that she stopped speaking, and responding to her name; however, she became more independent in getting whatever she wanted without using words, and she became more energetic and aggressive.

I contacted the local area education agency in Scott County, Iowa, and had a battery of assessments conducted. About two weeks after the assessment, one of the autism specialists and speech therapists came to me and discussed the results of the evaluations. They discussed age equivalencies and standard scores, and I just smiled and nodded pretending to understand these terms, until one of them gently said the following.

“Your daughter has spectrum characteristics of autism.”

“Autism, autism? What? Where did that come from?” I thought. “What are ‘spectrum characteristics of autism?’” I said.

Hence, I began the journey to discovery whatever I could do to help her. There were many family support services in Iowa; in retrospect, I am so glad we lived there when we did. We set up an Individual Family Service Plan (IFSP). Amberlee’s teacher and I participated in administering the discrete trials and educating her. By the time, she was three years old, Amberlee was attending a half-day preschool at Harrison Elementary School in Davenport, and I was reading to her, as well as teaching her how to play appropriately with toys, and with her brother and sister.

Since that time, Amberlee who is now seven years old has made exceptional progress. Had those services not been available to us, I would still be wallowing in my own ignorance. Now, her interactive speech is appropriate for a three year old, and yet at times she talks using words in sentences like a five year old. Amberlee can read on a first grade level independently and can add and subtract single-digit numbers, among other skills. I am glad that she is the little angel that pulled me from my ignorance and set me on a journey that I hope will touch thousands of lives for good.

CHAPTER 1

INTRODUCTION

For more than 20 years, national governments such as the United Kingdom, Australia, and the United States have provided financial assistance to individuals with disabilities in the form of family support services. Federal governments designate family support services to fund and assist families who have children severe disabilities including autism, Traumatic Brain Injury (TBI), and Mental Retardation (MR) or Intellectual Disabilities (ID). The intent of the services offered is to prevent the institutionalization of individuals with disabilities by assisting families with their care (Wikler, 1986).

Some of the types of family support offered include medical and financial aid, vocational training, transportation and respite care services (Chadwick, Beecham, Piroth, Bernard, & Taylor, 2002). Examples of medical coverage include the necessary therapies, dental and medical care related disabilities. Respite care services provide periodic relief of daily parental burdens and stresses of attending to the needs and behavior of their child with developmental disabilities. For instance, in the United States, the state of Utah's Department of Services for People with Disabilities (DSPD) provides support services to families in behalf of their child with disabilities that have applied and been approved to receive such services.

Although these services may be accessible, not everyone who applies receives them immediately and many others are not aware that these services are available. Many families are on long lists awaiting services. In Utah, approximately 8,800 families have applied for family support services through DSPD since 1985. According to R. Downing (personal communication, July, 2004) at the DSPD, about 3,500 still wait to receive services due to insufficient funding. Families typically wait five years and may wait indefinitely.

Many others, who finally do receive services, feel the services are inadequate to meet the child's and the family's needs (Beresford, 1995; Prewett, 1999; Stalker & Robinson, 1994; Treneman, Corkery, Dowdney, & Hammond, 1997). Baldwin and Carlisle (1994) reported that for many families respite care services are inadequate. Additionally, support services to assist families in changing difficult disability-related behaviors are limited.

In the state of Utah, adequate funding is an ongoing impediment. Many families continue to struggle with high levels of stress since they lack the knowledge and skills to teach appropriate behaviors, social skills, independent living skills, and do not know where to find funds to support medical and daily expenses related to their child with disabilities.

Statement of Purpose

A grant obtained by Dr. Lynn K. Wilder and Karolyn King-Peery through the state of Utah DSPD and Brigham Young University's Family Studies Center facilitated this body of research. The grant included two phases of research. Phase one focus included quantitative research using the Utah DSPD dataset. Phase two of the grant studied the implementation of positive behavior support by families on the DSPD waiting list with their children with disabilities. The results of phase two showed that positive behavior supports decreased the occurrences of problem behaviors and decreased family stress factors for mothers (King-Peery, 2005).

The frequency or occurrence of problem behaviors can contribute to family stress, family conflicts, financial burdens, and frustration (King-Peery, 2005). Therefore, it is important to measure the frequency and severity of problem behaviors and to examine them by gender among children with autism, TBI, and MR. Additionally, it is imperative to review ways parents have coped with challenging behaviors, as well as the researched-based interventions that have decreased the frequency and severity of these behaviors.

The majority of families that have applied for services in the state of Utah have children with autism, TBI, or MR. These developmental disabilities have high incidences of problem behaviors (Olsen, Wilder, Arp, & King-Peery, in press). Although the Utah Department of Human Services DSPD currently assists many families, and has collected data using the Inventory for Client and Agency Planning (ICAP), DSPD personnel have not yet analyzed this intake data to determine the frequency and severities of various problem behaviors.

The research in this study addresses the first phase of the grant, and employs quantitative measures in the investigation of problem behaviors in children with developmental disabilities whose parents and/or legal guardians have applied for support services in the state of Utah. Specifically, the examination of the intake data occurred to quantify the frequencies and severities of eight categories of problem behaviors that families deal with daily. Descriptive statistics utilized included frequency distributions that ascertained the occurrences and severities for each problem behavior and means and confidence levels for the severities of the problem behaviors. To draw conclusions about the severities for the problem behaviors, inferential statistics methods were utilized.

In order to determine a gender effect, the variables analyzed include (a) the range of frequency, and (b) the degree of severity of problem behavior among males and females. Because of the insufficient funding for services and programs, gender is an important variable that may illustrate who is in need of more services when compared to other individuals.

This study summarized data from the Utah DSPD dataset regarding the eight categories of problem behaviors obtained from the ICAP. In addition, it determines what types of behaviors occur most frequently and the seriousness or severity of each problem behavior. The results of this study inform professionals, parents, and caregivers about where to begin in helping children with disabilities that they interact with, to progress academically, socially, and intellectually. Furthermore, the results are provided to inform the public, professionals, DSPD, and legislature so that they may gain more understanding and knowledge about the frequency and severity of problem behavior of children with developmental disabilities and how that impacts family stress.

This quantified and verifiable data is helpful to DSPD and policy makers in determining the allocation of funds in order to help more families. The federal government allots each state two dollars for every dollar that the state contributes to assist family support services. Thus, it would behoove the Utah State Legislature to have research from DSPD regarding the status of families of children with disabilities in order to make data-informed decisions for the welfare of these families and in order to receive the benefit of funds the federal government offers.

Delimitation Scale

The Utah DSPD dataset included the completed ICAP for individuals with the following disabilities: Autism, blindness, TBI, cerebral palsy, chemical dependency, deafness, epilepsy or seizures, MR, physical health care problems requiring the assistance of nurses, mental illness, and emotional/behavioral disorder. This study focused on the sub-sample with the disability categories of autism, TBI, and MR. Initially intended was the analysis of problem behavior among individuals with autism, separate from those with TBI, and MR. However, the following specific reasons determined the collective analysis of the problem behavior occurrences and seriousness for these individuals with disabilities.

One factor was the substantial variation in sample size for MR (n = 4826) compared to the sample sizes for autism (n = 511), and TBI (n = 522). Another consideration was that fewer individuals were diagnosed with autism in the 1980s and 1990s than those diagnosed with Mental Retardation. Specifically, many of the individuals in the dataset were diagnosed as early as 1985. Many individuals labeled with mental retardation in the early part of the data may have later been diagnosed with autism, if the medical or educational diagnosis occurred in the 1990s. In addition, an increasing number of individuals were diagnosed with autism in 1999, 1 out of 285 births (Adams, Edelson, Grandin, & Rimland, 2004), unlike the 2-3 out 10,000 in the early 1980s (Byrnes, 2005).

In summary, to understand how effectively to support these families it is important to describe how frequent and severe the specific problem behaviors that individuals with developmental disabilities display. Future research should determine why these children engage in such behaviors, and examine the ensuing stress that parents and caregivers experience. This study (a) determined the most frequent and severe behaviors for these individuals, (b) compared the frequencies and severities of challenging behaviors among males and females, and (c) reported how the frequency and severity affects family stress factors.

Research Questions

This thesis is focused on the following questions:

1. How does the frequency of problem behaviors vary from problem to problem in children classified with autism, Traumatic Brain Injury, and Mental Retardation, whose primary caregivers requested family support services for these children through the Utah Division of Services for Persons with Disabilities (DSPD)?
2. How does the average degree of severity differ across the eight problem behaviors?
3. How does the frequency of problem behaviors differ across problems, among male and female children with disabilities?
4. How does the mean level of severity differ from problem to problem, among male and female children with disabilities?

CHAPTER 2

REVIEW OF LITERATURE

Historically, society in general has shunned and segregated individuals with severe disabilities with many residing in institutions and having little, if any opportunity for education. However, the creation of the Rehabilitation Act of 1973, Section 504, and the Education for All Handicapped Children Act (Public Law 94-142), and subsequent reauthorization in 1997 (Public Law 105-17), committed society to educate all children with disabilities. Accordingly, parties involved in the educational system have adjusted their treatment of individuals with disabilities. For instance, if individuals needed educational services while living in a residential facility, the school district was now responsible for paying the educational expenses, the costs of room and board, and transportation to and from the residential placement for the parents.

The recent reauthorization of IDEA in 2005 continues the adherence to the education of children with disabilities participating with their same aged, non-disabled peers in a variety of least restrictive environments (LRE) including inclusive settings where appropriate. The challenging behaviors of students with disabilities have contributed to many general educators' lack of support for inclusion of these students. Many general educators feel inadequately trained to meet these students' educational and behavioral needs, particularly when students with disabilities receive services in the general education classroom (Kamens, Loprete, & Slostad, 2003).

Additional legislation in the No Child Left Behind Act of 2001 (NCLB), supports students with disabilities by making schools accountable to demonstrate adequate yearly progress for individual students. According to the U.S. Department of Education (2004), when a school is shown to be “in need of improvement” (p. 2), then the principals and district administrators make changes to ensure that scientifically based research curriculum and instruction by highly qualified professionals is offered and supported. For instance, research supports that children with challenging behavior improve their behavior with mentoring through peer role models (Kamps et al., 2002). The passage of the mentioned laws has benefited the individuals and families of children with disabilities, however, taking care of the day-to-day needs, and behavioral problems of their children at home continues to be a stress factor for family members (Hughes, 1999).

Federal governments continue to support the establishment of programs to assist families with children with special needs. Nonetheless, insufficient funding continues as a causal factor of inadequate services. Prewett (1999) has reported that in the UK almost 60% of parents applying for support services have waited for over a year before receiving them, moreover, once rendered, services remain deficient for the families needs.

Many families with children with disabilities are applying for financial and medical assistance from state agencies. These families have children of various ages with a spectrum of disabilities. Some families apply for assistance due to the everyday expenditures associated with their child’s disability. Other families seek assistance for their children’s challenging behavior.

Therefore, to assist these families it is important to study the literature to ascertain the types of problem behavior and the frequency and severity of each. Further, in order to understand why so many families need services and why the amounts currently allotted are insufficient, it is necessary to know what family crisis or stress factors influence the requests for services, and what types of services and programs have helped families with behavioral changes that have diminished some of these stress factors.

Problem Behavior Experienced by Individuals with Autism

According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), autism is a neurological disorder that negatively affects the communication, behavior, and social interaction of an individual (American Psychiatric Association, 2000). Adams, Edelson, Grandin, and Rimland (2004) state that during the 1970s 5 births of children diagnosed with autism of 10,000. By the mid-1980s, 10 to 12 of 10,000 births had autism. In 1999, the diagnosis of autism occurred, a shocking 1 out of 285 births. Although their numbers come from data collected in California, other states have reported the same increase in the number of children with autism.

Challenging behaviors associated with autism are illustrated by deficient communication, poor social skills, self-injurious actions, tantrums, obsessive and compulsive manners, and incessant reliance upon others (Liwag, 1989). Consequently, children with autism do not interact typically with their same aged, non-disabled peers. Accordingly, others may look at them as living in their own world and strange because of the behavior displayed.

Often a child with autism will tantrum by falling to the floor crying or by self-injury behavior such as head banging and biting extremities. These behaviors are means to an end for the individual, because he or she lacks skill and ability to communicate needs in socially appropriate ways, and because in the past, these methods have delivered the desired outcomes. Most individuals that demonstrate such behaviors do so to communicate needs, wants, or frustrations, as well as for other reasons including acknowledgement, sensory, and escapism (Buschbacher & Fox, 2003; Dyches, Wilder, Obiakor, & Algozzine, 2004; Grandin, 2002; Snell & Brown, 2000).

Temple Grandin (1995), a professor at the University of Colorado, has autism and she has stated the reasons individuals with autism resist interactions with others. As a child, she would rather be by herself because associations with others created in her an intense feeling of sensory and tactile overload. In addition, she stated that children and adults with autism manifest poor language and social skills because these individuals think differently than others.

Grandin (2002) reported that she thinks in pictures, interpreting verbal and written language as a movie in her mind, therefore, the mental processing speed is slower and it takes longer for a response because she is translating words into pictures. Having exceptional visual spatial skills is beneficial to Grandin. She stated that the skill has given her a detailed imagination from which to design livestock equipment used during slaughter and veterinary procedures.

Children with autism may display obsessive and compulsive behavior. Often this behavior is displayed because the child with autism is overly stimulated or seeking needed stimulation. Most likely, these children with autism are seeking tactile and sensory stimulation or trying to de-escalate and calm down (Grandin, 2002).

Autism is one disorder that generates significant stressors for families due to problem behavior (Randall & Parker, 1999), with parents of children suffering from Autism reporting more stress than parents whose child bears a different disability (Bristol, 1987). It is particularly challenging for families, school personnel, and caregivers to assist children with autism because of their challenging behavior, poor communication, and social skills. Parents report that problem behavior negatively affects their relations among extended family members, interaction between siblings, involvement in religious and community events, and ability to maintain consistency in daily routines (Domingue, Cutler, & McTarnaghan, 2000; Fox, Dunlap, & Buschbacher, 2000).

Because of challenging behavior, some parents may forego attending religious functions, a source of communal and emotional sustenance (Hughes, 1999) in order to attend to the needs of their child with autism. In addition, parents may no longer take vacations and go on outings, a source of coping and relaxation, as well as give up employment prospects, a source of income that provides for their families needs (Fox et al., 2000). Families feel isolated and shunned from the public due to their child’s behavior (Domingue et al., 2000); hence, marital and family conflicts may result.

Problem Behavior Experienced by Individuals with TBI

Traumatic brain injury occurs from an accident that causes severe injury and function of the brain. Kraus (1995) reported that the occurrence of TBI among children in the United States is about 180 children out of 100,000. In 1998, Sharples reported that approximately 3,000 new cases of TBI occur each year. Taylor and Stancin (2003) stated that the typical results include possible long-term cognitive and behavior problems, including thinking and memory deficits and behavioral and emotional problems.

Among children with TBI, the most frequent behaviors include aggression, impulsivity, hyperactivity, temper, mood fluctuations, psychiatric disorders, and poor social skills (Hawley, 2003, 2004; Schwartz, Taylor, Drotar, Yeates, Wade, & Stancin, 2003; Taylor & Stancin, 2003). Problem behavior increases because of traumatic brain injuries. The level of increase is dependent in part on if the individual has suffered other significant injuries. Families who have fewer social supports to help them cope with changes and financial resources report more problem behavior. These families on average receive less help and less specialized programs to help them cope with the changes and the addition of problem behaviors in their child.

Hawley (2003) reported results of a study that she directed in the UK in which families of 97 young people with TBI, 49 mild, 19 moderate and 29 severe were interviewed. Initial interviews conducted included children injured recently to six years prior. Twelve months later, the researchers conducted follow-up interviews. Interviewed in like manner, was a control group of non-disabled peers. The interview questions specifically related to the types of problematic behavior parents and teachers observed since the injuries. Interviewees reported many different types of problems present.

The results indicated a total number of 1,097 problem behavior occurrences with an average of 11.31 problems per family. The severely disabled group reported the most problems, with a mean of 15.2. Most frequently reported problems included headaches, mood fluctuations, concentration problems, temper, and negative attitude toward siblings, as well as tiredness, incomplete school assignments, poor learning, and loss of friendships. The results found that apart from severity of injuries, the most significant problematic behaviors included temper, in the form of aggressive, non-responsive, loud, and argumentative behavior; school problems, in the form of disruptive behavior and refusing to work; and extreme withdrawn and internalizing behaviors. Although physical problems tended to subside over time, behavioral problems remained, with 8.4% experiencing worsening behaviors.

Schwartz et al. (2003) reported findings from their long-term study of behavior problems among children affected by TBI and the family outcomes. The sample included three groups, severe, moderate, and orthopedic injuries only. They assessed initially, then followed-up at six months, 12 months, and long-term, with a mean of four years. Results show that for the severe group, the prevalence of problem behaviors rose in the total population, from 10% to 36%. The moderate group stayed approximately the same and the orthopedic group's population with behavior issues decreased from 20% to 10%. These authors recommended that those individuals with severe TBI whose families had limited resources, were at greatest risk and should have access to support services, testing, and behavioral interventions.

Problem Behavior Experienced by Individuals with MR

The American Association on Mental Retardation (AAMR) recently changed the definition of MR or intellectual disability (ID) to what Luckasson et al. (2002) describes as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18." This definition supports a paradigm shift that provides for more access for these individuals to the general education curriculum. The AAMR definition encourages professionals to consider the individual's independent functioning in specific social contexts and settings when reviewing assessment data to determine categorization (Wehmeyer, 2003).

With more children with ID in the general education classroom, teachers, lunchroom staff, and peers may observe the types of problem behavior that these individuals display. This may result in more requests from inexperienced teachers who teach and interact with these students for understanding and skills to change problem behavior. In addition, the new definition promotes that the children with MR receive necessary support services to ensure progress. This in turn, should ensure legislation that assists families with children with MR.

Individuals with profound ID or MR may demonstrate challenging behavior depending upon severity level of the disability (Deb & Bright, 2001; Janssen, Schuengel, & Stolks, 2002). To determine levels of anxiety among the persons with severely profound ID, Chaney (1996) reported those 33 out of 35 individuals with IQ's less than 20 demonstrated psychological stress by elevations of their heart rates, blood pressure and respiratory rates. Notwithstanding the severity of MR, an individual may experience and that person's communication ability, these individuals still experience stress. Frequently, psychological stress including poor self-image, feelings of incompetence and learned helplessness affect these individuals (Bramston, 1993; Chaney, 1996; Janssen et. al, 2002; Olson & Schober, 1993). These factors also affect the well being of parents, family members, and caregivers.

Research has demonstrated that physical problems led to an increase in challenging behaviors. For example, Didden, Korzilius, van Aperlo, van Overloop, and de Vries (2002) reported that over 75% of children suffering from severe intellectual disability concurrently suffered from sleep problems. These problems often stemmed from medical problems such as seizures and sleep apnea. Children with a sleep disorder also had significantly higher rates of aggression, screaming, temper tantrums, non-compliance, and impulsivity than those without a sleep disorder. As a result, 32% of parents reported lacking sleep, with mothers of children with such sleep problems reporting higher levels of irritability, feelings of negativity toward their child, and the use of punishment.

Dekker, Koot, Ende, and Verhulst (2002) reported that children with intellectual disabilities showed problem behavior displayed as poor peer relationships, low self-esteem, running away from home, stealing, and vandalizing. Almost 50% of these individuals problem behaviors ranked in the deviance range. The most prevalent challenges included social, attention, psychological, and aggressive behaviors.

In summary, persons with autism, TBI, or MR exhibit numerous and various problem behaviors, however, differences among males and females with challenging behaviors also needs to be addressed. Furthermore, the investigation of family stress factors and coping strategies as they relate to problem behaviors provides a foundation for understanding the importance this research.

Gender Differences among Individuals with Autism and TBI

Generally, many differences exist between males and females. Thompson, Caruso, and Ellerbeck (2003) reported many variations in girls and boys. These distinctions occur in the typical diversity of play, intellectual functioning, and biological differences that include anatomy, hormonal, neurological interactions, receptor sites, and functions. Disparities also exist in the behavior exhibited by males and females. Women have higher rates of internalizing problems such as anxiety and depression, and mood swing and eating disorders, whereas males tend to be more aggressive or externalizing in their behaviors.

Autism. The National Dissemination Center for Children with Disabilities reports that gender is a factor for autism because four times more males have autism than females (NICHCY, 2004). Girls are 10 times more likely to have milder spectrum characteristics of autism than males (Thompson et al., 2003). Lord, Schopler, and Revicki (1982) found that when IQ and age were controlled for, females with autism experience less social and communication deficits than do boys. When age is accounted for, females at a younger age have better social and language skills, as well as less aggression and hyperactivity; however, after the onset of puberty and during adulthood, females with autism are rated as having more social and communication deficits than males of the same age and IQ. Research shows some differences in problematic behavior among males and females with autism.

Traumatic Brain Injury. Schwartz et al. (2002) found a gender difference in TBI with higher rates for boys than girls. As predicted, the male children with moderate to severe TBI had higher rates of clinically significant behavior problems than the control group. They also cited previous findings that most of these disorders emerge soon after the injury and become persistent.

Groswasser, Cohen, and Keren (1998) conducted a study examining at the recovery rates between male and female patients who recently experienced a TBI. Their study included at 72 females and 262 males who suffered TBI and found functional outcomes for female patients were better, meaning that they recovered more toward their previous levels of functioning than the males in the study did.

One possible explanation is that females may have some protection against TBI because of the level of progesterone in their bodies. Based on research conducted by Roof, Duvdevani, Heyburn, and Stein (1996), progesterone has a protective element in it that protects the brain from damage, and as most of the women experiencing TBI are of children bearing age, they would have more progesterone in their bodies than males who experienced a TBI. Donders and Woodward (2003) found among males and females tested, the females significantly outperformed the males. Yet, they warned that these results should not be a reason to neglect the rehabilitation treatment of girls.

Family Stress Factors

In a review of empirical studies, results varied concerning the amount of stress added to marriages and families due to the presence of a child with severe disabilities and/or behavioral disorders (Eddy & Walker, 1999; Mauldon, 1992; Randall & Parker, 1999; White & Booth, 1985; Wikler, 1986). Glenn (1989) found that for many couples, the presence of children without disabilities reduced marital happiness. It appears that if “normal” children or those without challenging behaviors decrease marital quality, then the rearing of a child with disabilities may only increase the likelihood of unhappy marriages (Eddy & Walker, 1999; Glenn, 1990). Therefore, it is important to examine what stressors create marital discord and when and how the stress manifests itself.

Stress among family members increases when they find out that their child and or sibling has a disability (Hughes, 1999). Added stress results from the daily management of the needs of the individual encountered by parents and guardians (Floyd & Gallagher, 1997; Turnbull, Brotherson, & Summers, 1986). These needs may include feeding, toileting, attention, and a structured environment. Often these demands continue into adulthood for children with autism, TBI, and MR. Although Floyd and Gallagher’s findings show that during adolescence, mothers usually report fewer demands on them, constant adaptations still occur in families throughout the lifespan of children with disabilities. Naturally, the intensive care taking can be emotionally taxing upon the caregivers and other family members.

Additional stressors affecting families related to the child's disability incorporates: (a) the child's age and functional abilities (Hodapp, Wijma, & Masino, 1997), (b) critical medical decisions to make concerning the child's survival (Turnbull, 1986), and (c) the child's psychological well-being (Bramston, 1993; Chaney, 1996; Janssen et al., 2002).

Stressors affecting couples with children with disabilities consists of (a) parental depression and marital tension (Bristol, Schopler, & McConnaughey, 1984; Herbert, 1995), (b) inadequate financial resources to meet the child's needs (Herman & Thompson, 1995), and (c) feelings of isolation (Powers, 1993).

Other factors include (a) concerns about the outcome for siblings (Gibbs, 1993), and (b) being known to others as a having a child with disabilities (Cheng & Tang, 1995; Orr, Cameron, Dobson, & Day, 1993). In addition, poor social development including limited communication and impaired or dysfunctional social relations of children with disabilities is another stressor for families (Liwag, 1989; Randall & Parker, 1999).

Children with moderate to severe intellectual and developmental disabilities including autism, Down syndrome, Cerebral Palsy, Aspergers, Traumatic Brain Injury and Mental Retardation most likely display numerous challenging behaviors when compared to typical developing children. Research from Floyd and Gallagher (1997) shows that stress among family members occurs with the manifestation of disruptive and challenging behaviors by the one with disability. King-Peery (2005) verifies that stress among family members increase with the interactions with the child during episodes of problem behaviors, and the subsequent management of these behaviors. Research has documented high rates of institutionalization of child with disabilities because of these stressors (DeMyer & Goldberg, 1983).

Specifically, Wallander, Pitt, and Mellins (1990) found a relationship between inadequate family adjustment and the degree of behaviors displayed. For example, Taylor and Stancin (2003) reported that TBI affects not just that member who became disabled but also all family members. They found that 67% of families with children who have TBI have at least one family member who sought after mental health services following the accident. Specific problem behavior is associated among individuals with TBI. Consequently, the more intense the behavior the more distressed and unskilled families feel about how to cope with and improve behavior.

In summary, poor social development, significant behavior problem, and caring for day-to-day needs are a few of the demands placed upon caretakers of children with moderate to severe disabilities that cause stress. Stresses manifested in families include marital strife, separation and divorce, financial difficulties including loss of employment, not enough funds to cover expenses, and bankruptcy, need for family counseling, and possible the institutionalization of the individual with disabilities. In addition, DeMyer and Goldberg (1983) found that the stress of raising a child with disabilities impacted housekeeping, emotional, mental and physical health of family members, relationships among siblings, extended family, friends, and neighbors and family recreational activities.

It follows that parents and families need assistance to support their child with disabilities and need access to the many different services available to help them cope with the stress and problem behavior daily faced as they provide for their child with disabilities. Research supports a variety of methods families and caregivers use to cope. Thus, review of self-efficacy and coping strategies is important to creating and implementing further support for families dealing with severe behavior.

Ways Parents Cope with Problem Behavior

Self-efficacy refers to a parent or caregiver's individual perception of his or her skills and awareness to deal with problem behavior. Previous studies indicate that low self-efficacy is predicative of higher stress and poorer relationships between parent and child or caregiver and child (Bandura, 1989). Hastings and Brown (2002) examined self-efficacy as an intervention to reduce parental stress, child behavior problems, and to strengthen the relationship between parent and child. The results showed that self-efficacy is more of a protective factor for fathers; however, low self-efficacy relates to higher stress, anxiety, and potential for mental illness for mothers. Therefore, it is imperative, that parents and caregivers, especially mothers have access to skills and interventions to reduce problem behavior.

Parents have found many ways to cope with the demanding behavior their child with disabilities demonstrates. The literature shows that social support services (Chadwick et al., 2002; Krahn, 1993) and parental training programs (Cook, 1990; Serketich & Dumas, 1996; Sopronoff & Farbotko, 2002; Vincent & Beckett, 1993) have been essential to helping parents work through challenges when assisting their child with disabilities.

Additionally, in coping with problem behavior, many families have found religious faith (Hughes, 1999) journal writing, and receiving massages effective (Singer, Irvin, Irvine, Hegreness & Jackson, 1993). Other approaches have helped many family members to better cope with challenging behaviors in their child with disabilities. Such effective tools include the applied behavior analysis methods of functional assessment (Hastings & Brown, 2000; Iwata, Dorsey, Slifer, Bauman, & Richman, 1994). Further, implementing choice making (Dyer, Dunlap & Winterling, 1990; Fisher & Mazur, 1997; Harding, Wacker, Baretto, & Ranking, 2002; Harding et al., 1999), utilizing reinforcement techniques (Wolfgang, 2000), peer training and mediation programs (Kamps et al., 2002), and augmentative communication (Frea, Arnold, & Vittimberga, 2001) will further assist the child. Kamps et al. state that implementation of research-based practices will decrease challenging behavior, and increase positive social interactions and access to the general education curriculum.

Conclusion

Review of the literature reveals that children with MR, autism, and TBI, experience a variety of numerous problem behaviors. These behaviors also occur across vast settings and people. Research demonstrates that resources are limited to assist the number of individuals with disabilities and their families. There is a need to determine the specific frequencies and degrees of severity of problematic behavior experienced by males and females with autism, TBI and MR, to encourage professionals to offer positive behavioral support and counseling to families who struggle to lessen problem behavior in their child with disabilities. In addition, it is imperative to lobby the legislature for the necessary money to fund support services for individuals with disabilities and their families.

This research employs quantitative measures in the investigation of families with children with disabilities. Specifically, quantified data from DSPD ascertains the frequency and severity of problem behavior that families in Utah deal with daily. This quantified and verifiable data can be helpful to policy makers in determining the allocation of funds in order to assist all families and individuals with disabilities who are in need of behavior change programs.

CHAPTER 3

METHOD

Research Design

This study looked at previously (1985-2001) collected data from interviews with parents and/or legal guardians of children with autism, TBI, and MR who applied for family support services in Utah. Examination of the interview intake data quantified frequency and severity of the eight problem behaviors and determined gender effect. Descriptive statistics ascertained frequencies and severities of the problem behaviors. Inferential statistics were used to draw conclusions about the severities of problem behaviors.

Participants

The full data set included 7,772 families with children with disabilities residing in the state of Utah who had applied to receive family support services from Division of Services for People with Disabilities (DSPD) from 1985 to 2001. Any legal guardian of a disabled child may have applied to receive family support services through the Utah DSPD. Legal guardians may have applied for services as soon as they knew their child had a disability. The DSPD dataset used in this study included data from the Inventory for Client and Agency Planning (ICAP) instrument used by state workers.

The sub-sample used in this research included responses from interviews with parents or caregivers, who have a family member with a primary diagnosis of mental retardation (82.4%), traumatic brain injury (8.9%), or autism (8.7%). Demographic features of this sub-sample include 5,859 persons with disabilities of which 56.5% (3305) were males, and 43.5% (2541) females. Most individuals were Caucasian (92.8%), understood English (97.9%), and were single (94%). Nearly three-quarters (74%) of the individuals had verbal communication skills, 13.2% were capable of communication using gestures, and 2.3% use sign language or finger spelling. Only 18.2% had vision loss, and 6.7% had hearing impairments.

The majority (84%) either had experienced no seizures or their seizures were controlled; however, 6.9% were reported to have experienced seizures weekly or more often. Most (88.7%) walked with or without aids, such as crutches or walkers, and 79.1% had no hand/arm limitations. One third (33.5%) had either slight or significant limitations in their daily activities.

Nearly half (48%) were considered legally competent adults. Forty-two percent of the children were 18 years and younger or adults with at least one parent or relative appointed as the legal guardian. A smaller percentage (9.3%) included individuals who had a non-relative, the state, or those who answered “other” as the appointed legal guardian.

The level of MR for the sample ranged from a rating of “not mentally retarded” (3.9%), “mild, IQ 52-70” (38.9%), “moderate, IQ 36-51” (18.3%), “severe 20-35” (11.6%), “profound IQ under 20 (13.1%), and “unknown, delayed, at risk” (13.6%).

The types of support services utilized for this population at the time of the interview were rated on the ICAP. The dataset showed that minimal support services were utilized at the time of the interviews for these individual with disabilities. Importantly, these services may or may not have been funded by DSPD. Example of the types and percentages of the support services used include the following: (a) home-based support services (16%), (b) specialized medical care and services (23%), (c) specialized mental health services (19%), (d) therapies including occupational, physical or speech (21%), (e) respite care services (12%), and vocational supports (9%).

Procedure

The Division of Services for People with Disabilities (DSPD) in the state of Utah followed a structured interview procedure for administering the ICAP. Intake workers made home visits and interviewed legal guardians about the individual with disabilities. The parent responded and the interviewer rated the caregiver's responses on the ICAP protocol. DSPD data entry clerks entered the data from each ICAP questionnaire into a prepared statistical database. The DSPD made this dataset available to Brigham Young University grant personnel for about two years. Statistical analyses conducted are described in a subsequent section of this paper.

Measures

The Inventory for Client and Agency Planning (ICAP) was developed in the early 1980's for many purposes; and is a standardized inventory of disabilities, problem behaviors, and adaptive/maladaptive scores (Bruininks, Hill, Weatherman, & Woodcock, 1986). The ICAP was designed to assess problem behaviors and their consequences by identifying and describing eight broad categories of problem behavior in the client's environment.

The ICAP can be used to assess individuals from infancy through adulthood. Many states may use the ICAP in order to determine eligibility and allocation of support services. The ICAP primarily provides a method to screen and assess client needs and eligibility status in initial evaluations and determine planning of services. It takes approximately 20-30 minutes to complete an interview (Bruininks et al., 1986).

For this study, the following sections of the ICAP were used, these sections are described below:

1. Descriptive Information used to gather demographic type of information.
2. Diagnostic Status used to record the primary and secondary disabilities.
3. Functional Limitations and Needed Assistance used to establish physical and mental functional abilities related to the diagnosis.
4. Problem Behavior used to assess the frequencies and severities that hinder personal and social adjustment and access.
5. Support Services used to gather the current services used, and the potential services an individual may need within two years. The specific types of support service responses included: (a) none, (b) case management, (c) home-based support services, (d) specialized dental care, (e) specialized medical care, (f) specialized nursing care, (g) specialized mental health services, (h) specialized nutritional, or dietary services, (h) therapies.

The ICAP was standardized on a national sample of more than 1700 participants. Validity and reliability was obtained for the ICAP. The criterion-related validity of the ICAP yielded correlation scores between .88 and .99 (Bruininks et al., 1986). For further information regarding validity, see Bruininks, 1986.

Reliability evidence was obtained through test-retest studies, and interrater reliability. Test-retest reliability coefficients for the problem behavior domain ranged from .65 to .95 for frequency and .42 to .84 for severity. However, the coefficients for the maladaptive behavior index were .75 to .89. Interrater reliability was shown by the comparison of assessments of two individuals who both worked with the children with disabilities. For example, for the problem behavior domains, teachers and teachers' aides completed the same assessment. Numerous tests were completed for interrater reliability, producing correlation coefficients in the .70's and the .80's.

The information from the ICAP used in this study included the descriptive information, diagnostic status, functional limitations, the problem behavior, and support services section. The eight areas of problem behaviors assessed include (a) hurtful to self, (b) hurtful to others, (c) destructive to property, (d) disruptive behavior, (e) unusual or repetitive habits, (f) socially offensive behavior, (g) withdrawn or inattentive behavior, and (h) uncooperative behavior. The frequency of occurrences of the eight different problem behaviors was rated on a six point scale ranging from 0 to 5: 0 (*never*), 1 (*less than once a month*), 2 (*one to 3 times a month*), 3 (*one to 6 times a week*), 4, (*one to 10 times a day*) and 5 (*one or more times an hour*).

The relative severity of the eight problem behaviors was also rated scale on a five-point scale: 0 (*not serious; not a problem*), 1 (*slightly serious; a mild problem*), 2 (*moderately serious; a moderate problem*), 3 (*very serious, a severe problem*), and 4 (*extremely serious; a critical problem*).

Specifically, a rating that was "not serious," for severity included behaviors that were peculiar and atypical, such behaviors were not considered a problem by most people. A rating that was slightly serious referred to behaviors that were embarrassing, bothersome, and a problem in some environments. Although not acutely limiting to normal activities in structured environments, these problems did encumber ordinary activities, when a highly controlled setting was not possible. It is most likely that behaviors with minimal seriousness were challenges for parents, caregivers, and education faculty to deal with.

A moderate problem with a rating of 2 indicated that the behaviors were problematic in all environments in which these occurred. Considered deplorable and objectionable, these behaviors limited typical activities for parents and caregivers in particular.

A rating of 3 for severity indicated repulsive and frightening behaviors that were very serious. These behaviors tended to be too difficult for one person to manage. Very serious behaviors limited many activities. The reduction of the behaviors required highly structured and consistent environments. Extremely serious or critical problem behaviors were rated 4 and were very difficult to reduce in frequency. Further, the consequences were complicated to minimize because of the serious nature of these behaviors. Extremely serious or critical problem behaviors might have been life threatening. Supports were needed for parents, caregivers, or professionals when dealing with problem behaviors with the extreme degree of severity.

Data Analysis Procedures

Question 1. How does the frequency of problem behaviors vary from problem to problem in children with autism, TBI, and MR, whose primary caregivers request family support services for them through the Utah Division of Services for Persons with Disabilities (DSPD)?

A two-way cross tabulation analysis of the type of problem behavior by frequency category was performed to compare the relative frequency of occurrence across the eight types of problem behaviors. A chi-square test of independence was conducted to determine whether the differences in the eight frequency distributions were statistically significant.

Question 2. How does the average degree of severity differ across the eight-problem behaviors?

To answer this question the mean and standard deviation of the severity ratings for the eight problem behaviors were calculated.

Question 3. How does the frequency of problem behaviors differ across problems, among male and female children with disabilities?

Eight different chi-square tests of independence were performed to assess whether differences in the frequency of problem behaviors were statistically significant between males and females. A Bonferroni adjustment was made to the alpha level to adjust for the multiple tests.

Question 4. How does the mean level of severity differ from problem to problem, among male and female children with disabilities?

This research question was answered by using a multivariate analysis of variance (MANOVA). Specifically, the MANOVA was employed because multiply questions were answered by the same respondent concerning one individual with disabilities. A Bonferroni adjustment was made for comparing the eight problem behavior means.

CHAPTER 4

RESULTS

Research Question 1

How does the frequency of problem behaviors vary from problem to problem in children with autism, TBI, and MR, whose primary caregivers request family support services for these children through the Utah Division of Services for Persons with Disabilities (DSPD)?

The frequency distributions for the eight problem behaviors showed that some behaviors occur often while others are less prevalent (see Table 1). The chi-square test showed statistical significance between the eight frequency distributions (Chi-square = 6,406.45; df = 35; p < .000001). Furthermore, the chi-square specifies which problem behaviors are most different.

As shown in Table 1, the behaviors that “never” occurred in the sample included (a) destructive to property (64%), (b) hurtful to self (60%), and (c) hurtful to others (57%). Individuals with these behaviors did have occurrences ranging from “less than once a month” to “1-10 times per hour:” (a) destructive to property (36%), hurtful to self (40%), and hurtful to others (43%). Further, about two-thirds had some occurrences of the other categories of problem behaviors: (a) disruptive behaviors (67%), uncooperative behaviors (67%), withdrawn or inattentiveness (65%), unusual or repetitive habits (64%), and socially offensive behaviors (62%).

Table 1

Percentages for the Frequency by Types of Problem Behavior (N = 5,849)

	Frequency Category					
Types of Problem Behavior	Never	Less than once per month	1-3 times per month	1-6 times per week	1-10 times per day	1 or more times per hour
Hurtful to Self	60.4	7.1	6.8	10.0	11.2	4.5
Hurtful to Others	56.7	12.3	9.7	11.0	8.9	1.5
Destructive to Property	63.9	9.8	8.9	9.8	6.7	1.0
Disruptive Behavior	32.5	4.8	9.5	19.1	24.8	9.2
Unusual or Repetitive Habits	36.4	2.5	4.5	10.5	26.9	19.2
Socially Offensive	38.3	4.0	8.8	16.9	23.2	8.7
Withdrawal or Inattentive	35.0	4.2	8.4	17.6	23.5	11.3
Uncooperative	33.3	6.0	11.5	20.4	22.2	6.6

Problem behaviors that transpire at least “1-6 times per week” are more likely to be exigent (see Figure 1). The percentages of problem behaviors that occurred for half of the sample at least “1-6 times per week” included unusual or repetitive habits (57%), disruptive behaviors (53%), withdrawal or inattentive behaviors (52%), socially offensive behaviors (49%), and uncooperative behaviors (49%).

One-third of the sample displayed the following behaviors daily: (a) unusual or repetitive habits (46%), (b) withdrawal or inattentive behaviors (35%), (c) disruptive

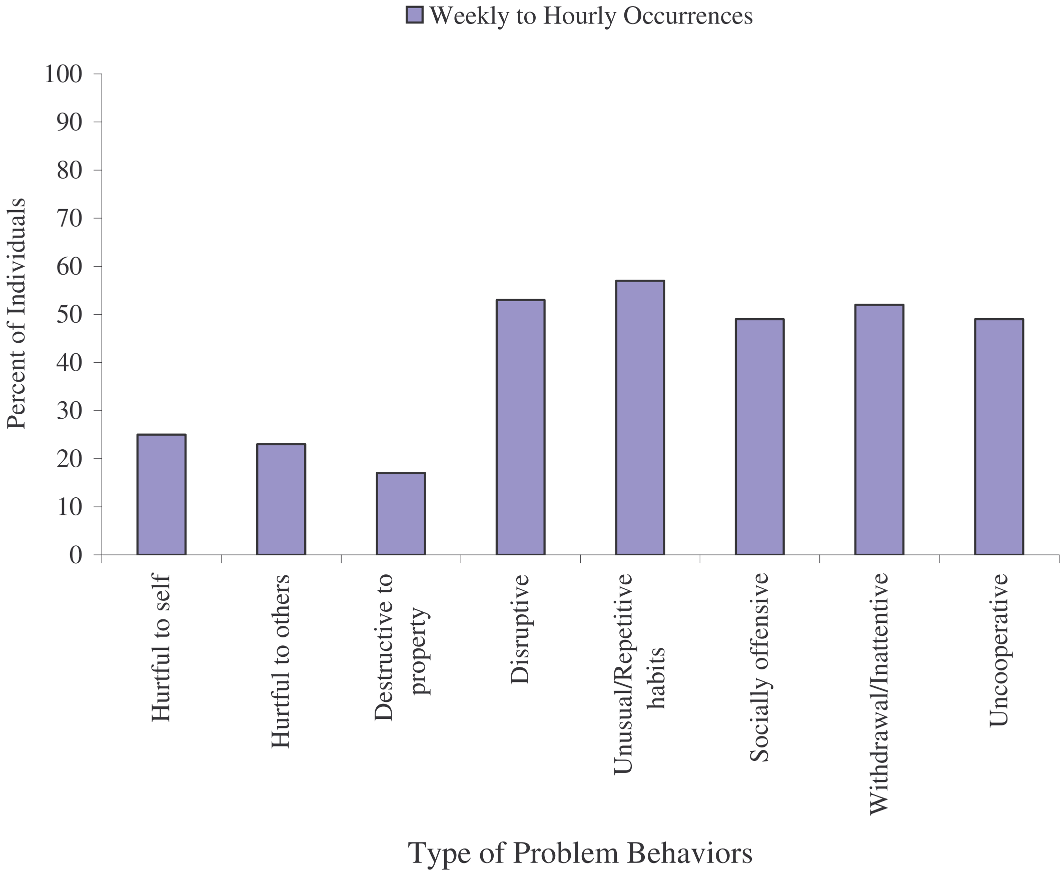

Figure 1. Problem behaviors that take place "1-6 times per week," to "1-10 times per day," to "1 or more times per hour."

behaviors (34%), (d) socially offensive behaviors, and (e) uncooperative behaviors (29%).

Research Question 2

How does the average degree of severity differ across the eight problem behaviors?

The statistical analysis answered how severe or serious these episodes of the eight problem behaviors were for individuals with these disabilities. The mean ratings showed that on the average, the eight problem behaviors differed for the degrees of severity (see Figure 2). The x-axis is the problem behavior types and the y-axis refers to the mean scores. The line represents the confidence interval for the mean and the dot represents the mean. The results show that the eight behavior means fall within the not "serious" to the "slightly serious" categories.

After examining the data, two groups of means were identified. The first group of means fell in the "not serious" degree of severity and included behaviors that were (a) destructive to property, (b) hurtful to self, and (c) hurtful to others. The second group of means in the "slightly serious" degree of severity included behaviors that were (a) unusual repetitive habits, (b) withdrawal or inattentiveness, (c) socially offensive behaviors, (d) disruptive behaviors, and (e) uncooperative behaviors.

As shown in Table 2, the first group had the lowest means because more than half of the respondents for each of the individuals with disabilities described the following behaviors as "not serious" (a) destructive to property (67%), (b) hurtful to self (66%), and (c) hurtful to others (61%). Table 2 depicts the distribution of occurrences for each degree of severity across the eight behaviors, as well the standard error for each mean.

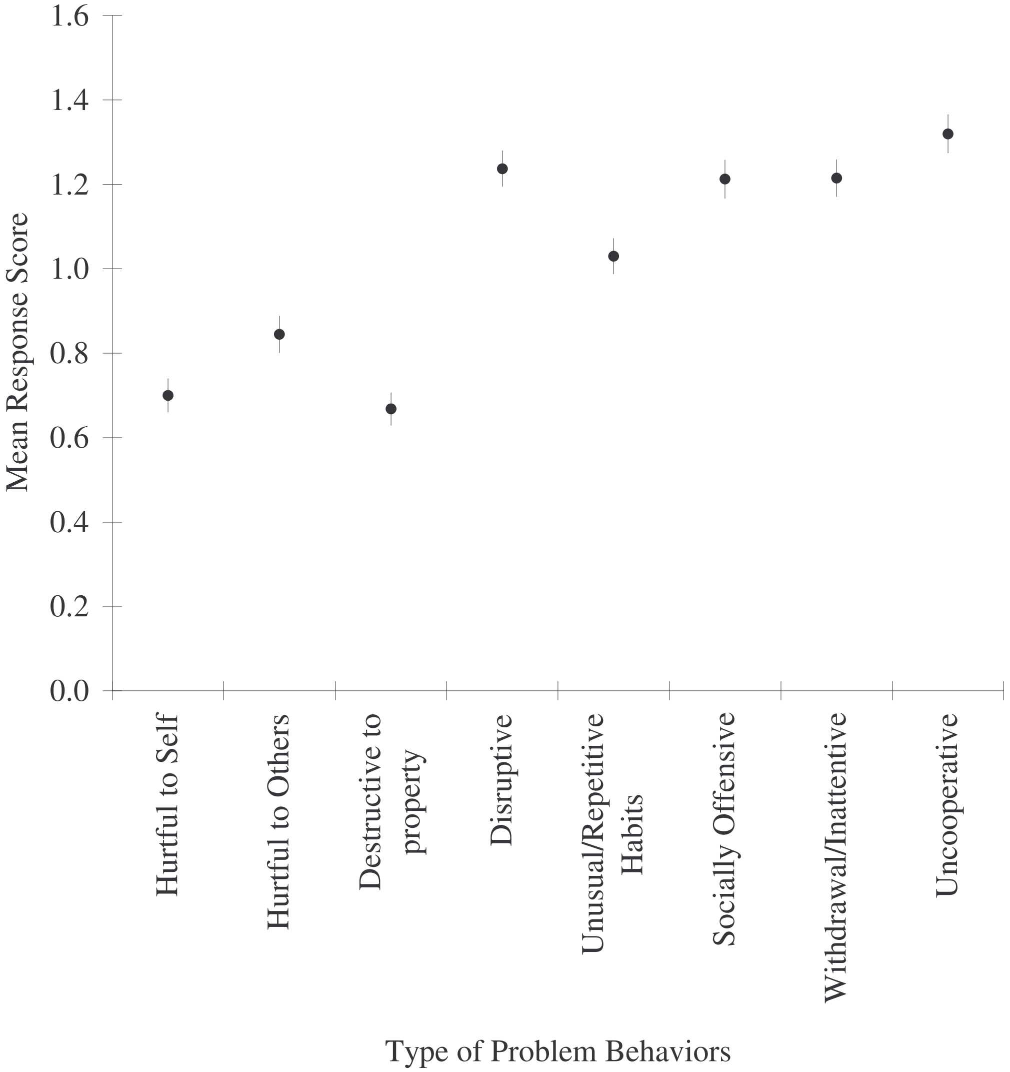

Figure 2. Mean response scores for the severity by problem behaviors, 0 (*not serious*), and 1 (*slightly serious*).

Table 2

Percentages for the Severity by the Eight-Problem Behaviors (N = 5,859)

	Response Variable				
Type of Problem Behavior	Not Serious	Slightly Serious	Moderately Serious	Very Serious	Extremely Serious
Hurtful to Self	65.6	12.7	11.9	5.9	4.0
Hurtful to Others	61.2	11.9	13.3	8.4	5.2
Destructive to Property	67.4	11.0	12.1	6.7	2.9
Disruptive Behavior	38.7	19.8	24.7	12.5	4.2
Unusual/Repetitive Habits	47.2	20.6	18.7	9.1	4.4
Socially Offensive	42.9	17.8	20.7	12.4	6.3
Withdrawal or Inattentive	41.4	17.5	24.1	12.2	4.7
Uncooperative	38.5	17.5	24.0	13.5	6.5

The second group of behaviors fell into the “slightly serious” degree of severity (see Table 2). This group of challenging behaviors had greater severities because more than half of the caregivers who rated their children with disabilities depicted these behaviors as “slightly serious” to “extremely serious:” (a) unusual and repetitive habits (53%), (b) socially offensive behaviors (57%), (c) withdrawal or inattentiveness (59%), (d) disruptive behaviors (61%), and (e) uncooperative behaviors (61%).

It is important to further examine the results analyzing both the frequencies and severities of problem behaviors. Although definitive findings cannot be ascertained, a few parallels and counterparts can be shown from the examinations. The behaviors that most frequently occurred (see Table 1) for individuals with autism, TBI, and MR were the same behaviors with the higher degrees of severity (a) disruptive behaviors, (b) unusual or repetitive habits, (c) socially offensive behaviors, (d) withdrawn or inattentiveness, and (e) uncooperative behaviors (see Table 2).

The categories of behaviors with the highest frequencies of (a) 1-3 times per month, (b) 1-6 times per week, (c) 1-10 times per day, and (d) 1 or more times an hour were both similar and dissimilar with the rankings of behaviors for the degrees of severity. Behaviors that were (a) disruptive, (b) withdrawn or inattentive, and (c) uncooperative occurred most often. However, the behaviors with the highest rankings for degrees of severity were (a) uncooperative, (b) disruptive behaviors, and (c) withdrawal or inattentiveness. Further, the problem behaviors with the highest frequency for the categories of (a) 1 to 10 times per day, and (b) 1 or more times an hour, included unusual or repetitive habits, whereas, uncooperative behaviors most often ranked highest on the severity scale for (a) very serious, and (b) extremely seriousness.

Research Question 3

How does the frequency of problem behaviors differ across problems, among male and female children with disabilities?

The three-way cross-tabulation results in Table 3 depict the differences in the distribution of occurrences for males and females across the eight problem behaviors. Forty-two percent of males were destructive to property, while 28% of females demonstrated the same behaviors. In addition, about 47% of the males displayed behaviors that were hurtful to others, and the percentage of females that were hurtful to others was 38%. For behaviors that were categorized as socially offensive behaviors,

Table 3

Percentages for the Frequencies of Problem Behaviors by Type of Problem and Gender (N = 5,846)

		Frequency Response Categories							
Type of Problem Behavior	Gender	Never	Less than once per month	1-3 times per month	1-6 times per week	1-10 times per day	1 or more times per hour	χ^2	p-value
Hurtful to Self	Males	59.3	7.4	7.0	10.7	10.8	4.8		
	Females	61.7	6.8	6.6	9.0	11.7	4.2		
								8.88	0.1130
Hurtful to Others	Males	53.0	12.6	10.2	11.9	10.4	1.9		
	Females	61.8	11.8	9.1	9.6	6.7	0.9		
								60.06	<.0001
Destructive to Property	Males	58.0	11.2	10.1	11.6	7.9	1.2		
	Females	71.6	8.1	7.2	7.3	5.1	0.7		
								118.1	<.0001
Disruptive	Males	32.1	4.8	8.4	18.8	25.8	10.1		
	Females	33.2	5.0	10.9	19.4	23.5	8.1		
								19.68	0.0014
Unusual or Repetitive Habits	Males	33.9	2.7	4.4	10.2	27.7	21.2		
	Females	39.7	2.2	4.7	10.8	25.9	16.7		
								31.88	<.0001
Socially Offensive	Males	35.0	4.5	8.8	17.7	24.3	9.7		
	Females	42.7	3.4	8.8	15.8	21.8	7.5		
								41.06	<.0001
Withdrawal or Inattentive	Males	33.2	4.4	8.6	17.0	24.5	12.3		
	Females	37.5	4.1	8.1	18.1	22.2	10.0		
								19.69	0.0014
Uncooperative	Males	31.7	5.7	11.4	20.0	23.7	7.5		
	Females	35.5	6.2	11.6	21.1	20.1	5.4		
								25.47	<.0001

65% of the males and 57% of females portrayed these challenging problems. Next 66% of males and 60% of females exhibited unusual or repetitive behaviors. Lastly, 67% of males displayed withdrawal or inattentive behaviors, while 62% of females did the same. Uncooperative behaviors occurred in males approximately 68% of the time compared to females at 64%.

The chi-square test verified statistical significance for males for all categories of problem behaviors, except for behaviors considered hurtful to self (see Table 3). The most significant differences for gender included greater frequencies of behaviors that were destructive to property for males when compared to females, followed by hurtful to others, and then socially offensive behaviors. Challenging behaviors somewhat significant for gender included (a) unusual or repetitive behaviors, (b) withdrawal or inattentiveness, and (c) uncooperative behaviors. The chi-square showed significance for behaviors that are disruptive and withdrawn or inattentive, for males; however, the difference is less for significant for gender.

Research Question 4

How does the mean level of severity differ from problem to problem, among male and female children with disabilities?

The three-way cross-tabulation shown in Table 4, depicts how the respondents rated the degree of severity for each of the eight problem behavior types regarding their child with TBI, MR, or autism. The behaviors that had the greatest number of responses for the “not serious” category for males were hurtful to self (64%), and destruction of property (75%) for females. Behaviors most often assessed as “slightly serious” for males included unusual or repetitive habits (21%), and disruptive behaviors for females (21%).

Table 4

Percentages for the Distribution of the Degrees of Severity by Gender (N = 5,846)

Type of Problem Behavior	Gender	Degrees of Severity Not Serious	Slightly Serious	Moderately Serious	Very Serious	Extremely Serious
Hurtful to Self	Males	64.4	12.9	12.0	6.2	4.5
	Females	67.2	12.4	11.6	5.5	3.4
Hurtful to Others	Males	57.1	11.9	14.2	10.1	6.7
	Females	66.8	11.9	11.9	6.2	3.3
Destructive to Property	Males	61.7	12.3	14.0	8.3	3.8
	Females	74.8	9.2	9.6	4.7	1.6
Disruptive Behavior	Males	37.7	18.9	24.8	13.7	5.0
	Females	40.2	20.9	24.7	11.0	3.3
Unusual or Repetitive Habits	Males	44.7	20.6	19.6	10.0	5.1
	Females	50.5	20.7	17.4	8.0	3.5
Socially Offensive Behavior	Males	39.4	17.7	21.3	13.9	7.7
	Females	47.6	17.9	19.8	10.3	4.3
Withdrawal or Inattentiveness	Males	39.5	17.9	24.2	12.9	5.5
	Females	44.0	17.0	24.0	11.3	3.8
Uncooperative Behavior	Males	36.4	16.8	24.2	14.7	7.8
	Females	41.4	18.3	23.6	11.9	4.8

Disruptive behaviors had the highest responses for both males and females (25%) that were rated as “moderately serious.”

Uncooperative behaviors had the greatest number of responses considered “very serious” for males (15%) and females (12%) with autism, TBI, and MR, as shown in Table 4. However, at least 10% of the males had the following additional behaviors rated as “very serious” (a) socially offensive (14%), (b) disruptive behaviors (14%), (c) withdrawal or inattentiveness (13%), (d) hurtful to others (10%), and (e) unusual or repetitive habits (10%). For females, at least 10% had the following behaviors that were seen as “very serious” in severity (a) withdrawn or inattentiveness (11%), (b) disruptive behaviors (10%), and (c) socially offensive behaviors (10%). The behaviors with the greatest responses for “extremely serious” included uncooperative behaviors for males (8%), and for females (5%). Socially offensive behaviors were almost as frequent for both males (8%), and females (4%).

Inferential statistics answered this research question. Figure 3 shows the mean difference in severity ratings and confidence intervals for each problem behavior. The y-axis is the mean difference in severity ratings, males minus females. The x-axis includes the types of problem behaviors. The dot represents the mean difference and the line is the confidence interval about the mean, or the expected range of values for an increase in a problem for males. Zero indicates no difference or gender effect. The F test was 21.27, which supports the conclusion that gender is predictive of the response ratings.

Three groups of means were examined. The first group included greatest difference between males and females. Figure 3 shows that males with autism, TBI, or

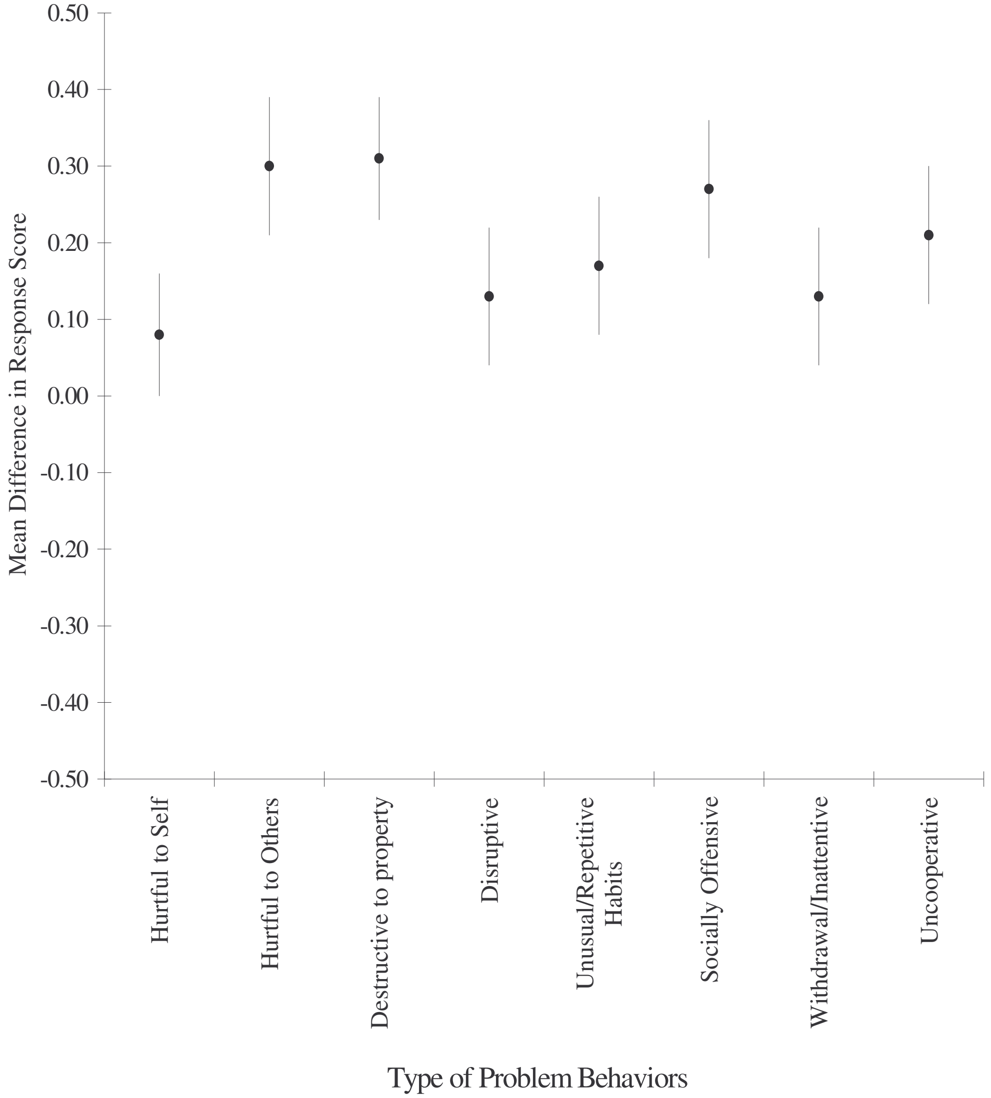

Figure 3. Confidence intervals for the mean difference in gender response for severity of problem behaviors.

MR had higher severity ratings for (a) destruction to property, (b) hurtful to others, and (c) socially offensive behaviors. The second group of behaviors that was somewhat less severe when compared to females included (a) uncooperative, (b) unusual and repetitive habits, (c) disruptive, and (d) withdrawal or inattentiveness. The last group of means of showed no gender effect for the severity and included the behaviors that were hurtful to self. Males tended to have more severe, as well as frequent problem behaviors. The behaviors that were more frequent for males were also more severe. Although the mean levels showed a significant difference for gender, some of the differences may have been due to the large sample size.

CHAPTER 5

DISCUSSION

Although the literature reports the kinds of challenging behaviors that exist for persons with autism, TBI, and MR, this study extends the literature by reporting the frequencies and severities of problem behaviors that children with disabilities exhibit whose legal guardians have applied for family support services through the Utah DSPD. The results of this study show that for each type of problem behavior, similarities exist in the frequency and degree of severity. These findings contribute to prior research by providing statistical evidence for the seriousness of the eight problem behaviors among individuals with autism, TBI, and MR. Further findings show gender differences in the frequencies and severities for males and females according to the eight categories of problem behavior on the ICAP.

Therefore, from the previous literature and the results of this study, it is hypothesized that the frequency and severity of various types of problem behaviors likely increase the stress levels for family members, teachers, and others as they interact with a person with a disability. In addition, the individual who demonstrated the problem behaviors may experience some internal stress related to the challenging behaviors. Accordingly, it is proposed that although not extinguished, if problem behaviors are lessened, stress factors for the individual, family members, and other care providers will likewise be lessened.

Ranges of Frequencies

To understand the implications of this research, and how it relates to families, policymakers, interested lobbyists, and professionals who support individuals with disabilities, it is important to recall the interpretation for the ranges of frequency and degrees of severity on the ICAP. The frequencies of problem behaviors are specifically defined and rated as 1 (*never*), 2 (*less than once a month*), 3 (*one to three times a month*), 4 (*one to six times a week*), 5 (*one to ten times a day*), and 6 (*one or more times an hour*).

The frequencies from the Inventory for Client and Agency Planning simply categorize how often the eight different problem behaviors that persons with disabilities demonstrate. To understand these individuals, one should consider the following questions about their own lives. Do we not all have in our own life some occurrences of one or more of the eight problem behaviors? Does one make choices that injure one's own body? Does one cause physical pain in another individual? Does one deliberately destroy something? Does one interrupt other people when they are speaking? Has one ever "zoned out" or unconsciously done the same thing repeatedly?

Additional questions to consider follow. Has one's conduct ever been offensive to someone else? Has one ever desired to escape a task by calling in sick to work? Has one ever refused to do something an authority figure has requested? The author believes that we all have demonstrated such behaviors in our lives and that problem behaviors are avenues to learning and progressing. However, to determine "how bad" or how severe a problem behavior is, one must measure the severity of that behavior.

Degrees of Severity

To understand how problematic a particular behavior is, it is important to understand the definitions of the varying degrees of severity or seriousness. The web provides access to the "Guidelines for completing the ICAP/SIB-R Problem Behavior Scale" (2001). This form defines the ICAP severity scale. Each definition is followed by a case study example:

1. Not serious, not a problem. This means that not everyone would consider it a problem. Although these behaviors are rated as "not serious," they might still be problematic because the behaviors are odd and annoying. For example, one talking to oneself in public it may be a problem to some people and in some places, like during the opening show of a long awaited movie.

2. Slightly serious, a mild problem. This seriousness of behaviors means that they are troublesome, embarrassing, and worrisome. These behaviors are problems, although in not all environments, and require interventions through management and structured environments.

For example, the author's daughter with autism likes to wade in the nearby canal. She lies on the ground and slides her thin body under a place in the fence where weathering has created a gap. Now that she is on the bank next to the canal, she proceeds to strip her clothes off, jump into the water, and laugh and play. A scenario that would not be a problem is bath time when this child strips her clothes off and jumps into the water, and laughs and plays. However, it is a problem in the previous scenario and requires interventions to prevent its occurrence. Therefore, behaviors that are slightly serious in severity likely require management beyond the child with no disabilities.

3. Moderately serious, a moderate problem. This means that the behaviors are unacceptable, and intolerable. These behaviors are problems in all environments, and require specific interventions to control and stop. Further, these behaviors limit activities for family members, or caregivers.

For instance, the author's daughter tantrums for different reasons in the form of (a) screaming, (b) head banging, (c) limbs flailing, and (d) body slamming all around. If not controlled, she will seek for the nearest objects and destroy them by tearing the items, or knocking them over, beating or breaking them apart. These episodes of behavior arise unexpectedly and consequently limit not only this child with autism, but also other family members' activities and interactions.

4. Very serious, a severe problem. This means that the problem is repulsive and upsetting. It is the number one behavior addressed on a written plan of action. The reduction of this behavior occurs with constant supervision and very structured environments. This behavior is very difficult or perhaps impossible to control by one person. Because of this behavior's severity, activities for the individual and caregiver are limited if the environment cannot be structured in specific ways.

For example, before and during toilet training, the author's daughter demonstrated very serious behaviors in all bathrooms. She required a person to be present and a structured system to manage her behaviors. The young girl would go into a bathroom and clog the toilet in various creative ways. For unknown reasons she would throw entire rolls of toilet paper into the lavatory and flush. After realizing that the rolls would not fit down the toilet, she would pull the rolls out of the bowl, break them apart, and then re-flush the toilet.

One day she discovered that the toilet paper was no longer available, and searched for something new to use, she found the paper towels. She invented a new approach when the paper towels were no longer accessible. This time she found little toys to put into the toilets. She always had toys accessible. This behavior became her number one problem because she needed to use the restroom more than once a day and at different locations throughout the day. If unsupervised the consequences of her behavior included expensive repairs for her parents.

5. Extremely serious, a critical problem. This is a behavior that could be life threatening. It necessitates a record of every occurrence, and occurs very frequently. Further, the consequences of this behavior are difficult to minimize or may result in death.

For example, after the author's daughter learned to open the front door of her home, she would leave the house alone and run. One day she was nude playing in the canal, another day she was on the other side of the street playing at a nearby park alone. This behavior of leaving the house unaccompanied became a critical problem for various reasons. She did not have fear. She did not know how to look both ways to cross the street. Further, she did not understand what could cause her serious harm or death.

The results were that she needed constant supervision and immediate actions to prevent the possibility of escaping anywhere by herself. Owing to experiences that the little girl may think of different ways to leave on her own, and due to the seriousness of this behavior, actions took place to lessen the possibility of her leaving without supervision. Nevertheless, this is still a problem and a cause of concern for her family, and caregivers.

In summary, behaviors that are not serious may be problems for some individuals, and not others. Slightly serious behaviors require education above, and beyond typical education and training. Behaviors that are moderately serious to extremely serious are unacceptable in all environments and very taxing to the parents and caregivers of individuals with disabilities. These behaviors require intensive interventions implemented specifically, such as written behavior plan procedures to follow during episodes of the behaviors.

Hurtful to Self

Frequency and severity. This problem behavior includes biting, hitting, picking nails or skin, head banging, pulling hair out, and other forms of physical abuse by the child with disabilities to self. From the dataset, 33% of children with disabilities exhibited this type of problem behaviors at least 1-3 times per month and 16% demonstrated it daily. According to the results of the study, 35%, or 2,000 individuals displayed slightly serious to extremely serious behaviors that were hurtful to self.

Gender. There were no significant gender differences in the frequency and severity of behaviors categorized as hurtful to self for male and female individuals with MR, TBI, and autism. For the frequency categories of (a) 1-6 times per week, (b) 1-10 times per day, and (c) 1 or more times per hour, males that were hurtful to self included 26% of the individuals, and females 25%. Slightly through extremely serious severities for gender were 35% for males and 34% for females.

Consequences for the individuals and families. Although the majority of individuals did not show behaviors that were hurtful to self, such behaviors can be life threatening for the child who experiences them and for the family members if they are frequent or extremely severe.

Previous research supported many reasons for the display of these behaviors. Problem behaviors associated with autism, TBI, and MR, had the function of obtaining a desired outcome. The behavior may have taken place because of (a) a medical condition, (b) the need for acknowledgement or attention, (c) to escape some event, and/or (d) for sensory stimulation (Buschbacher & Fox, 2003; Grandin, 2002; Snell & Brown, 2000). Further, self-injurious behaviors like head banging, and biting extremities (Liwag, 1989) may be the means that a child with disabilities used to communicate wants, frustrations, or needs (Dyches et al., 2004).

The seriousness of these behaviors demanded at least interventions to prevent occurrences and higher severities. Demonstration of this behavior indicated that the stress level for the individual and family members was likely to be great. According to Hughes (1999), parents and caregivers experienced higher levels of stress when they learned that their child had a disability and as they daily managed the child's needs and behaviors.

Additionally, Gibbs (1993) reported that many families were concerned with the outcome of behaviors that were hurtful to self on the siblings. Other researchers reported that another stressor for families were the poor social skills and poor communication skills that the child demonstrated, and that resulted in dysfunctional social relationships with others (Liwag, 1989; Randall & Parker, 1999). Furthermore, children that were hurtful to self alienated themselves from ideal role models that further hindered their acquisition of positive social skills and interactions.

Hurtful to Others

Frequency and severity. This behavior included aggressiveness towards others in the form of hitting, kicking, biting, and any other inappropriate physical contact that could injure another person, such as striking with or without objects or extremities. From the dataset, 31% of the individuals were hurtful to others at least 1-3 times per month and about 590 were hurtful to others daily. Moderate to critical seriousness of these kinds of behaviors occurred for 26% or about 1,400 of the individuals with autism, TBI, and MR.

Gender. For both the frequency and severity of problem behaviors gender is significant. About ten percent more males demonstrated this behavior for frequency and severity than did females. In general, many differences exist among males and females. Thompson, et al. (2003) report many variations in behaviors associated with gender. For instance, males tend to be more aggressive or externalizing in their behaviors, in the form of hurtful to others, whereas females have higher rates of internalizing problems such as anxiety and depression, mood swing and eating disorders.

Consequences for the individuals and families. Behaviors that are hurtful to others are likely to cause negative feelings, interactions, and frustrations among family members and the injured parties. If this behavior is also severe, it may probably contribute to high stress levels among individual family members. Such degrees of severity mean that behaviors that are hurtful to others are problems in all environments ("Guidelines for Completing the ICAP/SIB-R Problem Behavior Scale," 2001), and require behavioral interventions or restraints. In other words, the consequences that result from such behavioral actions could be fatal, and detrimental to the individuals involved. The more intense the behaviors, the more distressed and unskilled families feel to cope with, and to decrease such behaviors; consequently, the stress levels do not lessen (Wallander & Pitt, 1990).

Destructive to Property

Frequency and severity. These types of problem behaviors involve destroying any items or articles that belong to the individuals with disabilities and others. Sometimes it looks like tearing or cutting, burning or marking, and scratching or smashing objects. In the sample, 64% of the individuals with disabilities never demonstrated these behaviors, and a much smaller 8%, less than 500 people, engaged in destructive behaviors daily. The degree of severity influenced how acute these problem behaviors were for the families with members that were destructive to property. This study indicated that 21% or more than 1,000 of the individuals demonstrated this behavior with moderate to critical seriousness, and thus needed immediate interventions to decrease its occurrence and severity in the future.

Gender. Males showed the highest percentage of both frequency and severity for this kind of behavior from the dataset. For males, 42% of the sample exhibited behaviors that were destructive to property at least 1- 6 times per week or more, and 38% had severities of slightly through critically serious. For females, 28% of the sample exhibited these behaviors at least 1- 6 times per week or more, and 25% had severities of slightly up to critically serious. Schwartz et al. (2002) found gender differences among males and females with TBI. Higher rates of such behaviors occurred among males than females. They also reported that most of these problems emerged soon after the injury, and then became persistent.

Consequences for the individuals and families. Such frequency and severity of destruction to property contributes to the family's financial stress and pressure, if the child destroys expensive or irreplaceable items, such as a TV, stereo system, DVD player, wedding dress, or pictures and books. Herman and Thompson (1995) reported that stressors affecting couples related to the child with disabilities included the inadequate financial resources to counteract the consequences of their child's behaviors. This was a cause for stress between couples that contributed to marital tension, and depression for some members of the couple (Bristol et al., 1984).

Disruptive Behaviors

Frequency and severity. Behaviors including clinging, teasing, complaining, arguing, crying without reason, interrupting, and/or yelling are classified as disruptive behaviors. These types of behaviors had higher frequencies than most of the other problem behaviors. In the study, 53% of children with disabilities displayed some form of disruptive behavior at least 1-6 times per week and 34% did so daily.

For severity, the data analysis showed that disruptive behaviors were the second highest. Sixty-one percent of the individuals with disabilities exhibited disruptive behaviors that were considered slightly through critically serious. Once again, constant supervision and interventions were needed, and the continual demand of time and energy resulted in the appearance of stress factors (Floyd & Gallagher, 1997; Turnbull et al., 1986).

Gender. The differences for the frequency and severity of disruptive behaviors found between males and females were minor, although males were slightly higher for both. From the sample, 51% females were disruptive (a) 1-6 times per week, (b) 1-10 times per day, and (c) 1 or more times per hour, whereas 56% males were rated disruptive for these categories.

Disruptive behaviors that are rated as slightly serious by caregivers are troublesome and embarrassing for family members. From this sample of individuals with autism, TBI, and MR, more than half of the males (62%) and females (60%) displayed disruptive behaviors from slightly serious to extremely serious. Although statistical gender differences were shown in the severities for disruptive behaviors, the variation may not be practical in terms of the day-to-day interactions between the child with disabilities and other individuals.

Consequences for the individuals and families. Higher frequencies and severities of problem behaviors that were disruptive likely contribute to daily stress. If family members needed to go out into the community with their child with a disability, and the child exhibited such behaviors, then the stress levels likely increased. For example, when a child was disruptive in public, such behaviors ignited the stress levels of family members because of the feelings of isolation (Powers, 1993) and concern about being stigmatized by others as a having a child with disabilities (Cheng & Tang, 1995; Orr et al., 1993). It is probable that the more frequent and more severe the disruptive behaviors, than the more stress.

Unusual or Repetitive Habits

Frequency and severity. These behaviors included self-stimulation in the form of rocking, talking to self, grinding teeth, eating too much or too little, sucking on hands and objects, and staring into space. In the Utah DSPD dataset, 57% of individuals with disabilities exhibited these types of behavior at least 1-6 times per week, and 45% of the sample demonstrated such behaviors daily. This is consistent with past research concerning the types of problem behaviors seen for these individuals. However, 53% of the individuals with disabilities exhibited unusual or repetitive habits that were considered slightly up through critically seriousness in nature.

Gender. The frequency of unusual or repetitive habits for males and females differed. Fifty-nine percent of the males with disabilities had occurrences that were (a) 1-6 times per week, (b) 1-10 times per day, and (c) 1 or more times per hour, whereas 53% of the females did for the same categories. For severity, 55% of the males had slightly up to extremely seriousness in behaviors that were repetitive and unusual. For females, 49% demonstrated slight to extreme severity. These results for severity are similar to, yet somewhat greater than disruptive and withdrawal or inattentive behaviors.

Consequences for the individuals and families. The stress among family members is likely increased if the child with disability demonstrated unusual or repetitive habits in public (Cheng & Tang, 1995; Orr et al., 1993).

Socially Offensive Behaviors

Frequency and severity. Included in these problem behaviors were the following atypical and crude, socially offensive behaviors: exposing oneself, expelling gas, touching genitals, and relieving waste in inappropriate places. Not so unusual were behaviors such as swearing, standing too close to others, talking nonsense, picking ones nose, and talking too loudly. Fifty-seven percent of individuals with autism, TBI and MR displayed these forms of behavior (a) 1-6 times per week, (b) 1-10 times per day, and (c) 1 or more times per hour.

Severity factors into socially offensive behaviors for the following degrees of severity: (a) slightly serious (b) moderately serious, (c) very serious, and (d) critically serious. The USPD dataset illustrated that 57% of children with disabilities had slightly through critically severe episodes of these kinds of problem behavior. Such frequencies and severities can be very difficult to manage and change.

Gender. This study found that gender is significant for males with socially offensive behaviors when compared to females. Males exhibited these behaviors much more frequency and with greater severity. Specifically, 52% of the males with autism, TBI, and MR problem behaviors were considered socially offensive, whereas 45% of the females' behaviors were so at least 1-6 times per week.

For severity, these behaviors ranked third for gender differences. Particularly, 60% of the males, and 52% of the females had slightly to extremely seriousness for these behaviors. Thompson et al. (2003) reported that males demonstrated behaviors that showed poor social skills and interaction. Accordingly, males' social behaviors were more offensive.

Consequences for the individuals and families. Demonstration of socially offensive behaviors are highly probable of producing stress among families if the occurrence are in public or other substantial gatherings because such behaviors are unacceptable in most environments and require specialized interventions ("Guidelines for Completing the ICAP/SIB-R Problem Behavior Scale," 2001). As a result, the feelings of isolation and social stigma may arise among family members with severe occurrences of such behaviors. Parents and caregivers of children with disabilities will need to be aware of what interventions may reduce such behaviors and know how to utilize such interventions (Bandura, 1989).

Withdrawal or Inattentive Behaviors

Frequency and severity. These intrinsic behaviors of withdrawal or inattentiveness are seen in the following forms: expressing unusual fears, showing little interest in activities, sleeping too much, talking negatively about ones self, and keeping away from other people. The daily occurrences of inattentive behaviors were 35% for children with autism, TBI, and MR, and ten percent demonstrated these behaviors 1-6 times per week. This study found that 59% of these problems were slightly to extremely serious problems such degrees of severities were high, than the more problem and cause of stress for family members.

Gender. The occurrences of these kinds of internalizing behaviors that were at least weekly varied somewhat with about half of the males (54%) and females (50%). The gender differences for the severity of withdrawal or inattentive behaviors were comparative to disruptive behaviors and unusual or repetitive habits. Specifically, the behaviors that were slightly to critically severe included 60% of the males, and 56% of the females.

Importantly, the differences in severities for males and females who had internalizing behaviors, including withdrawn or inattentiveness, were similar to the results in severity for disruptive or externalizing behaviors. Although gender differences were shown in the severities for these withdrawal or inattentive behaviors, the variation may not be practical in terms of the day-to-day interactions between the child with disabilities and the others.

Consequences for the individuals and families. Behaviors that were withdrawn and inattentive added to the feelings of isolation and social stigmas associated with having a child with disabilities (Cheng & Tang, 1995; Orr et al., 1993; Powers, 1993). A frequent question that parents have asked themselves is, "how will my child develop socially, if he or she prefers to spend the majority of his or her time in isolation?" Unless, caregivers have had access to some kind of support services they may continue to wonder (Marshall & Mirenda, 2002; King-Peery, 2005).

Uncooperative Behaviors

Frequency and severity. These behaviors are demonstrated as refusing to obey, or follow rules, refusing to attend or arriving late to school or work, being defiant, cheating, stealing, and breaking the law in other ways. Uncooperative behaviors are the most frequent and the most severe type of problem behaviors demonstrated by individuals with disabilities included in the Utah DSPD dataset. For individuals with autism, TBI, and MR, who were uncooperative at least 1-3 times per month, included 71%. About half (49%) of these individuals were uncooperative at least once a week, and 29% were unmanageable daily. The severities that were considered slight to critical in seriousness included 61% of the population.

Gender. Results from the Utah DSPD dataset showed that the males had higher frequencies and degrees of severity for uncooperative behaviors, than females. Additionally, these results were similar to the behaviors on the ICAP (a) unusual or repetitive, (b) withdrawn or inattentive, and (c) disruptive. For at least weekly occurrences 51% of the males, and 46% of the females demonstrated uncooperative behaviors. These results for higher frequencies in males than in females were consistent with past research (Lord et al., 1982; Schwartz et al., 2002; Thompson et al., 2003). The severities for uncooperative behaviors that were slightly through extremely serious included 64% of the males, and 59% of the females with disabilities.

Consequences for the individuals and families. Uncooperative behaviors are especially difficult for parents and caregivers to deal with. Furthermore, this study's outcomes for the frequencies and severities of uncooperative behaviors for gender illustrates that gender differences are minimal in practicality considering the parents, siblings, and caregivers that interact with individuals with disabilities who is uncooperative.

Conclusions

The data analyses revealed five types of behavior problems that most often occurred for the entire sample, from the most to least frequent (a) disruptive, (b) uncooperative, (c) unusual or repetitive, (d) withdrawn or inattentive, and (e) socially offensive behaviors. The most to least severe type of problem behaviors for the population included (a) uncooperative, (b) disruptive, (c) withdrawn or inattentive, (d) socially offensive, and (e) unusual or repetitive behaviors.

For gender the categories of problem behaviors that were greatest to least frequent and severe included (a) destructive to property, (b) hurtful to others, and (c) socially offensive behaviors. Living with or providing care for an individual with a disability and the subsequent problem behaviors that are likely to be demonstrated, alone causes stress. Notwithstanding the caregiver has implemented behavioral management plans, just dealing with problem behaviors results in stress for the individual and the caregiver.

Nonetheless, the more severe or troublesome and dangerous the behaviors, the higher the stress factors for family members and probably for the individual.

It is proposed that occurrence and severity of these eight types of problem behaviors affect the family's autonomy, freedom to be involved in the community, and the levels of discord among members, particularly couples. For instance, imagine the tense feelings that would be present among family members if their child or sibling with autism, TBI, or MR experienced seizures at any moment. The severity of such seizures may have induced head banging and resulted in other behaviors that could be critically damaging to the individual, others, or objects. Consequently, the family has decided to keep a bike helmet on their child at all times, because they know that the seriousness of the problem behavior is likely to be pronounced, and because they are unsure when the seizures will occur.

Another example concerns disruptive behavior. Suppose the child is attending public school but constantly disrupts others by not following the teacher's directions in the form of interrupting others, yelling, teasing, or not keeping his or her hands, feet, and other objects to self. Such behaviors are likely demonstrated by the individual because of some desired outcome or some kind of internal stress. Unfortunately, the person with the problem is likely shunned and misunderstood by his or her peers. Further, if the teacher lacks the skill to manage or to help decrease the problem behavior, the social stigma, and isolation of the individual is likely to increase, and this could lead to devastating consequences in the future.

Limitations of Study

This study was limited for different reasons. Foremost, a social worker who is possibly undereducated in disabilities and positive behavior support interviewed parents or legal guardians concerning their child with disabilities. Perhaps the social worker perceived the child's behavior as less frequent and severe than in actuality because the child demonstrated no behaviors during the 30-minute interview. Perhaps the social worker was encouraged to underreport because of the lack of funding.

In regards to parents, perhaps the caregivers over reported the frequency and severity of their child's problem behaviors to get support services or to at least get their child on the waiting list. On the other hand, perhaps the parents underreported if they were struggling with feelings that included the social stigma that goes along with having a child with disabilities, and receiving governmental assistance.

Lastly, because it was unknown if any of the families were receiving assistance for their child in this sample from the government, other family members, friends, or the community, thus, it is uncertain whether those who had no problem behaviors for frequency and severity were those persons. It is probable that there would be a decrease in problem behavior frequencies and severities if the services were employed to change behaviors. However, the likelihood of changes in the frequencies and severities of problem behavior would vary notwithstanding support services, and interventions that were implemented.

Recommendations

1. Families. Parents should seek to be further informed so they can more effectively teach and assist their child with disabilities. Parents should find ways to cope with the changes that will occur, and develop their own self-efficacy to deal with problem behaviors. Adequate coping skills allow parents to deal with the difficult behaviors that occur and helps them to realize that some challenges will be changed and while other problems may never go away (Taylor & Stancin, 2003).

If parents want to initiate and accelerate behavioral changes, it is essential that they know the positive behavioral supports that decrease problem behaviors or increase alternate competing or replacement behaviors. It will be particularly helpful for parents to understand and determine the functions for why their child demonstrates certain behaviors as well. For instance, parents will want to note the settings and times of day or night in which the problem behaviors occur, and the individuals present (Buschbacher & Fox, 2003; Dyches et al., 2004; Grandin, 2002; King-Peery, 2005; Snell & Brown, 2000).

2. Policymakers. The results and hypotheses from this study are helpful and informative to policy makers who decide how much funding family support services receive from the state and federal governments. The author recommends that personnel from DSPD present this data to the state of Utah legislators, so as to help policymakers understand the frequencies and severities of various types of problem behaviors that parents, caregivers, teachers, social workers, respite care providers, and other professionals deal with when interacting with individuals with disabilities. In understanding, the legislators should provide more financial support for families with children who display the greatest frequencies and severities of problem behaviors.

The legislature should also financially support programs such as positive behavior supports by providing funds to school districts, or interested organizations to arrange, implement, and teach ongoing positive behavior supports. In this way, policymakers will contribute to lessoning the frequency and severity of problem behaviors, and to lessening the stress experienced by the individuals with disabilities, the caregivers, and other individuals who associate with the child.

3. Professionals. It is imperative that professionals including social workers, teachers, doctors, and school psychologist know how to use functional behavioral analysis to design and implement behavioral plans that are best utilized to change frequent and severe behaviors. Research supports the implementation of positive behavior supports as an effective tool to decrease problem behaviors (Lewis & Sugai, 1999; Marshall & Mirenda, 2002; Summers, Houlding, & Reizel, 2004; Young & Marchant, 2002).

Lloyd, Forness, and Kavale (1998) conducted meta-analyses of 18 published methods that claimed to alleviate problems in individuals with disabilities. These interventions are helpful for professionals to know so that the best options are presented to the family. These 18 interventions were ranked from the least effective to the most effective. The practices that were not very effective included perceptual training, Feingold diet, modality-based instruction, and psychotropic drugs.

The methods that were effective to assist children with disabilities included small class size, social skill training, psycholinguistic training, peer tutoring, computer-assisted instruction, stimulant drugs and early intervention. The approaches revealed to produce the most benefit incorporated formative evaluation, cognitive-behavior modification, direct instruction, behavior modification or positive behavioral supports, reading comprehension instruction, and mnemonic training.

Furthermore, professionals, including administrators, educators, and school district personnel who have acquired skills and knowledge concerning the frequency and severity of problem behaviors have an ethical obligation to teach families and caregivers coping skills, and research based practices such as peer mediation, communication skills, and positive behavioral supports. In this way, those who daily interact with the child with disabilities will be empowered to assist in decreasing challenging behaviors and increasing positive academic, social, and intellectual behavioral changes in their child.

Future Research

The Utah DSPD dataset contains over 240 variables concerning 7,500 individuals with various categories of disabilities. The following ideas although limited may be helpful to promote future research.

1. The frequency and severity of problem behaviors could be measured for individuals with just TBI, or one of the other 12 diagnostic statuses from the ICAP. Further, problem behaviors could be compared with adaptive behavior levels, age, race, residence location, intellectual functioning, and support services.
2. From this sample of individuals with autism, TBI, and MR, race and the use of current support services could be examined.
3. Gender and the use of support services could be studied.
4. Race, gender, or age and adaptive behaviors might extend the literature.
5. Residency and problem behaviors could be examined for frequency and severity.
6. Residency and support services could be examined.

7. Examination of problem behaviors and residency as it relates to gender, race, and intelligence could be researched and rated.

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