

9-2015

# Parents' Needs After Their Child Receives a Diagnosis of Developmental Disability

Talia Pearl

Sarah Lawrence College, tpearl@gm.sl.c.edu

Follow this and additional works at: [http://digitalcommons.sl.c.edu/child\\_development\\_etd](http://digitalcommons.sl.c.edu/child_development_etd)



Part of the [Child Psychology Commons](#), and the [Social Work Commons](#)

---

## Recommended Citation

Pearl, Talia, "Parents' Needs After Their Child Receives a Diagnosis of Developmental Disability" (2015). *Child Development Theses*. Paper 4.

This Thesis - Open Access is brought to you for free and open access by the Child Development Graduate Program at DigitalCommons@SarahLawrence. It has been accepted for inclusion in Child Development Theses by an authorized administrator of DigitalCommons@SarahLawrence. For more information, please contact [alester@sarahlawrence.edu](mailto:alester@sarahlawrence.edu).

Parents' Needs After Their Child Receives a Diagnosis of  
Developmental Disability

Talia R. Pearl

Submitted in partial completion  
of the Master of Arts Degree in Child Development at  
Sarah Lawrence College  
September 2015

## **ABSTRACT**

In the existing literature, there seems to be a lack of attention focused on the needs of parents of children with developmental disabilities. For this thesis, I analyzed survey data and examined case material to try to identify parents' needs after their child receives a diagnosis of developmental disability. Through my work I identified three major themes: parents' yearning for more information, the degree to which every family's needs are individualized and unique, and the significant degree of psychosocial stressors this population experiences. At the end of the thesis, I provide recommendations for an agency such as the one I interned at during my advanced year of social work placement to help ensure that there are proper services in place to address the needs of this under served population.

## ACKNOWLEDGMENTS

I would like to acknowledge and thank the following people who have supported me, not only during the course of this project, but throughout my Masters degrees. This thesis would not have been possible without the flexibility, guiding feedback, and never ending encouragement from my program director Dr. Barbara Schecter and my thesis advisor Dr. Jan Drucker. I would also like to acknowledge my colleagues in the dual-degree program: Danielle, Molly, and Sasha; the last three years would not have been nearly as fulfilling or as fun without you by my side. Finally, my biggest thank you goes to my family. I am forever indebted to my mom for her endless patience, feedback, editing, guidance, love, and support when it was most required. Mom, Abba, Adin, and Uri -- you have encouraged and believed in me. You have helped me focus on what has been a hugely rewarding and enriching process and experience. Thank you.

This thesis is dedicated to the memory of two angels – two of the most pure, empathetic, caring, loving, funny people.

Thank you for making my life and this world a better place.

I love you, Zeide and Moishe.

**TABLE OF CONTENTS**

Introduction .....	6
Literature Review .....	8
Present Study .....	15
Methodology .....	15
Setting .....	15
Population .....	15
Surveys .....	17
Case Material: Revisit Appointments .....	18
Case Material: Ongoing Individual Psychotherapy .....	19
Results .....	19
Surveys .....	20
Revisit Appointments .....	27
Ongoing Individual Psychotherapy .....	32
Case 1: Molly .....	32
Case 2: Anita .....	37
Discussion of Cases .....	40
Issues for Practice .....	45
Concluding Comments .....	51
References .....	55
Appendix .....	57

## INTRODUCTION

There exists a plethora of research on children with developmental disabilities; however, the majority of this research focuses on the child with the diagnosis and less available research exists on the experiences of the parent of that child<sup>1</sup>. The responsibility for raising a child in the most ideal of circumstances, if there even is such a thing, is difficult and stressful, and even more so raising a child with a developmental disability. Whether the diagnosis is expected or not, a parent hearing that your child has a developmental disability that will most likely affect the rest of his or her life can be extremely overwhelmed and distressed.

The child's wellbeing and chances of success depend on the role of the caretaker. All children, and specifically children with disabilities, need an advocate on their behalf. The likelihood of the child receiving the most appropriate services depends on the success of the person supporting them in getting the services to meet their specific needs; this large responsibility is most often placed upon the parent

Support for the parent is often overlooked. A parent may feel lost and alone in the overwhelmingly large and confusing systems. A parent may not know where to begin to locate the most relevant information or may not entirely understand the diagnosis and thus not know what to be advocating for. Because receiving the diagnosis can often be emotional, the parent may not feel emotionally stable enough to take on the responsibility this process requires.

---

<sup>1</sup> The terms 'parent' and 'caretaker' are used interchangeably throughout this thesis, and for the purposes of this project are intended to mean the same thing.

In this thesis, I intend to identify and explore the categories of need a parent requires after receiving a diagnosis of a developmental disability for their child<sup>2</sup>. With more insight into how to best support the parent, the parent will hopefully be better served and in return be better equipped to advocate for and support their child.

---

<sup>2</sup> In this thesis, all identifying characteristics have been eliminated and all names have been changed.



## LITERATURE REVIEW

Parenting a child with a developmental disability presents unique challenges, among which are the adjustments of parental expectations and hopes for the child and the resolution of feelings associated with the child's diagnosis. A lack of resolution can interfere with a parent's capacity to respond sensitively and appropriately to a child's signals and needs (Feniger-Schaal & Oppenheim, 2013, p.306). Parental resolution is important for the parent's own wellbeing, in addition to the overall development of the child. The impact the assessment and diagnostic procedure has upon parents is a relatively neglected research area. Of the research that does exist, most focuses on parental experiences of actually receiving the diagnosis, as opposed to the parents experiences after the diagnosis has been given (Braidon, Bothwell, & Duffy, 2010, p.379).

Caring for a child with special needs can pose stressors beyond those experienced raising a typically developing child (Smith, Grzywacz, & Grzywacz, 2014, p. 303). According to a cross-sectional analysis, "parents of a child with special needs reported poorer self-rated mental health, greater depressive symptoms, and more restrictions in instrumental activities of daily living" (Smith, et al., 2014, p.303). Some of the stressors impacting the parents may include increased medical expenses, additional time demands, supplementary physical care, and added anxiety about the future (Smith et al., 2014, p.303). Parents raising a child with special needs often also report insufficient supports and feelings of helplessness (Smith et al., 2014, p.304). Research suggests that caring for a child with special needs may have long-term health consequences for the caregiver, including greater physical disability and depressive symptoms across a 10-year period (Smith, et al., 2014, 308).

Recent years have witnessed a significant emphasis placed upon parent involvement, and thus the experience of parents is an especially relevant and important area of continued research (Braiden et al., 2010, p.379). The declining health of the adult caretaker is not only a health issue for the individual, but is also very likely to negatively impact the child's development and wellbeing. As the proportion of children with special needs continues to grow so too will the number of caretakers experiencing steep health declines (Smith et al., 2014, p.308). If the main caretaker's health is compromised, the adult will likely lose the ability to sufficiently address the child's needs, possibly leaving the child without proper care.

In general, parenting stress is likely determined by the degree of severity of a child's behaviors and needs, and the parents' coping strategies. According to Chua Ah Keok's (2012) integrative literature review, having a child with Autism Spectrum Disorder (ASD) has an enormous impact on a parent's psychosocial well being (p.8). Keok (2012) used an integrative review method to collect, analyze, interpret, and present data on parental experience of having a child with ASD. A common theme that emerged in his work is the importance of addressing parents' feelings from the start of the diagnostic process. It is important to address parental needs and stressors so that the most appropriate and effective support can be given to the family throughout. With proper support for the parent throughout the diagnostic process the parent is better able to identify his or her own emotions along the way. By identifying and addressing one's own feelings the parent will be better equipped to redirect the focus back to addressing the child's needs (Keok, 2012, p.9).

Most parents who receive a diagnosis of a serious developmental disability for their child experience some emotional reaction. Feelings may include shock, sadness, despair,

confusion, blame, guilt, frustration, and or relief. It has been argued that the experience of receiving a developmental diagnosis for a child shares similarities to the experience of grief and mourning. It has been compared to a metaphorical loss of the hoped for typically developing child (Feniger-Schaal & Oppenheim, 2013, p.306). Parental resolution involves the readjusting of a parent's expectations for the child based on the reality of the child's diagnosis.

Based on many changing variables the process of becoming more understanding and accepting of a diagnosis is different for each individual and for every family. It is often especially difficult for a parent to accept their child's diagnosis when the child's physical appearance seems comparable to a typically developing peer (Keok, 2012, p.9). Additionally, perhaps because of the permanent nature of the diagnosis, neurological impairment seems to be another category that is particularly challenging for parents to accept (Feniger-Schaal & Oppenheim, 2013, p.311).

Poslawsky, Naber, Daalen, and Engeland (2014) conducted a study that aimed to better understand parents' reactions subsequent to receiving a diagnosis of ASD for their child. For this study the researchers interviewed seventy-seven parents of recently diagnosed children with ASD. The parents' responses were analyzed with specific focus on associations between parental reactions and severity of diagnosis, parental and child characteristics, and pre-diagnostic circumstances. The study found that ASD severity was a significant factor affecting parental reactions (Poslawsky et al., 2014, p.294). Parental mental health showed above average levels of complaints compared to typical population levels. These included high levels of depression and above average levels of somatic symptoms and insufficiency in thinking and acting (Poslawsky et al., 2014, p.299). Parental coping style is an important

moderator of stress. Mobilizing family members and support systems is one of the effective coping strategies parents use to manage daily stressors (Poslawsky et al., 2014, p.301).

Parents who felt greater confidence in their ability to raise their child effectively were found to be better able to adjust and respond to the challenging demands of the experience (Poslawsky et al., 2014, p.294).

Keok (2012) found that parents who are more accepting of their child's diagnosis are also more likely to collaborate with the necessary professionals to address their child's needs and maximize their child's potential (p.9). In support of this idea, Feniger-Schaal & Oppenheim (2013) found that being resolved regarding a child's diagnosis seemed to promote a mother's ability to perceive and respond sensitively to her child's signals during interaction. Mothers who were unresolved had greater difficulty reorienting to the present reality of the diagnosis, and communicating and responding sensitively to their child's needs. The authors speculate that an unresolved mother might be preoccupied with her own feelings, making it more difficult to recognize and respond to her child's presenting needs (p.311).

Research has highlighted that the way in which the diagnosis is delivered to a family may have a significant impact on the levels of distress and anxiety that the family experiences (Braiden et al., 2010, p.382). By communicating the most applicable information in addition to exercising a positive attitude, health care professionals serve an important role in helping family members decrease their fear and anxiety surrounding a child's diagnosis. The health care professional's role should include evaluating the level of parental acceptance, advocating on behalf of the parent and child, and helping the family to navigate through the complexity of the health care system (Keok, 2012, p.18). It should be noted that providing sufficient information to parents is not without problems – a lack of coordination of available

support services results in significant deficits in the information relayed to both professionals and parents (Braiden et al., 2010, p.385).

To reach an accord with parents that is both honest and sufficient, health care professionals must delicately balance realistic information with hope (Abrams & Goodman, 1998, p.88). Parents who receive vague interpretations of their child's diagnosis seem to be left with many unanswered questions, especially when the material presented is particularly difficult to handle, the diagnosis is uncertain, or the language used by the professional is ambiguous. Conversely, when parents receive straightforward information they are better able to move on to addressing issues of prognosis and treatment services (Abrams & Goodman, 1998, p.87). It is found that this category of parents is more equipped to integrate the new diagnostic information into the activities of their lives (Abrams & Goodman, 1998, p.92).

Braiden et al. (2010) conducted a study that aimed to document parents' experiences of the process of receiving a diagnosis of ASD for their child. The study took place in Northern Ireland and included eleven parent participants. Because the study was small and used a self-selected sample, the findings cannot be generalized to the general population. Nonetheless, the data collected can provide valuable insight and serve as a model for future research on this topic. Semi-structured interviews were used for gathering information; the participants' qualitative responses were gathered and analyzed using thematic analysis.

Seven parents noted being informed of their child's diagnosis while simultaneously receiving verbal information related to the condition. Parents expressed that at this stage they felt unable to both listen and process the additional information and feared missing important details. One explanation is that perhaps the emotional response surrounding receiving the

diagnosis may have influenced the parent's capacity to retain information (Braiden, et al., 2010, p.382). Participants of this study indicated that what was most useful to them was receiving written information about the disorder at the time of diagnosis (Braiden et al., 2010, p. 383). Parents noted that while they overall were generally satisfied with the quality of information they received from the professionals, they relied heavily on the Internet and on friends to help them understand the information (Braiden et al., 2010, p.384).

Seven parents reported feeling confident in their understanding of the diagnostic process; however, when further explored it became clear that the degree of understanding varied greatly among the parents (Braiden, et al., 2010, p.384). When there was a multidisciplinary assessment parents seemed to not fully understand the role of each professional. Parents suggested that a flowchart or diagram detailing the multidisciplinary team and the roles within the team would have been very helpful in facilitating understanding (Braiden, et al., 2010, p.385). With hindsight parents seemed better able to understand which and why certain professionals were involved.

The participants generally agreed that they would prefer to be provided with information when the child is initially referred. The parents expressed being more in favor of being given information at an early stage, even if this is based on suspicions rather than certainties. Many parents realized that the professionals did not want to preempt a diagnosis, but all the parents felt that receiving the information early in the diagnostic process would prepare them and enable them to begin to process the information and formulate questions should their child receive a diagnosis (Braiden, et al., 2010, p.383).

Parents who report suspicions of their child's developmental difficulties early on are more likely to receive an early diagnosis and more adequately cope with the prognosis

(Poslawsky et al., 2014, p.295). Early diagnosis and intervention enables parents to avail themselves of support, which in turns helps parents develop more effective coping and management techniques. Early diagnosis and subsequent early intervention are also highly associated with better long-term outcomes for the child (Braiden et al., 2010, p.378).

When asked about the support a family receives after a formal diagnosis is made, the participants' responses varied. About half the participants reported a void between receiving the diagnosis and subsequently receiving support services with some parents reporting a lapse of a few months (Braiden et al., 2010, p.385). Three parents reported having received a diagnosis some time ago but not receiving any support or being made aware of any services available to them (p.385). Other parents expressed positive feelings towards receiving information about summer programs, parent evenings, support groups, seminars, and respite workers (p.385).

It can be difficult to distinguish whether a parent's emotional response to receiving the diagnosis of a developmental disability for their child is related to the process of the diagnosis or the diagnosis itself. Most likely the parent's reaction is the result of a combination of many factors. How and when information is provided, and the support provided to the family along the way are factors that may play a role in the family's experience of the diagnostic process. While it can be argued that dissatisfaction with the diagnostic process is not inevitable, receiving a diagnosis of developmental disability for a child is something that is never going to be simple (Braiden et al., 2010, p.386).

## **PRESENT STUDY**

I carried out the present study in order to further explore observations from my previous experience working with this population and issues raised by the literature. The study includes data collected from surveys in addition to case material from therapeutic sessions with parents.

## **METHODOLOGY**

For this study I used multiple forms of data that were available through the agency I worked at this year; I did not offer any new services that did not already exist.

### **Setting**

The data for this project were gathered at the internship site of my advanced year social work field placement -- a large private outpatient diagnostic-treatment center for individuals with developmental disabilities. The clinic is an affiliate of a large teaching hospital and is located in a low-income neighborhood in a borough of New York City. The center consists of an interdisciplinary team of social workers, psychologists, psychiatrists, developmental-behavioral pediatricians, occupational therapists, physical therapists, speech and language pathologists, audiologists, geneticists, and nutritionists.

### **Population**

Individuals are referred to the clinic with a range of disabilities, including physical, developmental, language, and learning disabilities. The agency serves individuals ranging from infancy through adulthood. Based on the clinic's policy to accept Medicaid and the population residing in the surrounding neighborhood, the general population of the center tends to be non-white one-parent families with low socio-economic status and a history of many psychosocial stressors. The most frequent diagnoses include: Intellectual Disabilities,



Communication Disorders, ASD, Attention-Deficit/Hyperactivity Disorder (ADHD), Learning Disorder, Anxiety, and Depression.

For my research I used multiple forms of data. All of my research studied the general population described above though based on the different forms of data I used the specific characteristics of the population varied. There was no classifying information collected about the survey respondents regarding age, gender, socio-economic status, relationship to child, and so forth. What is known is that all the respondents were parents or caregivers of a patient at the agency.

For the 2014 surveys, there were 37 respondents for the pre-survey and 34 respondents for the post-survey. For the 2015 surveys, there were 23 respondents for the pre-survey and 26 respondents for the post-survey. For the 2014 pre-survey, 35/37 of the respondents indicated having a child who had already undergone evaluations and received a diagnosis. This information was not collected on the 2015 pre-survey.

For the data collected through the one-time sessions following the parent conference, I received nine total referrals. Of the referrals, 8/9 were referrals for a male patient and 1/9 was a referral for a female patient. At the time of scheduling the age range for the patients was between 7.2-years-old and 11.9-years-old; all parents who wanted an appointment were seen within two weeks from the date of scheduling. The patients ranged from having two diagnoses to five diagnoses, with a few patients having additional possible diagnostic rule outs. In all cases the attendee of the session was the direct caretaker of the patient either a biological, foster, or adoptive parent, and the main informant was always a female. For all but one of the cases, the female caretaker participated in-person. In one case the mother

participated by telephone and was the main informant while the father attended the session in-person.

The case material I used from ongoing weekly individual psychotherapy involved two mothers of sons with developmental disabilities. One mother identified as Puerto-Rican and the other mother identified as Italian-American. The women ranged in age from 30-35 and identified as heterosexual. One of the women had been married to her son's father for many years and was in the process of divorcing, and the other woman had been in a long-term relationship with her son's father and was now separated. Both women had significant psychosocial stressors in addition to caring for the special needs child and were referred for individual therapy following the psychosocial evaluation.

### **Surveys**

For the first part of my data collection I analyzed surveys that were created by another professional for her own research purposes. The material included pre and post surveys from a three-year period (2013-2015) measuring program success of a one-day parent workshop. The first year's survey (2013) was a pilot study; the surveys from the other two years (2014-2015) were not identical in form, but were similar in content. Because the pilot study was considerably different in form and content from the other surveys, I decided to exclude it from my data collection.

A copy of all the surveys was offered to participants in both English and Spanish; however, only the responses from the 2015 surveys were reverse translated back into English. Because of my language limitations, for my research purposes I only used the survey responses that were in English. I analyzed survey data by individual responses and by questions across all responders.

### **Case Material: Revisit Appointments**

In addition to data collected from the surveys, I also used case material from individual one-time sessions I conducted with adult caretakers. One of the roles of social workers at the agency is to meet with parents who have been referred for a revisit appointment. This appointment is scheduled to give the parent a chance to speak with a social worker about any issues arising for the child or the family so that the social worker can connect the patient and family to appropriate services. When I arrived at the agency the protocol was to have this type of appointment scheduled as issues arise for the family.

As part of the present study, I wanted to give parents the option of having a revisit appointment as a preemptive opportunity following the news of receiving the diagnosis as opposed to having the appointment scheduled as a reactive response to an incident that has already occurred. Thus, I created a form for the case manager to fill out following every parent conference conducted in English in which the professional, or the parent, indicated wanting to make a referral for a revisit appointment with a social worker<sup>3</sup>. As stated earlier, because of my language limitations, for my research purposes I only accepted forms from appointments that were conducted in English.

For the parents who were interested in a revisit appointment, I called the caretaker and scheduled a revisit for three to four weeks after the original meeting. In this meeting I discussed with the parent any progress or changes that have occurred since the parent conference and explored what the parent's greatest needs are at the moment. Prior to my meeting with the parent, I reviewed the child's chart for information regarding the child's developmental, family, school, and social history. Following my session with the parent I

---

<sup>3</sup> Appendix A

wrote up a summary note of what was discussed. Depending on the individual situation the opportunity for another revisit appointment was arranged and scheduled. If a follow up appointment was not necessary at the time, the parent was reminded that should anything arise and they would like a revisit appointment to be scheduled they should contact the clinician at any time. I analyzed case material by individual situation as well as themes across the group.

### **Case Material: Ongoing Individual Psychotherapy**

A third source of data I used for the present study is case material from ongoing weekly individual psychotherapy with two mothers of sons with developmental disabilities. I met consistently with one mother over 6 months, and the other mother over 4 months. In both cases therapy was prematurely terminated as a result of the therapist having to end the therapeutic relationship because of external factors related to the ending of the internship year, rather than the accomplishment of goals.

Following each therapeutic session I wrote up a session note summarizing the appointment. For some of the sessions I wrote a process recording with excerpts of verbatim dialogue from the conversation. I analyzed case material by individual session and progress of work and themes across individuals.

## **RESULTS**

In this section I will first address individually the results of the surveys, revisit appointments, and ongoing individual psychotherapy, and then I will discuss the collected data and material and how they relate to each other.

## Surveys<sup>4</sup>

Although the specific findings of the surveys varied, there was significant overlap among some of the common themes across the data. Both pre-surveys asked respondents to check off from a list of topics the topics that they are most interested in learning more about in relation to their child's diagnoses. Below are the results (highlighted categories signify a response of 55% or more, indicating a majority):

*2014 pre-survey, topics of interest check list:*

General diagnoses	43.2%
Education	62.2%
Community resources	62.2%
Recreational activities	62.2%
Family difficulties and stressors	54.1%
Speech and language/ communication	43.2%
Behavior management	70.3%
At home interventions	35.1%
Self care skills	43.2%

*2015 pre-survey, topics of interest check list:*

Education across the age span	78.26%
Community resources	65.22%
Accessing the playground and other places in the community	26.09%
Family difficulties and stressors/ coping	60.87%
Medication	39.13%
Feeding (picky eaters)	30.43%
Adapting to high school	34.78%
Sex education	52.17%
Sensory processing	34.78%
Speech and language/communication	69.57%
Behavior management	73.91%
Self-care skills (toileting, dressing, bathing)	26.09%
Sleep	26.09%
General information on diagnoses	80% *not every copy had this listed

---

<sup>4</sup> Appendix B

As indicated in the above charts, “education”, “community resources”, and “behavior management” remained among the most desired to learn more about topics for parents across years. Another topic that remained relatively similar is “family difficulties and stressors” though it was not signified as a majority response for 2014 because it fell under the majority percentage by less than one percent (54.1%). In 2014 “recreational activities” also received a majority response from parents; however, in 2015 the topic was listed using different language – “assessing the playground and other places in the community” – and did not receive a significant response (26.09%). “Speech and language/communication” was the third most popular topic of interest in 2015, and in the bottom half of parents’ interests in 2014. Because “general information on diagnoses” was not listed on all the surveys for 2015 the percentages listed could not be interpreted as meaningful data.

Three out of thirty seven respondents of the 2014 pre-survey checked all 9 categories as being relevant and important. Five respondents’ marked 8 out of 9 categories, twenty respondents’ marked 5 or more categories, and 2 respondents did not check any of the categories listed. On the 2015 pre-survey there was an added instruction reading, “please only check 4-5 topics”. Even with this instruction, ten out of twenty three respondents marked 6 or more categories as being relevant and important.

Both post-surveys asked respondents to rate on a scale of 1-5, strongly disagree to strongly agree, their satisfaction with the one-day parent workshop. Below are the results (highlighted categories signify a response of 3.5 or more, indicating a majority):

*2014 post-survey, ratings (1 strongly disagree- 5 strongly agree):*

The workshop was helpful in understanding your child's specific needs	4.63
The information was easy to understand	4.83
I will be able to use this new information at home	4.70
Overall this workshop was a positive experience	4.93
I feel like this workshop provided me with relevant information regarding my child's diagnosis and treatment	4.43
I feel more comfortable with managing my child's individual needs after this workshop	4.50

*2015 post-survey, ratings (1 strongly disagree- 5 strongly agree):*

The workshop was helpful in understanding your child's specific needs	4.56
The information was easy to understand	4.76
I will be able to use this new information at home	4.64
Overall this workshop was a positive experience	4.68
I feel like this workshop provided me with relevant information regarding my child's diagnosis and treatment	4.44
I feel more comfortable with managing my child's individual needs after this workshop	4.44

Across both years all categories measuring satisfaction and helpfulness of program received a score of between 4 (somewhat agree) and 5 (strongly agree). In both 2014 and 2015 no respondent marked any category with a score of less than 3 (neutral). In 2014 thirteen out of twenty-four (54.2%) respondents marked all 5's and in 2015 eleven out of twenty-six (42.3%) respondents marked all 5's. These findings indicate that the large majority of respondents found the workshops to be highly productive and valuable across both years. To

reiterate this point, when asked “Would you recommend this workshop to other *agency* parents?” every respondent on the 2014 post-survey marked “yes” and on the 2015 post-survey, aside from two respondents (one who marked maybe and one who left the question blank), everyone else responded “yes”.

The 2014 pre-survey asked respondents to answer the question, “Do you often feel stressed or overwhelmed?” with the option to respond “yes”, “sometimes”, or “no”. One respondent left this answer blank, 3 marked “no”, thirteen marked “sometimes”, and twenty marked “yes”. When asked “Would you be interested in a parent or sibling support group with other families at *agency*?” Four respondents did not mark an answer, another 4 responded “no” and the remaining thirty responded “yes”. The 2015 pre-survey asked respondents an open-ended question of “Do you feel that there are any topics that would not be useful to you or other parents?” About half the respondents left this answer blank and the other half answered in one of two ways: “no” or “everything is important”.

On the 2014 pre-survey a question asked parents to rate on a scale of 1-5, strongly disagree to strongly agree, how confident they feel about their understanding of their child’s diagnosis and treatment. The mean was 3.47, and the mode and median were both 4. Below is the breakdown of the data:

<b>Options for Response</b>	<b># Of Respondents Who Marked Response</b>
1- Strongly Disagree	4 people
2	2 people
3 – Neither Disagree/Agree	8 people
4	14 people
5- Strongly Agree	6 people
*No response	3 people



The next question on the survey asked respondents to check off all that apply from a list of resources that they use to find information about their child’s diagnosis. Below are the results (highlighted categories signify a response of 55% or more, indicating a majority):

*2014 pre-survey, check all that apply:*

Pamphlets from office	32.4%	
Internet	64.9%	
Agency clinicians	62.2%	
Primary pediatricians	21.6%	
Books	37.8%	
School and teachers	51.4%	
Friends and family	16.2%	
Other	Early Intervention	.05%
	Support group	.03%

The results indicate that the majority of parents feel that they sufficiently understand their child’s diagnosis and treatment, and that the most popular resources for gathering information are via the Internet and specialized clinicians.

Across the surveys there was great variety in the responses received to the open-ended questions. For example, parents were asked to answer the question, “What other topics would you like future workshops to focus on?” and the responses seemed to be individualized to the specific needs of the individual child and family. Although the responses to the question varied greatly, I did find that the replies could be characterized into four general themes: transitions, behavior management, psychoeducation, and self-care for child and family. Below are the complete lists of answers collected divided into general groupings based on theme:

*2014 post-survey:***Transitions**

“After high-school”

“Adapting to high school”

**Behavior management**

“More on behaviors and picky eaters and how to handle it”

“More time on behavior management techniques and toilet training techniques for children with disabilities”

“How to facilitate social interactions with children”

“Typical ADHD problems”

“Executive function”

**Psychoeducation**

“Someone to explain changes coming from DOE that may affect my child”

“Mental illness”

“Resources- where they are, how to get them, how to qualify”

“Evaluation process, discussion of possible causes of Autism supported by the latest research- ongoing research findings”

“Workshops to inform other children without disability how they can support children with disability”

“Sexual education according to age”

“Acoustic music that help special kids, piano, guitar, class or therapy”

“Consider discipline specific workshops for parent questions instead of round robin”

**Self-care for child and family**

“Toilet training”

“Sleep problems”

“Balancing family/work, perhaps classes based on disability, ages, support groups, community, life skills”

“The positive stories of the kids and parents with ADHD”

*2015 post-survey:***Transitions**

“Teenagers with Autism- learning how to work with the teenage years helping your child”

“Kindergarten information and nutrition information”

“Transitions and services available to children and parents”

“Turning 21 and nutrition”

“Sessions geared towards older females”

**Behavior management**

“Learning how to handle aggressive behaviors at home and school”

“Behavior”

“More behavior”

“Visuals for communication”

**Psychoeducation**

“Resources for activities for special needs child”

“Financial workshop, insurance”

“Sex education”

“What services are available for children with special needs, workshop on ABA”

“Talk about different syndromes”

**Self-care for child and family**

“Sibling support”

“Parent support”

“Parents helping parents”

“I would like to receive more information for me as a parent”

In another example, when responding to the question “What did you find useful about the workshop?” parents answers ranged from stating that “all the information” was beneficial to listing the title of specific sessions (ex. “The school panel and the social thinking”) to detailed techniques and strategies that were learned (ex. “Positive reinforcement when he is not doing maladaptive behaviors and suggestion to provide my son with a visual schedule”)<sup>5</sup>. When responding to the question “What did you not find useful about the workshop?” parents answers were grouped into three general categories: needing more time per session (ex. “Sessions are too short”), some session topics were not relevant to the specific diagnosis or age of individual child (ex. “I did not find that the reading and play skills workshop were geared to parents of children with special needs like Autism”), and being disappointed that could not attend all sessions because of overlap in scheduling (ex. “I was interested in three sessions all during the same time”)<sup>6</sup>. From the collection of responses of what parents found useful and not useful it is evident that most, if not all, parents were able to take away

---

<sup>5</sup> Appendix C

<sup>6</sup> Appendix D

something from the workshop, if not everything, as being important and relevant. To sum it up in the words of one parent, “Everything was useful because I will share with other parents”.

In the space provided for additional comments and concerns regarding the workshop respondents mostly provided words of thanks or logistical suggestions<sup>7</sup>. There were a few comments that stood out: “Please make workshops more often. We need support,” “All presentations should be in the registration packet since we are only able to choose one topic per session would be helpful to read the material from others,” “I wasn’t sure what to expect when I arrived but I left with an array of resources and positive feedback and have new energy to go forth,” “It would be great to have a workshop for parents with kid together and a coping skills workshop for parents with kids for special needs.” From these examples, some of which are words of thanks and some logistical suggestions, it seems that parents are very appreciative of the opportunity to attend the workshop and are looking for more opportunities to continue to learn about their child’s diagnosis and treatment.

### **Revisit Appointments**

The first revisit appointment of this kind took place in the end of October 2014 and the final revisit appointment I had with a parent took place in the middle of March 2015. According to the agency calendar one hundred and two parent conferences were scheduled in that time period. However, only 9 total referrals were made to me and of those 9 cases I scheduled and met with 5 of them. Of the remaining 4 cases that were referred but that I did not meet with, 3 parents were no longer interested or had no availability at the time of scheduling, and 1 parent scheduled an appointment but did not show up. Of the 9 referrals

---

<sup>7</sup> Appendix E

made, my supervisor, who is a Licensed Clinical Social Worker and who understands the value of the service, made 4 of them.

The first parent I met with is the grandmother, and adoptive parent, of Daniel, a 10.9-year-old boy at the time of appointment. Daniel was being seen at the agency for updated evaluations for diagnostic clarification due to ongoing academic and behavioral difficulties. During the parent conference grandmother was informed of the team's diagnoses and recommendations<sup>8</sup>. The grandmother became tearful during the visit noting ongoing lack of academic progress and worries over what may happen to Daniel if she were to die. The case manager referred grandmother for a revisit appointment for additional emotional support.

The revisit appointment was scheduled at same time as Daniel's therapy that was taking place in the same building. Prior to session beginning the grandmother became very anxious having thought that Daniel went missing though he was found moments later in the bathroom. As a result, I started the session by helping the parent work on breathing techniques to relax. During the revisit appointment the grandmother shared that she is happy with Daniel's current class placement, however she continues to be very concerned about his reading level. I reviewed with the parent the team recommendations and asked how she is feeling about all the information presented to her. The parent reported that she has been experiencing many physical symptoms (i.e. headache, chest pains, weight gain) but testing at hospital indicated nothing was wrong. I discussed with the parent the possibility of the physical symptoms being related to stress/anxiety. The parent indicated that she does not know what additional services are available to Daniel. After exploring current social supports and discussing possible additional services (i.e. tutoring, after-school activities) the parent

---

<sup>8</sup> Appendix F

expressed interest in learning more about free after-school programs. Following the revisit appointment, I emailed the parent a list of outpatient mental health services for herself and a list of websites to get more information about some free after-school programming for Daniel.

The next parents I met with are the adoptive parents of Ben, an 11.1-year-old boy at the time of appointment. The father was in-person for the session and the mother participated by telephone. Ben was being seen at the agency for diagnostic clarification and assistance in school advocacy. During the parent conference the parents were informed of the team's diagnosis and recommendations<sup>9</sup>. The case manager referred the parents for a revisit appointment as an opportunity for check in to provide needed support and assistance with advocacy.

According to the mother, she handed in the forms for reconvening an Individualized Education Program (IEP) meeting about a month ago but had not heard anything from the school. The mother would like Ben's IEP classification to be changed from Speech and Learning Impaired to Autism. I informed the parents of their rights as it relates to Ben's schooling and IEP. With permission from the parents, following the revisit appointment I called the school to inquire about the status of reconvening the IEP and advocated on behalf of Ben and his parents to have the IEP appointment scheduled for the immediate future.

The third parent I met with is the biological mother of Ana, an 11.9-year-old girl at the time of appointment. Ana was being seen at the agency for diagnostic clarification and assistance with educational needs. During the parent conference the mother was informed of

---

<sup>9</sup> Appendix G

the team's diagnosis and recommendations<sup>10</sup>. The case manager referred the mother for a revisit appointment for emotional support and logistical guidance. The parent arrived for the revisit appointment a week early and was sent home and told to come back the next week.

Ana's mother reported that at Ana's most recent IEP meeting the school suggested placing Ana in a 12:1 classroom but the mother did not approve. The mother shared that Ana had previously been placed in this type of classroom but the mother insisted on pulling her out because according to her all the children in the class had behavioral issues and she was nervous that Ana would mimic the bad behavior. I reviewed with the parent the structure of Self-Contained Classrooms and discussed with the mother her options. The mother inquired about other tutoring/homework help programs. The parent shared that she would like to keep Ana in her current classroom setting for consistency, as a lot of other changes will be taking place in the next few months. The mother reported that due to domestic violence she and Ana would be moving out of the home. I assessed home situation for danger and gave the mother a list of referrals for mental health services for herself and tutoring/ homework help programs for Ana.

The fourth parent I met with is the biological mother of Ian, an 11.5-year-old boy at the time of appointment. Ian was being seen at the agency due to concerns about his academic and behavioral problems. Ian had been previously evaluated by the Department of Education (DOE) and was classified with "Speech or Language Impairment." During the parent conference the mother was informed of the team's diagnosis and recommendations<sup>11</sup>. The case manager referred the mother for a revisit appointment for additional emotional support.

---

<sup>10</sup> Appendix H

<sup>11</sup> Appendix I

The mother presented as overwhelmed by the information presented to her at the parent conference; mother stated, “I do not want to stay ignorant, but it is too much to swallow at once.” During this appointment I reviewed with the mother the evaluation reports, answered her general questions, and suggested she contact the individual evaluators for specific questions about the reports. At times throughout session the mother became tearful when speaking about how she believes the school system failed to meet Ian’s needs and her fears that it will continue to negatively affect his potential. The mother noted that she would like to start Ian on medication to address ADHD symptoms but that is also nervous that the side effects may change who Ian is as a person. She also stated that she does not want to tell Ian about his diagnosis for fear that he will use it as an excuse to not do well in school. Support was provided throughout the appointment. I offered the option to schedule a revisit in order to continue helping the mother understand Ian’s diagnosis. The mother agreed and an appointment was scheduled; however, the mother had to cancel due to other obligations and the appointment was never rescheduled again.

The last parent I met with is the biological mother of Jay, a 10.9-year-old-boy at the time of appointment. Jay was being seen at the agency due to concerns about possible dyslexia and difficulties with reading, writing, and penmanship. During the parent conference the parent was informed of the team’s diagnosis and recommendations<sup>12</sup>. The case manager referred the mother for a revisit appointment in order to help her advocate for additional school services on her son’s behalf. The mother arrived to session over an hour late and presented as overwhelmed speaking quickly and continuously for the majority of the session.

---

<sup>12</sup> Appendix J



The mother asked for support in helping to advocate to get Speech and Language Therapy added to Jay's IEP. I informed the parent of the process of reopening his IEP case and reviewed parents' rights. Although the mother expressed being interested in getting more services added to Jay's IEP, she also asked about when and how to know if Jay no longer needs services. I discussed with her taking the process one step at a time and trying to stay in the moment as not to overwhelm herself. Per the mother's request, I emailed her a sample letter to bring to the DOE to request reopening Jay's case.

All of the parents I met with for a revisit appointment presented as anxious, frustrated, and or overwhelmed. One parent reported experiencing physical symptoms, another parent became tearful, and a different parent spoke quickly and continuously throughout the session. The case manager referred each family for a revisit appointment noting either needing emotional support or assistance with advocacy. Although the initial referral may have been made with a specific purpose in mind, each appointment addressed multiple issues. For example, in a given session topics ranged from reviewing reports and answering general questions, providing parent emotional support, informing parent of rights as it pertains to advocating on child's behalf with the school, and discussing free after-school opportunities.

### **Ongoing Individual Psychotherapy**

#### ***Case 1: Molly***

The first patient I met with for weekly individual psychotherapy is Molly, the biological mother of a 12-year-old boy named David who is diagnosed with ADHD, ASD, Intellectual Disability, and Anxiety. I met with Molly for a total of 16 sessions that lasted 45 minutes each over the course of 6 months. Molly was referred for supportive therapy services

following a psychosocial evaluation in which she presented as highly stressed without any outlet for support.

Molly separated from David's father about 2 years ago and finalized the divorce during the time period she was in treatment. Molly reports that she feels that David's father does not accept David's developmental delays and behavior issues and that she and he often get into fights about David's treatment and care.

David currently lives with his mother and sister (age 4) in the home of his maternal grandmother. The family receives food stamps and Supplemental Security Income (SSI), and is waiting to hear back about David's eligibility for services from the Office of People With Developmental Disabilities (OPWDD). Current psychosocial stressors for the family revolve around caring for David. Below are the session notes summarizing Molly's course of treatment:

#### Session 1:

Initial treatment session with mother--mother presented as overwhelmed. She spoke quickly and continuously for majority of session. Mother spoke about strained relationships with family members due to David's behavior. Mother became tearful when speaking about her recent divorce. Mother reports feeling as though she is a burden to others and has a difficult time accepting help, which she feels leads to feelings of isolation for her and David. Continued work will focus on exploring mother's anxiety and feelings of guilt as it relates to caring for David as well as possible coping and self care strategies for herself.

#### Session 2:

Mother reported an incident from the past weekend when she felt David's aunt treated him unfairly. Social work intern and mother explored mother's feelings towards family members for how she perceives they treat David. Mother reflected on being "super-duper protective" of David. Clinician assisted mother in reflecting on her expectation of others, her reactions to criticism and how it impacts relationships. Mother reported having high expectations for herself and then feeling deflated when she is not able to meet these. Mother spoke about her history of Crohn's Disease and recent flare-ups due to stress. Work will continue to focus on helping mother to recognize and reflect on her feelings, and to identify coping and self-care strategies.

### Session 3:

Session focused on mother processing emotions related to origin for David's challenges and struggles. Additionally, mother discussed recent break up with a boyfriend of 1.5 years largely because she felt much of focus had to be on David. Social work intern assisted mother in reflecting on relational patterns in her life and impact on emotional well-being. Social work intern and mother began a discussion about the way mother thinks she presents herself and her view on her how others perceive her. Mother spoke about her current priorities of wanting to find a job and move out of her mother's home.

### Session 4:

As session began mother presented as overwhelmed and flooded information to clinician focusing on David's ongoing behavioral difficulties and challenges in family interactions. Clinician assisted mother with reframing and identifying strengths in her family/social circles. Clinician and patient continued to explore mother's anxiety. Mother reported flare ups with her Crohn's Disease and stated that she is considering applying for disability payment for herself. Support was provided.

### Session 5:

Mother expressed feeling anxious and frustrated with what she perceives as little to no progress being made with David's mood and behavior. Due to reports of David's increasing aggressive behavior clinician and mother reviewed a safety plan. Mother went on to discuss her own health issues and expressed fears related to her own illness and death. Support was provided. Clinician and parent began a discussion about mother's anxiety (i.e. what it feels like, what leads up to it, responses to it). Work will continue to assist parent in learning coping techniques to decrease anxiety.

### Session 6:

Social work intern assisted mother in reflecting on triggers for anxiety in her day-to-day routine. Mother expressed feeling anxious and frustrated as a result of David's behavior. Support was provided. Clinician assisted mother in reframing David's behavior and viewing the multiple factors/systems impacting him. Social work intern and mother reflected on mother's own part and impact on David's behavior. Clinician and parent began a discussion about methods of seeing intense situations in a calmer way in order to provide more appropriate reactions to situations and better manage them. Mother expressed a willingness to focus on implementing these strategies this week.

### Session 7:

Mother presented as overwhelmed becoming tearful at times throughout the session. Mother expressed feeling helpless as a result of David's increasingly aggressive and difficult behaviors. Safety plan was reviewed. Clinician helped mother explore her fears of David being a danger to himself and others, and mother feeling like she does not understand the

root of the behavior. Support was provided. Mother shared ongoing stress related to co-parenting and various approaches and beliefs others have. Clinician and mother discussed having dyad sessions with other family members. Work will continue to assist parent in increasing her understanding of child's diagnosis and managing anxiety/stress.

#### Session 8:

Mother arrived 30 minutes late and presented as tired and sad. She spoke at length with little break about David's recent hospitalization. Clinician assisted mother in identifying and reflecting on her emotions surrounding the situation. Mother shared feeling "paralyzingly sad" and described the experience as "the worst experience of my life". This was explored and support was provided. Clinician and mother discussed the importance of self-care and strategies to help reduce anxiety and stress (i.e. breathing techniques, writing in a journal).

#### Session 9:

Mother reported on David's discharge from recent hospitalization. She spoke about his transition home and some of the behavioral changes she has observed. Mother shared feeling confused about what to expect from David. Clinician helped mother reframe the hospitalization as another intervention as opposed to a 'fix it all'. Discussion followed about possible expectations for David's behavior and strategies to help manage and reduce mother's stress and anxiety. Clinician helped mother develop positive self-talk to assist in stress management. Mother was given homework to practice this self-talk over the week.

#### Session 10:

Mother arrived late to session and brought David's sister (4-year-old) to the appointment because she did not have available child care. A joint session followed. Session initially focused on sister and exploring her experience in the home and her feelings related to David's behavior. For the remainder of the session sister did a puzzle while clinician and mother discussed David's recent troubles in school (i.e. fighting with another kids para on bus). Support was provided and clinician and mother reviewed mother's self-mantra from previous session. Mother spoke briefly about her current priority of wanting to move out of her mother's home.

#### Session 11:

Mother reported on yesterday's medication appointment. Mother presented as angry and annoyed. Clinician helped mother reflect on these feelings. Mother shared feeling overwhelmed by what she perceives as others expectations for her regarding caring for David and controlling his behaviors. Support was provided and discussed mother's perception of her own expectations and boundaries. Also discussed last's week's family session and began conversation about termination.

Session 12:

Focus of session was discussing plans for a family trip at the end of the summer. Mother shared feeling both excited and anxious about the plans. Clinician assisted mother in exploring these feelings. Support was provided. Clinician and mother discussed separating her anxiety from her son's anxiety and possible strategies to decrease anxiety for both of them. Continued work will focus on increasing parent's ability to recognize impact of child's disability on herself and her family, and to continue learning and practicing coping techniques to decrease anxiety.

Session 13:

Focus of session was clinician's upcoming termination. Clinician and mother reviewed therapeutic work and discussed positive development and growth. Mother shared story from the past week in which she utilized learned technique (positive self-talk) and recognized that she felt less anxious due to her ability to no longer give as much importance to others' perceptions and expectations of her. Clinician and mother reviewed methods of reframing thoughts and responses to situations in order to provide more appropriate reactions and to better manage difficult situations.

Session 14:

Clinician assisted mother in reflecting on wishes and dreams she has for herself. Mother stated that she wants to have "a life again, one where I can have fun." Social work intern assisted mother in identifying what this means to her (i.e. having her own home, working, feeling self-sufficient). Clinician and mother discussed possible self-care strategies (i.e. gym routine, alone time). Continued discussion about termination and mother asked if she could invite David's father to next week's session. Mother explained that before clinician terminated she wanted David's father to be part of a joint-session.

Session 15:

Mother presented as put together and relaxed. Clinician reflected this observation and mother responded that when she has the time it makes her feel good to get dressed. Mother stated that she reached out to David's father to join today's session but he would not commit to coming. Clinician assisted mother in reflecting on the ways David's father may play a role in her thoughts/feelings/behaviors. Discussion focused on appropriate expectations for self and others. Clinician reminded mother that next week will be the last session.

Session 16:

Final session with social work intern – future treating clinician joined beginning of session to discuss transition in services. Mother was tearful throughout session and reported feeling overwhelmed though she was unable to identify specific stressors. Social work intern helped mother reflect on the possible impacts of termination, and discussed progress of therapeutic work, and goals for future work.

***Case 2: Anita***

The second mother I met with for ongoing individual psychotherapy is Anita, the biological mother of a 6-year-old boy named Adam. Adam is diagnosed with ASD and Global Developmental Delay. I met with Anita for a total of 12 sessions that lasted 45 minutes each over the course of 4 months. Similar to Molly, Anita was referred for supportive therapy services following a psychosocial evaluation.

Adam's father had a stroke 2 years ago resulting in significant limitations in his cognitive abilities and behavior. Anita reports that as a result of the stroke she and Adam's father separated because she could not care for both Adam and his father. They had previously been in a relationship for 9 years. Adam's father has daily phone contact with him and in-person supervised contact about once a week.

Anita reports a history of being in the foster care system for many years and being reunited with her biological mother in young adulthood. She denies any other history of protective services involvement, or exposure to violence or trauma related to Adam. When treatment began, Anita and Adam were living in the home of Anita's brother. Anita and Adam had previously lived in a private apartment; however, they were forced to move in with family when the previous landlord would not renew their lease and Anita could not find someone to rent to her as single parent with a part time job. Adam receives Supplemental Security Income (SSI). Current psychosocial stressors relate to Adam's behavior and lack of communication, as well as, housing and financial difficulties. Anita reports that she currently has no additional support resources. Below are the session notes summarizing Anita's course of treatment:

### Session 1:

Initial treatment session with mother -- mother presented as anxious and overwhelmed. Mother spoke about ongoing concerns with school related issues. Mother spoke about stressful relationship between her and Adam's father. Mother became tearful when speaking about her own history with foster care system and her fears that Adam will be taken away. Support was provided. Continued work will focus on developing coping techniques to decrease anxiety.

### Session 2:

As session began mother presented as overwhelmed and flooded information to the clinician focusing on current living situation and desire to leave the home. Clinician assisted mother in practicing breathing techniques as immediate coping strategy for anxiety. Social work intern and mother discussed strategies to better manage anxiety and stress (i.e. listening to music, self-talk, reading the bible, and going on a walk). Mother became tearful when speaking about her childhood. Support was provided.

### Session 3:

Focus of session was she and Adam's upcoming move to their own apartment. Mother expressed mixed emotions about the change. Social work intern and mother explored these emotions and support was provided. Social work intern and mother continued discussion about strategies to manage anxiety and stress. Continued work will focus on developing strategies for parent to better manage stress levels in relation to child, family interactions and current psychosocial stressors.

### Session 4:

Mother arrived at session eager to share that she and Adam moved apartments. Mother presented as excited and relieved. Mother reported on the positive experience of the transition for herself and her son sharing that Adam's teachers have reported seeing a difference in his behavior as well. Mother spoke about her plans and goals moving forward (i.e. applying for public assistance, researching going back to school, boundaries in relationship with Adam's father). Continued work will focus on developing coping strategies for parent to better manage stress levels.

### Session 5:

Throughout session mother spoke at length about Adam's positive behavior in the recent weeks and her mixed feelings about her family interactions. Mother expressed hurt feelings and became tearful when discussing how she feels the family treats her and Adam. Support was provided. Clinician and mother began exploring connections between current feelings and mother childhood experiences. Clinician helped mother reframe boundaries as a way to protect herself as opposed to pushing others away. Future work will continue to assist parent in learning coping techniques to decrease her anxiety and stress.

Session 6:

Focus of session was discussing recent family interactions and connections between mother's current feelings and her childhood experiences. Mother became tearful when sharing memories of entering foster care. Support was provided. Clinician and mother discussed the meaning of family to her and the influence it has on her current familial relationships. Mother spoke at length about her complicated relationship with her sister. Continued work will focus on developing strategies for parent to better manage stress levels.

Session 7:

Mother arrived with upbeat affect and was eager to share her thoughts on prior week's session. Mother shared how last week was one of the first times she allowed herself to simply reflect on feelings triggered by her childhood experiences. Mother spoke at length about her unconditional love and support for all family members, and specifically about her close relationship to her biological mother. Clinician helped mother identify and reflect on pressure she feels to not disappoint her family. Support was provided. Mother stated that she is ready to start putting boundaries in place between herself and family members in order to protect herself and her son. Clinician helped mother identify one boundary she would like to implement this week. Prior to end of session Clinician introduced topic of clinician's termination.

Session 8:

Throughout session mother shared with clinician that she was proud of herself for the boundaries she has implemented in her relationships with family members. Clinician helped mother explore these feelings and how to maintain them during challenging times. Clinician and mother discussed other support systems outside of family. Mother shared with clinician an argument she had with her son's father this week. Clinician helped mother explore underlying factors that may have played a role in the disagreement. Future work will continue to assist parent in developing self-reflecting skills to increase ability to address psychosocial stressors.

Session 9:

Mother arrived 15 minutes late to session. As session began mother spoke about her concerns regarding Adam's current paraprofessional (re: Adam's safety and progress). Support was provided. Clinician reminded mother of clinician's upcoming termination. Mother shared feeling sad about terminating and clinician assisted mother in reflecting on these feelings. Discussion focused on reviewing past therapeutic work and clinician helped reframe termination as having a potentially positive impact.



#### Session 10:

Mother arrived to session prepared to share about an incident in which she bumped into Adam's paternal half-siblings at church. Mother became tearful when discussing how she feels the family has treated Adam in the past. Clinician assisted mother in identifying her feelings (i.e. angry, hurt) and helped mother distinguish her feelings from Adam's feelings. Support was provided. Discussion explored connections between current feelings and mother's childhood experiences. Work will continue to assist parent in learning coping techniques to decrease her anxiety and stress.

#### Session 11:

The focus of today's session was helping mother separate and individuate Adam from herself. Mother shared feeling insecure that she is sometimes not able to recognize and determine how Adam feels. Clinician normalized mother's feelings and provided support. Discussion focused on reviewing therapeutic work and strategies to decrease anxiety and stress (i.e. putting in place boundaries, self-reflection, breathing techniques). Clinician reminded mother that next week will be the last session.

#### Session 12:

Final treatment session with social work intern-- mother shared feeling overwhelmed by current psychosocial stressors (i.e. flooding in home), and feeling proud of implementing learned strategies to reduce anxiety and stress. Support and praise was provided. Remainder of session focused on termination and progress of therapeutic work.

#### ***Discussion of Cases***

As treatment progressed both mothers continued to develop coping mechanisms and strategies to address anxiety and stress related to raising a child with developmental disabilities. Depending on the individual and family needs at the moment, and influenced by the development of the work, the topic of the sessions varied from week to week. However, I identified some overall themes that were weaved throughout the therapeutic work from beginning to end. The themes included: behavior management, relationship patterns, nature of the disability and expectations for self and others, fear about the future, and emotional support.

Below I will give examples for each of the general themes. For behavior management issues ranged from, “The last three nights have been bad with Adam. He hasn’t slept through the night for three nights so then I can’t sleep” to “I don’t know what to do anymore. It is getting dangerous. He is bigger and very aggressive. He ripped the phone off the wall twice this week.” In the category of relationship patterns both mothers discussed how their child’s disability plays a role in their familial and social relationships. The mothers felt hurt by how they perceived other family members treat their child, and spoke about their lack of social relationships due to their inability to devote the time and effort to maintain friendship. Additionally, the mothers spoke about the added stress involved in the relationship of co-parenting a child with a disability.

Throughout the therapeutic work a theme that remerged was helping the parent to understand the disability and expectations for self and others. Below is an excerpt from a session with Molly:

**Molly:** I understand that, but when are these pieces going to fall into place!

**Social work intern:** What if I were to tell you there may never been a time when all the pieces fall into place?

**Molly:** I would say I think that is a cop-out answer. There has to be something causing this to happen and if there is something causing it, then there should be something to stop it. I have two children who are the complete opposite on the spectrum. They have the same parents, were born in the same environment, and I didn’t do anything differently in pregnancy or in raising them, lived in same place, did same things and they are so different! How could that be if there isn’t something different inside of them to explain it. I did genetic testing 3 times with David and they didn’t find anything. 3 times just to make sure each time something wasn’t missed!

**Social work intern:** How does it feel to think about the fact that there might not be something that will fix it?

**Molly:** To me that is not acceptable. I have been dealing with this since he was 2, now he is 13 something has to change. I wont stop trying even if there isn’t an answer; I wont stop trying.

In this theme another topic that often came up in discussion was the mothers feelings of insecurity in not being able to identify their child’s wants and needs. For example, Anita

stated, “I am very hard and stern and can come off as aggressive, but what if my son needs me to be softer? He can’t tell me he needs that so how am I supposed to know? He has a lot of sensory stuff. Maybe he needs me to be softer and my fast pace is scaring him.” In another example Molly said, “I don’t know how much my son understands and how much he chooses to not listen to.” While simultaneously feeling insecure both mothers also felt as though they were the only ones who could care for the child and feared what would happen to the child if they, as the main caregiver, were to get ill and die. For example in another session Molly stated, “And what if something were to happen to me? My damn Crohn’s disease is having a flare up...what if I were to get an infection, then what? At this point I am the only one who can handle David.”

The most common theme that emerged is the parents’ need for emotional support. This topic came up in every session whether the parent was conscious of it or not. In one example Anita was crying and shared, “Sometimes I feel like it isn’t fair, we all know what my sister-in-law did when she was pregnant and she has three healthy kids. I mean my niece has ADHD and the other one has my sister-in-law’s same crap but the baby seems to be doing okay. How is it fair that she gets a baby like that and I have a son with Autism?” In another example Anita stated, “Real religious people tell me ‘you are blessed’. Let me tell you that is the worst thing to say; I want to slap them! I am cleaning up my son’s shit and I am blessed? I sure as hell don’t feel blessed.” In one of Molly’s sessions she said, “I just don’t know what to do anymore. Things seem to just keep getting worse and not better.”

Within each of the general themes the specific needs of the mother varied based on the individual child and the context. Additionally, because of the nature of ongoing therapy the discussion often wandered deeper than addressing the surface issues surrounding specific

needs and focused on the impact the current issue may have on other parts of life. For example, in session 4 Molly stated:

It's just been quite the morning. Started with David's bad behavior, he was pretty good over the holidays but since yesterday things have been really bad again. His teacher texted me yesterday saying he was complaining his head hurt so she was sending him to the nurse. I spoke to the nurse and she said she thinks he is probably just tired. She said all the kids in school are walking around like zombies post break. So then when they sent him back to class he was misbehaving and cursing at the teacher, nothing new. Last night I told him he had to go to bed early, he and his sister. His sister went to bed but David refused. He kept running up and down the stairs and telling me he was going to call his dad. That is his new thing. He always threatens to call dad. And this morning it was a huge struggle getting him up and off to school. He told me his head hurt. So I said "you are going to school". Well first I took his temperature and it was normal and then I told him he was going to school and he complained of being tired so that was a fight. Getting him on the bus this morning, the driver must have thought I was a lunatic. It took a full five minutes of us fighting outside for me to get him on the bus. And then I was supposed to get updated blood work done this morning and I waited there for over an hour and then they told me one of the tests I needed could not be done at the location and I hadn't eaten because of the blood work so then I went and got this coffee and now here I am.

From this example it became clear that David's challenging behaviors influence many parts of his mother's life, including relationship patterns, boundaries, expectations and pressures placed on self, health care issues, and overall mood and functioning.

Later in the session when discussing strategies to help promote positive behavior, the following dialogue took place:

**Social work intern:** So it sounds like that incentive of getting gifts helped him behave better?

**Molly:** Yea

**Social work intern:** I am wondering if when it isn't holiday time there is another sort of incentive, instead of Santa, that you can maybe think of that may help him better control his behavior?

**Molly:** I have tried it all. I have used charts and positive reinforcements, none of it works. And he is getting bigger. I have to puff out my chest so he knows I am big too. I want him to know he can't get away with not following rules. Believe me I will do anything for my kids. I lost my marriage and gave up on my recent relationship and my career. My kid always come first, but they also need to know there are rules.

In this example, it became evident that this is not only about Molly looking for strategies to help manage her son's challenging behaviors, but there is a deeper component of Molly feeling as though she has given up relationships and career as a sacrifice for caring for her son. In a later session Molly stated, "I know David is a key player in all of this. I would say he is about 90% of the reason me and my mom fight and 90% of the reason me and his dad fight."

Adam's mother stated, "I am not feeling 100% and I know if I am not feeling my best I can't help my son." This statement serves as an example that a parents' needs might not always seem directly related to caring for the child but certainly affect the child in an indirect way. Like Anita said if she is not feeling her best then she cannot care for her child in the best way, which then affects her child's functioning and further negatively influences her physical and emotional well-being.

## ISSUES FOR PRACTICE

After reading existing literature on the topic and analyzing the data collected for this project, I identified three key issues for practice. The first key issue I observed is parents' yearning for more information. Based on parents' responses to the surveys and the case material from revisit appointments and ongoing psychotherapy it is evident that parents generally feel that they are lacking information about their child's diagnosis and available services. Some parents do not even have enough of a basic understanding of the diagnosis and recommendations to be able to formulate questions to gather additional material on the topic. Regardless of the stage in the diagnostic process and the parents' level of comprehension about the child's prognosis, most parents seem to have a thirst for more information.

As seen in the literature parents note that they would prefer to be provided with information as early on as when the child is initially referred for evaluation (Braiden, et al., 2010, p.383). Parents recognized that the professionals may not want to preempt a diagnosis, but the parents felt that receiving the information early in the process would help prepare and enable them to formulate questions should their child receive a diagnosis.

Figuring out what information to share with the parent, when the most appropriate time to do so is, and how to relay the information in an understandable way are tricky concepts the professional must address. Information can be a double-edged sword. On the one hand the more information the parent has the better able they are to advocate for the most appropriate services for their child. However, on the other hand too much information can feel overwhelming in a way that may paralyze the parent to not be able respond at all.

In the literature, parents noted that in addition to the information they received from the professionals they relied heavily on the Internet to help them understand (Braiden, et al., 2010, p.384). In support of this idea, the Internet was the most popular answer on a survey question that asked parents which resources they use to find information about their child's diagnosis. Similar to how the quantity of information can be a double-edged sword, there are both pros and cons to having the Internet available as a resource for gathering information.

Some of the positives of having the Internet available as a source of information for parents to use in learning more about their child's diagnosis are the Internet's accessibility, vastness, and connections. While professionals may only have a designated amount of time to meet with a family and convey important information, the Internet is accessible to the parent from home and is able to be used all hours of the day. In the limited time the professional has with the family there may not be time for all the parents questions to be answered, and the professional may not be able to answer every question in the moment. However, because of the massiveness of information provided on the Internet it is relatively easy for a parent to search a term and find hundreds of pages of material on the subject matter. Also, because the Internet allows users to post information in addition to retrieving it there are many personal stories users have shared. These stories help build connections and a community of support around very specific issues.

With all the ways the Internet can be a useful tool for parents to gather information, it should be noted that there are also many concerns. The accessibility and vastness of the Internet can be a problem when a parent believes all the information that is written, does not have a professional to explain the material, and becomes overwhelmed by the abundance of information available. It can be difficult for parents to determine what sources of information

are reliable and what applies or does not apply to the individual child. It is evident that parents have a thirst for more information about their child's diagnosis and prognosis, but it also seems to be the case that there is a lack of accessible trustworthy sources available.

The second key issue I observed is the degree to which every family's needs are individualized and unique. A number of factors including, the child's diagnosis, age, and functioning, the family structure, the support systems available, the parents coping strategies, and so on and so forth influence the specific needs of the child and family. Although parents' needs tend to be individualized, there are common themes that emerge as collective areas of concern for most parents. As evidenced through the data collected from the surveys and the case material, some common concerns parents share when raising a child with developmental disabilities, include: transitions, behavior management, self-care, relationship patterns, psychoeducation and nature of the disability, and emotional support.

School related issues were a common theme amongst the families I met with for the revisit appointments. This is not surprising as all the children were school age; however, the specific concerns were individualized based on the child's diagnoses, the type of school he or she attends, and so on. A workshop for parents on school related issues seems to be a topic many parents would benefit from but it is also important to remember that such a workshop cannot address every issue for every family. On the post-surveys one of the common complaints from parents was that individuals often vented about personal situations taking away from the speakers time for presentation.

Since every family's needs are individualized and unique to the particular situation, in this case the Internet may be seen as a positive tool for gathering information. Because of the vastness of information available on the Internet specific challenges and issues can be



addressed. On the Internet there is information even on those topics that may not seem “popular” enough for professionals to discuss in the limited time available or for brochures and books to focus on in the restricted amount of space.

The benefits of group work with this population are recognizable based on feedback from parents of how helpful and productive it is to hear from and interact with other parents experiencing similar struggles. Information session, workshops, and support groups that bring together this population certainly serve an important role that cannot be replaced. Though it is important to keep in mind that these groups require a skilled facilitator who has the ability to weave together the commonalities but also differentiate and address the individual needs.

The third key issue I observed is the significant number of psychosocial stressors this population experiences in addition to caring for a child with special needs. Based on the clinic’s policy to accept Medicaid and the population residing in the surrounding neighborhood, the general population of the center tends to be non-white one-parent families with low socio-economic status and a history of many psychosocial stressors. Most of the families seen at the agency have financial struggles, housing difficulties, family and relationship stressors, and a lack of higher education.

For example, Anita, the mother I met with for ongoing psychotherapy, shared the following complicated family history within our two first sessions: Anita and Adam’s father separated about a year ago after he had a seizure that affected his cognitive abilities and level of functioning. They had previously been together for 9 years. In the recent past, multiple family members told Anita that Adam’s dad had cheated on her with two of Anita’s family members, one of which was under age, during the years they were together. She was kicked

out of her most recent apartment and her and Adam were forced to live in her brother's apartment. In the apartment were also the brother's wife, a new baby, and an older daughter, who is in the foster care system and is back in the home temporarily until she is placed somewhere new. Anita and her siblings were in the foster care system for much of their childhood until they were reunited with their mother in early adulthood. Currently Anita's brother and his wife have an open ACS case with three of their children (two of which are in the home). Anita's brother has been in jail multiple times and the most recent time was released within the past 6 months. He and his wife both have a history of drug abuse. He continues to smoke crack, but the wife has stopped. The wife smoked crack for 6 months of her most recent pregnancy. The brother with whom she lives is HIV positive, as are many other family members. Her mother is her main support system, and she moved out of state about a year ago.

The stressors these families experience often play a role in parents not showing up to appointments or cancelling appointments last minute. In the revisit appointments I conducted 2 parents explained that they work full time and cannot financially afford to take any more time off for appointments and thus had to decline the offer for an additional appointment. I had 1 parent schedule an appointment and not show up, 1 parent show up a week early mistakenly confusing it with another appointment, 1 parent arrive at the session over an hour late, and 1 parent participate by telephone because of obligations to other children at home.

I met with multiple parents who lived with their special needs child in the home of other relatives since they could no longer afford to pay rent. Many of the parents I met with were interested in additional services and programs to help their child, but stated that the services must be free since they could not afford anything with a fee. Molly shared that she

felt that a large reason for the decline in her and David's father's relationship was due to the stressors of co-parenting a son with special needs.

## CONCLUDING COMMENTS

In order to address the key issues for practice raised in the literature and the findings from this project, it is important to identify the existing gaps in services and the systems in place that are currently working for the agency. The experience of receiving the news that your child has developmental disabilities has been compared to the experience of grief and mourning. Based on the research it is found that parents raising a special needs child often report feelings of insufficient supports, helplessness, and loneliness (Smith et al., 2014, p.304). In order to make sure the child is receiving the proper care it is important to make sure the parents' needs are being met.

In the literature, parental mental health showed above average levels of complaints for parents of children with special needs compared to the population levels of parents raising a typically developing child. The complaints included higher level of depression and somatic symptoms (Poslawsky et al., 2014, p.299). This finding was also seen in the case material collected from the parents in my study. Molly complained about recent flare-ups in her Crohn's Disease as a result of stress exacerbated by challenges in dealing with David. And Daniel's parent reported that she has been experiencing many physical symptoms (i.e. headache, chest pains, weight gain) but testing at hospital indicated nothing was wrong.

The declining health of the adult caretaker will likely negatively impact the child in addition to the adult. By having available the proper supports and services to help identify and address a parent's physical and emotional needs, the parent will be better equipped to redirect the focus back to addressing the child's needs (Keok, 2012, p.9). It was also found that parents' who perceived greater confidence in their ability to raise their child effectively

were better able to adjust and respond to the challenging demands (Poslawsky et al., 2010, p.294).

Thus, my recommendation for an agency such as the one I interned at during my advanced year social work placement would be to ensure that there are proper services in place addressing the needs of parents. The agency I interned at had available 1 weekly support group for parents meeting in English and 1 weekly support group for parents meeting in Spanish, an annual one-day parent workshop, and a curriculum for a 9-session parent discussion group. There was also offered for some parents, depending on the parent's needs and the clinician's availability, the opportunity for weekly individual psychotherapy. And every family was supposed to be scheduled for a revisit appointment for an opportunity to check-in every 6-12 months.

Although these opportunities seem to address some parts of the major themes found in my research, parents' yearning for more information, degree to which every family's needs are individualized and unique, and the significant amount of psychosocial stressors this population experiences, in reality many of the parents needs are still not being met. In my opinion, the services in place for parents are a good beginning but are not sufficient. Having only 1 English-speaking support group and 1 Spanish-speaking support group does not seem like enough. In order to be able to address some of the individual needs of the families and to accommodate the families' hectic schedules, I believe it would be beneficial to have additional and more specifically focused support groups and discussion groups available to parents.

Research has highlighted that the way in which the diagnosis is delivered to a family may have a significant impact on the levels of distress and anxiety that the family

experiences (Braiden et al., 2010, p.382). The attitude of the professional, sources of information available at the time of the delivery, and opportunities for follow-up may all play a role in helping family members decrease their fear and anxiety surrounding a child's diagnosis. In my opinion the agency I worked at did an okay job of relaying this information to parents. At the time of the parent conference the case manager presented the reports and gave the parent two copies of the reports to take home.

I would recommend that in order to continue improving this process, the agency require all professionals to participate in a short training on appropriate strategies and skills to use when delivering this difficult information to a parent. Also, the literature indicates that parents found written information about the diagnosis at the time of receiving the diagnosis to be most useful (Braiden et al., 2010, p.382). Thus, I would recommend that the agency create reading material with basic information on specific diagnoses, answers to frequently asked questions, and a list referrals for additional resources and services. Lastly, I would also recommend that the agency continue to offer the parents the opportunity for a revisit appointment to meet with a social worker a few weeks after the original parent conference. In order for this service to be implemented, there would need to be buy-in from all the case managers. The case managers would need to be educated on the value of this service so that they could present it to the parent in a way that is understandable and attractive.

Based on the existing literature and the findings from this study, I believe my recommendations would build on the agency's current strengths and help the agency continue to be one of the most well respected multidisciplinary diagnostic treatment centers for children with developmental disabilities in the New York area. Though it should be noted

that like most social service agencies a lack in funding and staffing could present major limitations in implementing recommendations.

## REFERENCES

- Abrams, E.Z. & Goodman, J.F. (1998). Diagnosing developmental problems in children: parents and professionals negotiate bad news. *Journal of Pediatric Psychology, 23*(2), 87-98.
- Barak-Levy, Y. & Atzaba-Poria, N. (2013). Paternal versus maternal coping styles with child diagnosis of developmental delay. *Research in Developmental Disabilities, 34*(6), 2040-2046.
- Braiden, H.J., Bothrwell, J. & Duffy, J. (2010). Parents' experience of the diagnostic process for Autistic Spectrum Disorders. *Child Care in Practice, 16*(4), 377-389.
- Feniger-Schaal, R. & Oppenheim, D. (2013). Resolution of the diagnosis and maternal sensitivity among mothers of children with Intellectual Disability. *Research in developmental disabilities, 34*(1), 306-313.
- Fonseca, A., Nazaré, B. & Canavarro, M.C. (2011). Patterns of parental emotional reactions after a pre- or postnatal diagnosis of a congenital anomaly. *Journal of Reproductive & Infant Psychology, 29*(4), 320-333.
- Gau, S.S., Chou, M. & Chiang, H. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders, 6*(1), 263-270.
- Keok, C.A. (2012). Parental experience of having a child diagnosed with Autistic Spectrum Disorder: An integrative literature review. *Singapore Nursing Journal, 39* (1), 8-18.
- Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N. & Levi, S. (2010). Resolution of the diagnosis among parents of children with Autism Spectrum Disorder:



- Associations with child and parent characteristics. *Journal of Autism & Developmental Disorders*, 40(1), 89-99.
- Nelson Goff, B.S., Springer, N., Foote, L.C., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G.E. & Cross, K.A. (2013). Receiving the Initial Down Syndrome Diagnosis: A Comparison of prenatal and postnatal parent group experiences. *Intellectual & Developmental Disabilities*, 51(6), 446-457.
- Popp, J., Robinson, J., Britner, P & Blank, T. (2014). Parent adaptation and family functioning in relation to narratives of children with chronic illness. *Journal of Pediatric Nursing*, 29(1), 58-64.
- Poslawsky, I., Naber, F., Daalen, E., & Engeland, H. (2014). Parental reaction to early diagnosis of their children's Autism Spectrum Disorder: An exploratory study. *Child Psychiatry & Human Development*, 45(3), 294-305.
- Schuengel C., Rentinck I., Stolk, J., Voorman, J.M., Loots, G., Ketelaar, M., Gorter, J. & Becher, J. (2009). Parents' reactions to the diagnosis of cerebral palsy: Associations between resolution, age and severity of disability. *Child: Care, Health & Development*, 35(5), 673-680.

## APPENDIX

### Appendix A

Example of form for the case manager to fill out following every English speaking Parent Conference in which the professional or the parent indicated wanting to make a referral for a revisit appointment with a social worker

<b>Referrals for Follow-Up Appointment to Parent Conference</b>	
Name of Patient: _____	Birth date: _____
Agency ID #: _____	Diagnosis: _____
Date of PC: _____	Case Manager: _____
Name(s) of caretaker who attended the PC: _____	
Reason for referral: <i>Check all that apply</i>	
<input type="checkbox"/> Advocacy on patient's behalf	
<input type="checkbox"/> Logistical information (i.e. available services and how to access them, referrals)	
<input type="checkbox"/> Psychoeducation on diagnosis	
<input type="checkbox"/> Emotional support to parent related to diagnosis	
<input type="checkbox"/> Parent not interested	
<input type="checkbox"/> Other: _____	
If applicable, any other relevant information:	

## Appendix B

Template of 2014 and 2015 pre- and post- surveys

## B1. 2014 pre-survey

<b>Pre-Workshop Survey</b>				
Please circle your answer				
1. Does your child currently have a diagnosis?				
Yes		No		
2. Do you feel like you have a good understanding of your child's diagnosis and treatment?				
1	2	3	4	5
Strongly disagree		Neither agree/disagree		Strongly agree
3. Where do you find information about your child's diagnosis? (Check all that apply)				
<input type="radio"/> Pamphlets from office <input type="radio"/> Internet <input type="radio"/> <u>Agency</u> clinicians <input type="radio"/> Primary pediatrician <input type="radio"/> Books <input type="radio"/> School and teachers <input type="radio"/> Friends and family <input type="radio"/> Other: _____				
4. As a parent, do you often feel stressed or overwhelmed?				
Yes		Sometimes	No	
5. What topics about your child's diagnosis do you wish you had more information about? (Check all that apply)				
<input type="radio"/> General diagnoses <input type="radio"/> Education <input type="radio"/> Community resources <input type="radio"/> Recreational activities <input type="radio"/> Family difficulties and stressors <input type="radio"/> Speech and language/ communication <input type="radio"/> Behavior management <input type="radio"/> At-home interventions <input type="radio"/> Self-care skills (e.g. toileting, dressing, bathing, etc.) <input type="radio"/> Other: _____ _____				
6. Would you be interested in a parent or sibling support group with other families of <u>agency</u> ?				
Yes		No		

## B2. 2015 pre-survey

**Pre-Workshop Survey**  
Please circle your answer

1. Did you attend any of the previous agency parent workshops?  
Yes      No (please skip to question 3)
  
2. The previous workshop was a positive experience  
Agree      Somewhat agree      Disagree
  
3. We are considering several different setups for this year's workshop. Which of the following possible formats would you most prefer?
  - Fewer topics across longer sessions (four 1 + hour sessions)
  - More topics across shorter sessions (six 30-45 minute sessions)
  - Panel style (different specialists talk briefly about related topics all in one session)
  - Other \_\_\_\_\_
  
4. We are considering several topics for the agency 2015 parent workshop  
(Please only check 4-5 topics)
  - Education across the age span
  - Community resources
  - Accessing the playground and other places in the community
  - Family difficulties and stressors/coping
  - Medication
  - Feeding (i.e. picky eaters)
  - Adapting to high school
  - Sex education
  - Sensory processing
  - Speech and language
  - Behavior management
  - Self-care skills (e.g. toileting, dressing, bathing, etc.)
  - Sleep
  
5. What topics would you most like to learn about or attend at the workshop not mentioned above?
  
6. Do you feel there are any topics that would **not** be useful to you or other parents?
  
7. Additional comments:

## B3. 2014 and 2015 post-survey

<b>Post-Workshop Survey</b>					
<b><u>Please rate the following questions on a scale from 1 to 5</u></b>					
	1	2	3	4	5
The workshop was helpful in understanding your child's specific needs					
The information was easy to understand					
I will be able to use this new information at home					
Overall this workshop was a positive experience					
I feel like this workshop provided me with relevant information regarding my child's diagnosis and treatment					
I feel more comfortable managing my child's individual needs after this workshop					

1: *strongly disagree*  
 2: *somewhat disagree*  
 3: *neither disagree nor agree*  
 4: *somewhat agree*  
 5: *strongly agree*

- What did you find useful about the workshop?
  
- What did you **not** find useful about the workshop?
  
- Would you recommend this workshop to other *agency* parents?  
                   Yes                    No                    Maybe
  
- What other topics would you like future workshops to focus on?
  
- Any additional comments/concerns regarding today's workshop?

## Appendix C

Full list of responses sorted by year to the question, “What did you find useful about the workshop?”

## C1. 2014 post-survey

“Everything”  
 “Having a lot of solutions to solve challenging problems”  
 “A lot info about new research info and routine also strategies when it is difficult for kids”  
 “Everything at the workshop”  
 “School advice and learning about learning disability”  
 “Various topics”  
 “Finding ways to help my child”  
 “Information is always useful and the ability to question the experts is a plus”  
 “Sleep and sensory”  
 “Very informative”  
 “Meeting doctors who can work with my child”  
 “The information given about the topics”  
 “I feel that the workshop was suitable and appropriate to assist my family with dealing with a child with a diagnosis and behavioral problems. The information will be instrumental in assisting us as a family”  
 “Different topics”  
 “Variety of sessions”  
 “Q&A from experienced staff, handouts”  
 “I learn a lot”  
 “Resources/ info”  
 “Everything about this program, well organized, friendly staff that are also informed and dedicated”  
 “The talk regarding providing positive reinforcement when he was not doing maladaptive behaviors and suggestion to provide my son with a visual schedule”  
 “The interaction between speaker and parents. It allowed me to see that I was not alone”  
 “Having experts speak to the group”  
 “The information and strategies for parenting kids with special needs”  
 “The clarification of some terms”  
 “The parenting skills workshop was helpful”

## C2. 2015 post-survey

“Personal small groups, break down of info and good info”  
“All the information”  
“Learning more about my child's needs”  
“Learning new ways to help my child”  
“How to use technology”  
“I found preparing your child for transitions very useful and the support”  
“Playing for communication”  
“I found the what, where, and when of behavior, when do we use medication in ADHD, and positive parenting skills have given some useful points to go home and try to implement”  
“Hearing from other parents”  
“Meeting other parents”  
“Behavior”  
“Everything that I needed even more”  
“A lot of different info”  
“Discussion period with parents”  
“The school panel and the social thinking”  
“Longer sessions”  
“The session on medications and strategies on transition”  
“The information was very important”  
“Everything”

## Appendix D

Full list of responses sorted by year to the question, “What did you not find useful about the workshop?”

## D1. 2014 post-survey

“Not all for my son's age group”  
 “I did not find that the reading and play skills workshop were geared to parents of children with special needs like Autism”  
 “Afternoon session not long enough”  
 “Session not long enough- presenters not managing audience and allowing parents to monopolize conversation”  
 “Parents venting about personal situations which prevented speakers to moving along”  
 “I was interested in 3 sessions all during the same time”  
 “Sessions were good but the amount of information vs. amount of time given for Q&A can be adjusted.  
 More or equal time for Q&A. Not one presented gave out a business card”  
 “Sessions are too short”  
 “Limited time”  
 “Needed longer time”  
 “Everything seem to gravitate to Autism more than ADHD”

## D2. 2015 post-survey

“Long presentation, little time to ask questions”  
 “There were topics that I was unable to attend because they coincided with other stuff that I was interested in”  
 “Maybe have a 3-6 month follow up concerning strategies”  
 “Everything was useful because I will share with other parents”



## Appendix E

Full list of responses sorted by year and divided into general groupings based on theme to the question, "Any additional comments/concerns regarding today's workshop?"

## E1. 2014 post-survey

**Words of thanks**

"Excellent workshop- glad I came"

"I wasn't sure what to expect when I arrived but I left with an array of resources and positive feedback and have new energy to go forth. Good energy!"

**Logistical suggestions**

"Please include in your program therapy sound, paint, art, they can teach guitar, piano, flute, trumpet, singer, etc."

"Please find ways to reach out to the community about this workshop; I happened to find this workshop by luck"

"Today was great; however, not enough time for Q&A, need 10 more minutes per session. Need to repeat sessions at different times."

"More time in the workshops"

"1 day workshops for specific topics allowing more time. Great day but could have had more time- felt rushed."

"A two day workshop to allow us to be able to attend all seminars"

"More information on behavior management"

"All presentations should be in the registration packet since we are only able to choose one topic per session would be helpful to read the material from others"

"You should have more workshops than this one per year"

"Perhaps workshops should be longer. It should also be open to the general population"

"Should encourage the speakers to only allow questions at the end, parents tend to go off on tangents and talk about 'them' not allowing speaker to finish presentation"

"It would be great to have a workshop for parents with kid together and a coping skills workshop for parents with kids for special needs"

"More time"

## E2. 2015 post-survey

**Words of thanks**

“Very informative, thank you”

“Overall I enjoyed the workshop, looking forward to attending others”

“I enjoyed this workshop today”

**Logistical suggestions**

“Provide water for people who don't drink coffee”

“Some sessions were offered when you had the choice between 2 topics”

“Please make workshops more often. We need support”

“Extra time for discussion of the topics”

“I really enjoyed the different topics, however there were 2-3 topics that I wanted to attend but they were at the same time”

“I was interested in all session but could not attend all at once; I wanted to attend all the topics”

## Appendix F

Diagnosis and recommendations presented to Daniel's parent at parent conference.

### Diagnosis

315.32 Mixed Expressive/Receptive Language Disorder

314.01 Attention Deficit Hyperactivity Disorder- Combined

315.5 Mixed Learning Disorder

Other emotional/psychiatric diagnosis deferred to treating clinician

### Recommendations

1. Continue current classroom placement and related services
2. Provide intense, structured, progressively tailored to skill level, individualized reading program
3. Get new school report and copy of IEP
4. Follow up on agency referrals to Speech and Language services and Psychoeducation program
5. Review current ADHD treatment and address reported sleep issues (nightmares)
6. Continue current outpatient services at mental health clinic

## Appendix G

Diagnosis and recommendations presented to Ben's parent at parent conference.

### Diagnosis

299.0 Autism Spectrum Disorder

315.32 Mixed Expressive/Receptive Language Disorder

314.01 Attention Deficit Hyperactivity Disorder – Combined

315.8 Borderline IQ

History of Developmental Coordination Disorder

### Recommendations

1. Reconvene on IEP and change classification to Autism
2. Gather information about current school placement/services and get a new school report. If Ben is performing well academically/behaviorally then he should remain in ICT classroom
3. Continue Speech and Language, Occupational Therapy, and Physical Therapy services
4. Increase Speech and Language services to include Social Skills
5. Refer to agency Speech and Language services for social skills group
6. Continue work and follow up with Endocrine, Neurology, Genetics
7. Continue any current treatment of ADHD

## Appendix H

Diagnosis and recommendations presented to Ana's parent at parent conference.

### Diagnosis

315.32 Mixed Expressive/Receptive Language Disorder

315.00 Reading Disorder

315.1 Mathematics Disorder

315.2 Disorder of Written Expression

### Recommendations

*Not available*

## Appendix I

Diagnosis and recommendations presented to Ian's parent at parent conference.

### Diagnosis

315.8 Borderline Intellectual Functioning

314.00 Attention Deficit Hyperactivity Disorder – Inattentive Presentation

315.32 Mixed Expressive/Receptive Language Disorder

315.39 Phonological Disorder

### Recommendations

1. Discuss diagnosis and treatment of ADHD
2. Ian should continue his present school program with the same services, accommodations, and modifications
3. Follow-up with pediatrician on medical issues
4. Consider Speech and Language Therapy at *agency* this summer
5. Developmental follow-up, with collaterals, as needed, to monitor progress and make recommendations for further assessment and/or treatment

## Appendix J

Diagnosis and recommendations presented to Jay's parent at parent conference.

### Diagnosis

315.00 Reading Disorder

315.2 Disorder of Written Expression

315.32 Mixed Expressive/Receptive Language Disorder

315.39 Phonological Disorder

Rule out Developmental Motor Coordination Disorder

### Recommendations

1. ICT classroom placement to provide necessary support for language based learning
2. Intensive, structured reading program to address deficits in phonological processing and reading efficiency
3. Speech and Language therapy, 3 times a week, small group and individual, include addressing narrative and written expression
4. Occupational therapy, consider introduction of word processor
5. Accommodations/modifications for curriculum and assessments