

OUTPATIENT PEDIATRIC NEUROPSYCHOLOGY ASSESSMENT
RECOMMENDATIONS: ADHERENCE, BARRIERS TO IMPLEMENTATION, AND
THE RELATIONSHIP BETWEEN RECOMMENDATION ADHERENCE AND
OUTCOME

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by

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For Chris and Emilia, the loves of my life and my biggest
fans, with heartfelt gratitude for believing in me

Abstract

Outpatient pediatric neuropsychological assessment (PNA) is a time consuming undertaking and can require significant financial commitment from parents. What happens after the family leaves the assessment feedback session is largely unknown. Clinicians often assume that parents understand and enact the recommendations as directed and that ultimately the child's difficulties improve. In addition, PNA is often the last resort for frustrated parents whose child continues to struggle even though they have had various assessments and tried various interventions. The efficacy of recommendations that are made, including evidence based interventions, in these often complex cases has not been explored. This exploratory study investigated parental perceptions of the types of recommendations they were given after a PNA at a university-based outpatient neuropsychology clinic, the barriers to implementation of these recommendations, and the relationship between adherence and outcome. Parents whose children were evaluated in the past two years at this clinic were asked to complete an online survey. Only parents whose children were under 14 years of age at the time of assessment were included in this study. Twenty-six parents completed the survey. Findings indicated high overall recommendation adherence, with 92 percent indicating that they at least partially followed the given recommendations. Partial or greater adherence rates were high across recommendation types including recommendations to use a tutor (100%), pursue non-medical assessments (92%), make home changes (94%), participate in family therapy (100%), and use study or other learning resources (100%). Recommendations concerning school accommodations or changes, and medical referrals

had more partial adherence and non-adherence than other types of recommendations. Only one quarter of respondents reported full adherence to school recommendation while two thirds said such recommendations were only partially followed. Referrals for addition medical assessments had the highest non-compliance rate (27%) and equal full and partial compliance rates (both 36%). The types of barriers to adherence that parents encountered varied across recommendation types. Overall, across recommendation categories, the barriers most frequently endorsed were disagreement with the recommendation (both parents and school disagreement – 27%) and that the recommendation was too expensive or not covered by insurance (27%). A positive, significant relationship between recommendation adherence and outcome (increase in functioning) was found. A large number of respondents endorsed increased functioning after the assessment with 42 percent indicating their children were better and 31 percent much better.

Table of Contents

	Page
Abstract.....	v
Introduction.....	1
Background.....	2
Recommendation Adherence.....	3
Barriers to Recommendation Implementation.....	6
The Relationship Between Recommendation Adherence and Outcome.....	7
Importance and Scope of this Study.....	8
Methods.....	8
Participants.....	9
Measures.....	9
Procedure.....	17
Data Analysis.....	13
Results.....	14
Survey Return Rate.....	14
Participant Characteristics.....	14
Recommendations Given.....	15
Recommendation Adherence.....	15
Barriers.....	16
Outcome.....	18
Discussion.....	19

Implications of Findings.....	19
Future Research.....	25
Limitations.....	26
References.....	29
Tables.....	32
Figures.....	37
Appendices.....	44
A. Parent Online Survey.....	44
B. Email Requesting Study Participation.....	66

List of Tables

	Page
Table 1. Parental Recommendation Adherence Rates Previous Research	
Summary (% adherence).....	32
Table 2. Participant Characteristics.....	33
Table 3. Child Characteristics.....	34
Table 4. Percent of Partial and Non-compliant Participants Endorsing	
Each Barrier.....	35
Table 5. Percent Adherence by Recommendation Type for Past Versus	
Current Research.....	36

List of Figures

	Page
Figure 1. The percentage of respondents who reported being given each Recommendation type.....	37
Figure 2. The percentage of participants endorsing each adherence category across recommendation types.....	38
Figure 3. Percent of participants reporting barriers to recommendation adherence by recommendation type.	39
Figure 4. The percent of participants reporting each barrier type by recommendation category with “other” response re-categorized.	40
Figure 5. Percent of parents reporting each category of improvement in their child’s functioning.....	41
Figure 6. Average adherence across all recommendations versus improvement in functioning.....	42
Figure 7. Proportion of participants endorsing each adherence category across recommendation types who reported their children were “Better” or “Much better” after the assessment.	43

List of Appendices

	Page
Appendix 1: Parent Online Survey.....	44
Appendix 2: Email Requesting Study Participation	38

The Efficacy of Outpatient Pediatric Neuropsychology Recommendations: Adherence, Barriers, and Relationship to Outcome

Introduction

The parents of children who are struggling academically, socially, or emotionally are often desperate to learn how to help their children be successful. They have tried many different things including tutors, summer programs, hours of assisting with homework, but often without complete success, especially if their child has a more complex medical history or faces multiple deficits. Sometimes the school has completed an evaluation and put accommodations in place, yet the problems persist. What is really the problem? What should they do next? Many times these are the types of questions that prompt a parent to seek a neuropsychological evaluation. They want a clearer picture of their child's strengths and needs. They want advice and recommendations based on their child's abilities and skills. A pediatric neuropsychology assessment offers a detailed formulation of the problems, confirms or modifies diagnoses, and most importantly provides detailed recommendations. Recommendations offer a road map to parents – where to go and how to get there to improve their child's functioning. After parents receive feedback regarding the results of their child's assessment, they are often left to enact the given recommendations on their own and may encounter unforeseen barriers, compromising their ability to help their child. In addition the evaluating clinicians are not always apprised of the effectiveness of the recommendations that parents do follow, and if those recommendations lead to changes, positive or otherwise, in the child's functioning. It is important for clinicians to gain an understanding of

recommendation adherence, barriers to recommendation adherence, and the relationship between adherence and outcome to inform future practice and improve the effectiveness of pediatric neuropsychology assessment.

Background

Typically, the main goal of outpatient pediatric neuropsychological assessment is an increased understanding of a child's strengths and weaknesses in order to facilitate appropriate recommendations that will in turn lead to interventions to alleviate the identified deficits. The neuropsychologist's role in the assessment process typically ends when he or she provides the client with feedback regarding the individual's strengths and weaknesses and provides recommendations to compensate for the deficits. After the assessment feedback has been given, the neuropsychologist may often be unaware of the outcome. In fact, research has indicated that healthcare providers typically overestimate adherence rates and are unable to accurately judge which clients are prone to noncompliance (Martin & Dimatteo, 2014). In the realm of outpatient pediatric neuropsychology assessment, there are generally many recommendations involving changes to complex family and school systems. The complex nature of the types of recommendations often given in this setting, in addition to the fact that parents are often left to navigate these changes on their own, make it important to understand what happens after the feedback session is complete. Gaining insight into the level of recommendation adherence for the most commonly given recommendations, the barriers parents often encounter when trying to follow these recommendations, and the

relationship between recommendation adherence and outcome will facilitate more thoughtful and efficacious recommendations.

Recommendation Adherence

Very few studies have investigated adherence rates for recommendations resulting from an outpatient pediatric neuropsychology assessment (PNA). In the past, parental satisfaction with the neuropsychology assessment process and resulting recommendations has been quite high for outpatient neuropsychology assessments performed by neuropsychology departments at both a large and medium sized hospital in the Midwestern United States (Bodin, Beetar, Yeates, Katrina, Colvin, & Mangeot, 2013; Farmer & Brazeal, 1998). An increased understanding of their children's strengths and weaknesses, as well as positive ratings of the given recommendations, have been correlated with overall satisfaction but some parents reported that the assessment did not offer them as much help as they had expected in terms of improving their children's lives or improving school services (Bodin et al., 2013). In a separate study, parents also reported having a positive reaction to recommendations addressing needs at school, means to improve self-esteem, and for interventions from the medical profession (Farmer & Brazeal, 1998). Even though parental satisfaction with outpatient neuropsychological assessment has been high, no research was found to support a correlation between satisfaction and outcome or recommendation adherence and outcome. The most pertinent finding in terms of research specific to PNA indicated higher recommendation adherence rates for children with ADHD who were assessed by a neuropsychologist (both independent practices and a hospital-based neuropsychology department) in comparison

to children assessed otherwise, such as by a pediatrician, at school, or by other professionals (Pritchard, Koriakin, Jacobson, & Mahone, 2014). In this study ninety-four percent of parents indicated that participation in neuropsychological assessment was well worth their time although satisfaction ratings dropped slightly over time. Similarly, research regarding recommendation adherence by adults who have had a neuropsychological evaluation is also limited. As with PNA, high overall satisfaction with the recommendations given has been reported by adults assessed at a hospital-based outpatient neuropsychology department. Adult clients are more likely to adhere to recommendations concerning safety such as driving restrictions, establishing guardianship, or increasing supervision, than those recommendations offering support or coping methods (Westervelt, Brown, Tremont, Javorsky, & Stern, 2007).

More research exists regarding adherence to recommendations from other types of assessments such as psycho-educational and psychological assessments, and may serve to inform expectations regarding PNA recommendation adherence. Research regarding adherence rates across other fields has resulted in variable findings. Adherence to medical recommendations for acute illness ranges from 60 to 80 percent, for chronic illness from 40 to 70 percent and from 20 to 50 percent for preventative medical recommendations (Levensky, 2006). Adherence to outpatient psychotherapy has been found to be similar to that of chronic conditions, with research indicating anywhere from 40 to 50 percent of clients eventually dropping out of treatment (Levensky, 2006). More specifically, there are several areas that may be useful in informing expectations regarding PNA recommendation adherence. The area most closely aligned with what

occurs in PNA is parental adherence to recommendations from other forms of child assessments, including psychoeducational and general psychological assessments.

As shown in Table 1, adherence rates vary across assessment and recommendation types. Overall adherence rates have been found to range from 67 percent for recommendations resulting from a pediatric psychological assessment to nearly 82 percent for recommendations from university-based ADHD clinic (Dreyer, Milam, Moore, & O'Laughlin, 2010; MacNaughton & Rodrigue, 2001). The highest adherence rates reported were for active-self help recommendations provided to parents of children evaluated at the ADHD clinic (Dreyer, Milam, Moore, & O'Laughlin, 2010). Adherence to recommendations to implement a behavior plan, make school changes, seek non-psychological consultations, employ an academic tutor, and use medication have all ranged from 60 to approximately 80 percent for varying populations and research methods as noted in Table 1 (Dreyer et al., 2010; Human & Teglassi, 1993; Ibrahim, 2002; King, Hovey, Brand, Wilson, & Ghaziuddin, 1997; MacNaughton & Rodrigue, 2001; Moore & Symons, 2009; Pritchard et al., 2014). Recommendations to participate in individual therapy or to seek other psychological services have had slightly lower adherence, from approximately 50 to 70 percent also varying across populations and the source of the recommendation (Dreyer et al., 2010; Human & Teglassi, 1993; Joost, Chessare, Schaeufele, Link, & Weaver, 1989; King et al., 1997; MacNaughton & Rodrigue, 2001; Pritchard et al., 2014). The lowest recommendation adherence rate has been for family therapy as recommended to self-identified parents of children with

ADHD, with only about one third following this recommendation (Pritchard et al., 2014; King et al., 1997).

Barriers to Recommendation Implementation

While past research has indicated that many different types of social and economic factors can influence adherence rates, one of the most consistent findings, in terms of parental recommendation adherence, has been the negative correlation between perceived barriers to implementation and adherence (Dreyer et al., 2010; MacNaughton & Rodrigue, 2001; Human & Teglas, 1993; Meichenbaum & Turk, *Facilitating Treatment Adherence*, 1987). The greater the number of barriers perceived, the lower adherence rates become (Kazdin, Holland, & Crowley, 1997).

Limited research exists regarding parental adherence barriers for pediatric assessment recommendations, neuropsychological or otherwise. One study found that parents of children diagnosed with ADHD at a university-based ADHD specialty clinic reported having encountered at least one barrier when implementing recommendations. The most cited was time limitations (38.8%) and the least was lack of insurance coverage (8.8%), with lack of teacher cooperation (37.5%), unavailable resources (28.8%), waiting to try the recommendation (23.8%), waiting for appointment (18.8%), and not believing the recommendation would help (13.8%) falling in between (Dreyer et al., 2010). MacNaughton and Rodrigue (2001) reported that the barrier to implementing recommendations resulting from a pediatric psychological outpatient assessment that was cited most often by parents was difficulty gaining access to recommended resources (39%) followed by a negative attitude or belief about the recommendation (30%). They

found fewer parents reported financial limitations (11%) or time limitations (13%). Children in this study ranged from 4 to 12 in age, were mostly White, had lower socioeconomic backgrounds, and had mostly been diagnosed with ADHD, behavioral, or academic problems. There was no research identified regarding barriers encountered after a PNA and very little regarding barriers experienced by adult neuropsychology clients. One study found that adults who were assessed by a large hospital-based outpatient neuropsychology department mostly identified not agreeing with the recommendation, not seeing the need for the recommendation, or disagreement within the family on the importance of the recommendation as adherence barriers (Westervelt et al., 2007).

The Relationship Between Recommendation Adherence and Outcome

As mentioned, it is often assumed that if clients are satisfied with their assessment, then they will follow the recommendations they are given, which will in turn improve their functioning in some desired way. Very little research exists to confirm this string of assumptions. While parents' overall satisfaction with their child's PNA has been reported to be quite high, satisfaction with improvement in functioning has not been so (MacNaughton & Rodrigue, 2001). Forty-five percent of parents indicated they did not think the assessment had improved their child's life and 43 percent felt it had not improved school services (Bodin et al., 2013). Overall, parents felt they had an increased understanding of their children, but that understanding did not necessarily translate to a change in their children's functioning. Research regarding improvement after a psycho-educational evaluation for ADHD indicated that the degree to which parents reported

complying with recommendations was significantly related to the level of improvement they reported in their child's functioning. A little over three-quarters of parents believed their child's behavior had improved since receiving the assessment recommendations (Dreyer et al., 2010). In contrast, a survey of parents with children having a wider array of educational difficulties who had received a psycho-educational assessment at varying private agencies did not support a positive relationship between adherence and outcome (Human & Teglasi, 1993).

Importance and Scope of this Study

Although some preliminary conclusions regarding assessment adherence can be drawn from past research, factors unique to neuropsychological assessments may lead to different rates of adherence and outcome relative to other types of assessment. PNA assessment is usually employed for more complex cases and leads to a deeper understanding of strengths and needs, and potentially to more detailed and personalized recommendations. The expectation is that these recommendations lead to increased functioning and a positive outcome. For these reasons, exploratory research regarding adherence rates, recommendation adherence barriers, and relationships between adherence and outcome is necessary to gain a preliminary understanding of strengths and weaknesses of PNA in terms of addressing clients' reasons for seeking an assessment. In addition, this study will serve to focus the direction of further research in this area.

Methods

This study involved a retrospective on-line survey of parents whose children underwent a neuropsychological assessment at Widener's Neuropsychology Assessment

Center (NAC) in Chester, Pennsylvania. The main purpose of this survey as it pertains to this study was to investigate recommendation adherence, barriers to recommendation implementation, and the relationship between recommendation adherence and change in functioning.

Participants

The parents of children who were assessed at NAC between 2013 and 2015 and whose child was 14 years or younger at the time of assessment were contacted to participate in the study. In addition, the parent had to have provided an email address and consented to participate in research activities at the time of his or her child's assessment. After accounting for these exclusions, the researcher e-mailed 80 past clients a link to an online survey along with an explanation regarding the purpose of the study and the reason they were being asked to participate.

Measures

The online survey (Appendix A) was developed specifically for this study as well as a separate study about the pediatric neuropsychology assessment feedback process. Participant demographics were collected including current parent and child age, parent and child racial/ethnic background, parent marital status, parent and child highest level of education completed, parent and child sex, approximate household income, child's age at the time of the assessment, and whether or not the child was adopted. This information was collected solely to provide a description of the sample population. Information regarding parents' experience of their children's neuropsychological assessments, including the feedback session, the written report, adherence to recommendations, and

changes in their children's functioning were collected. In regard to recommendations, the survey asked parents to identify the types of recommendations they were given, the level they felt they had adhered to those recommendations, and finally any barriers to adherence for recommendations they did not fully implement. The survey consisted of Likert-style and open-ended questions. Participants were asked to select the recommendations that had been given for their child from seven different types of recommendation categories that included the need for school changes, the use of an academic tutor, referrals for additional non-medical assessments (e.g. speech and language, and physical therapy), changes at home, participation in family therapy, the use of study resources, and a referral for a medical assessment (e.g. medication and neurological examination). For the recommendations that were given, participants were then asked to rate the degree to which they felt they followed each (Not at all, Somewhat, Very much). Those who did not endorse the higher Likert-type scale value ("Very much") were asked to identify the barriers that hindered their adherence. Barriers varied slightly by recommendation type, but generally included the following options:

- I did not agree with the recommendation
- I did not understand the need for this recommendation
- I did not know how to follow the recommendation
- It was too expensive/not covered by insurance
- I could not find someone who could provide the service
- It was too time consuming
- My child resisted acting on the recommendation
- Other

Those that selected "Other" were asked to provide details regarding the barriers they faced.

Outcome was assessed by first asking parents if they thought the assessment process led to improvement in their children's functioning. If they answered 'yes', they were asked to rate improvement as "A little better", "Better", or "Much better." Those who did not think their children had improved were asked to rate their children's functioning as "No change", "Worse", or "Much Worse." In addition to information regarding recommendation adherence, barriers, and outcome, parents were asked to rate the number of recommendations they were given (Too few, Right amount, or Too many), if the recommendations had been personalized to their child (Not at all, Somewhat, or Very much), if there were additional changes that had helped their child that had not been recommended, and any ways they felt implementing recommendations might be made easier.

Given that the survey was created specifically for the purposes of this research study, no psychometric properties have been validated, although questions were based on industry best practices and surveys developed for other similar studies. The recommendation categories included in the survey were developed with the intent of allowing comparison to existing research. The survey was pilot tested by having several individuals who were not related to this study complete the survey and provide feedback to the evaluator about the clarity of the questions.

Procedure

A list of email addresses of the participants that met the study's criteria was provided by the university clinic. This list was imported into the on-line survey platform that anonymously managed these emails in terms of contacting participants and tracking

responses. Prospective participants were sent an automated email (Appendix B) from the survey website containing a brief explanation of the survey and how the collected data would be used. The email stated the importance of parental feedback to the assessment process and the practice of neuropsychology, and asked parents to consider completing the online survey. Parents were informed that participation was voluntary, and the data would be used anonymously in the research study. Parents who decided to participate were able to click a link to an online survey hosted by [surverymonkey.com](https://www.surveymonkey.com). The survey began with an informed consent page that parents were asked to read and agree to before beginning the survey. Upon completing the survey, participants were given the option of receiving an incentive gift card. If they chose to do so, they were asked to provide an email address where the gift card could be sent. Participants were notified that this address was to be stored separately from their survey data and used only as a means of emailing their gift card. This address was in no way connected to their survey data and was destroyed upon emailing the gift card. An automated reminder email was sent approximately one week after the initial email and another about a month later. This email was generated through the survey website in order to obscure the email addresses that had or had not responded. This reminder was sent only to potential participants who had not already completed the survey. The survey was closed the following month and participants were sent an email thanking them for their time. Finally, an automated email was sent from a retailer's website providing those who had completed the survey with a link to collect their gift card reward.

Data Analysis

The data collected from this research were analyzed using Microsoft Excel and IBM SPSS Statistics 23. Given this study is exploratory in nature and small in size, the type of recommendations given, adherence rates, and barriers to adherence were calculated as a percentage of respondents across the seven main recommendation areas explored. Similarly, adherence barriers were calculated as a percentage of respondents for each barrier category type. A large number of participants endorsed “Other” as a barrier and then provided an explanation of the barrier. These explanations often described one of the original barriers listed on the survey. For this reason the investigator made the decision to move many “Other” responses to the appropriate barrier category. A person not involved in this study then crosschecked each decision. The relationship between outcome and adherence rate was explored by comparing the average adherence rate across all recommendation types to reported outcome. To facilitate this comparison, each of the possible outcome rankings was assigned a numeric value from one to six (1: Much worse, 2: Worse, 3: No change, 4: A little better, 5: Better, 6: Much better). Next an average adherence score was calculated by assigning a numeric ranking, from one to three, to each adherence variable (1: Not at all, 2: Somewhat, 3: Very much). The average of these values across all the recommendations that each participant endorsed was used as an overall average adherence score for that participant. A plot of these variables, average adherence versus outcome, was generated to see if a relationship existed. The linear correlation between these variables was calculated using Pearson product-moment correlation coefficient.

Results

Survey Return rate

Eighty people met the participant requirements and were emailed a link to the survey. Of these, nine emails were returned as undeliverable, leaving 71 participants. Twenty-six parents completed the survey and two partially completed it. The response rate for the survey was 36.6 percent.

Participant Characteristics

Socio-economic characteristics of the parents who completed the survey are contained in Table 2 below. All participants were female and their average age was 44.7 years and ranged from 37 to 55 years with a standard deviation of 6 years. The mean gross yearly family income was \$161,000 with a range of \$30,000 to \$500,000 and standard deviation of \$130,000 (median of \$137,5000). Participants were largely married (81%), white (69%), and had earned at least an undergraduate degree (81%). More than half had a level of education beyond undergraduate education.

The parent reported characteristics of the children who had been assessed (at the time they were assessed) are listed in Table 3. The average age was 8.9 years (standard deviation of 2.3 years; median 8.5 years) with a range from 5 to 14 years. They were in kindergarten through 10th grade at the time of assessment, largely male (73 percent male versus 27 percent female). Ethnic background was very similar to that of the participating parent with a few more children being described by the other category (typically the parent noted her child was multi-racial in this case). Only two children were adopted (7%). The most reported primary diagnosis was ADHD (38.5%) followed by reading disorder (23.1%).

Recommendations Given

Eighty-four percent of participants felt they were given the right number of recommendations, two percent felt they had been given too many, and two percent felt they had been given too few. Many participants felt the given recommendation were adequately personalized to their child (73%), about a quarter felt they were somewhat personalized (26.9%), and no one reported receiving recommendations that were not at all personalized. As Figure 1 shows, most respondents (92.3%) reported that they were given recommendations for changes at their children's schools, followed by recommendations for changes at home (69.2%), and then non-medical assessments (46.3%). Those who were given the recommendation to seek additional, non-medical assessments were largely recommended to seek a speech and language assessment (66.6%) followed by other types of assessments (25%) and lastly a physical therapy assessment (8.3%). Equal numbers of parents reported that specific resources and additional medical assessments were recommended (both 42.3%). About a third of respondents reported that using a tutor to assist their children was recommended (30.8%). The least recommended activity was family therapy (19.2%).

Recommendation Adherence

Figure 2 shows that overall the majority of parents reported that they followed the given recommendations "Very much." Adherence across the recommendation categories, including use of a tutor, seeking additional non-medical assessments, making changes at home, participating in family therapy, and using additional resources, was greater than half in terms of those who endorsed "Very much" and greater than 90%

adherence when those endorsing “Somewhat” and “Very much” were combined. Subsequently, these categories had very low noncompliance (“Not at all”). Recommendations to use a tutor, attend family therapy, and use additional resources all had zero non-adherence while recommendations for non-medical assessments (8.3%) and home changes (5.6%) had low non-adherence rates. In contrast adherence for recommendations that focused on school changes and additional medical assessments did not follow this pattern. While the total adherence rate for those who reported either “Somewhat” or “Very much” adherence to school recommendations was around 90%, there were many more parents reporting only “Somewhat” (66.7%) adherence in comparison to those reporting “Very much” (25%) adherence. The second recommendation category that differed from most others was that for further medical assessments. This recommendation category had the highest noncompliance (27%) while compliance and partial compliance were identical (both 36%).

Across all the recommendation types that were included in this study, in total, participants reported that 7.9 percent were not followed at all, 44.9 percent were followed somewhat, and 47.2 percent very much. The rate for partial (“Somewhat”) or greater adherence was 92.1 percent.

Barriers

Parents who endorsed an adherence level of “Not at all” or “Somewhat” were asked to identify the barriers that they encountered for each recommendation. The types of barriers encountered by parents varied across recommendation types, as shown in Figure 3, with the exception of the “Other” category, which accounted for a significant

portion of the barriers reported for of all recommendation types. For this reason those who endorsed “Other” and provided a description of the barrier they encountered were re-categorized, when appropriate, to the most similar non-other category (categorization process described above).

Figure 4 shows the percent of participants endorsing the different barrier types by each recommendation type after the “Other” responses were re-categorized. Participants endorsed many different types of barriers for home changes and resources. Other types of recommendations had more agreement with regard to the types of barriers experienced. Disagreement with the recommendation was the most consistently cited barrier (School: 28%, Non-medical assessment: 60%, Home changes: 13%, Family therapy: 50%, Medical assessment: 43%). For school recommendations only, disagreement referred to school (rather than parental) disagreement; for the remaining categories this pertained to parental disagreement with the recommendation. Many participants across the different recommendation categories also reported that the recommendation was too expensive or not covered by insurance (School: 50%, Family therapy: 50%, Resources: 25%, Medical assessment: 29%). This barrier entailed the parent reporting she did not have the financial resources for the recommendation with the exception of the school category. This barrier for school recommendations referred to the school not having the recommended resource. Also noteworthy was that 40 percent of those who did not fully follow the recommendation for non-medical assessments said it was too time consuming. The total number and percentage of participants who reported each barrier is listed in Table 4. The most reported barriers across all recommendation

types were “Too expensive/not covered by insurance” and “Did not agree”, with 27.7% of partial and non-compliant participants endorsing both of these barriers. The third most reported barrier was “Other” (17.0%).

Outcome

As shown in Figure 5, the majority of respondents reported that their child’s functioning after the assessment was either better (42%) or much better (31%). None of the parents reported that their child’s functioning had gotten worse or much worse. About 15 percent saw no change and around 12 percent felt their children were a little better.

To assess the relationship between recommendation adherence and outcome, an average adherence rating across all recommendations was calculated for each respondent. In Figure 6, a plot of average recommendation adherence across all recommendations that were given and the parent rating of her child’s improvement (the higher the rating the more improvement reported) shows a positive relationship between adherence to recommendations and improvement in functioning.

Likewise average adherence and outcome demonstrated a statistically significant positive Pearson correlation coefficient (0.619). This positive correlation was relatively strong and statistically significant (0.01 level).

To further investigate the relationship between outcome and the different recommendation types, the proportion of participants for each adherence category who reported their child was “Better” or “Much better” was compared across recommendation types. Figure 7 shows this comparison. In general, a greater proportion of participants

who claimed their child was “Better” or “Much better” endorsed higher adherence rates across most recommendation categories. The exception to this finding was for recommendations for non-medical evaluations and home changes. For these types of recommendations the relationship between adherence and outcome is less clear with partial adherence and non-adherence associated with a positive outcome. Also of note was that many parents that did not fully adhere to medical referrals also reported positive outcomes.

Discussion

Implications of Findings

Parent adherence. Parent adherence to recommendations given as a result of a PNA was higher than findings from previous research with overall adherence rate (i.e., those reporting Somewhat - 47.2% or Very much - 44.9% following recommendations) of 92 percent in comparison to past research findings of 67 to 82 percent overall adherence (Dreyer et al., 2010; MacNaughton & Rodrigue, 2001). In combination, partial adherence or greater (“Somewhat” and “Very much”) was high across all recommendation categories. All participants who were given recommendations to use an academic tutor (100%), attend family therapy (100%), or use assistive resources (100%) reported that they had at least partially adhered to the recommendation. In all of these cases, full adherence was greater than partial adherence. Similarly, full adherence was greater than partial adherence for recommendations to make changes at home (full and partial: 94%) and pursue non-medical evaluations (full and partial: 92%), although these recommendation types did have some who reported non-compliance (Home: 6%, Non-

medical: 8%). Those who did not fully adhere to recommendations to make changes at home reported that their children resisted this recommendation (25%) or they did not know how to follow it (25%). Thirteen percent reported this recommendation was too time consuming (13%) or they did not agree with it (13%). The recommendation to seek a non-medical evaluation, while having high adherence (partial adherence: 33%, full adherence: 58%), was also rated by some as not followed at all (8%). Of those who did not fully adhere to this recommendation, 60 percent said they did not agree with it and 40 percent said it was too time consuming.

The two recommendation types that (while having high combined partial and full adherence) had more partial than full adherence were those for school changes and medical assessment referrals. About two-thirds of parents reported that school recommendations were only partially followed and about 8 percent said they were not followed at all. The two most frequently reported barriers for this recommendation were that the school did not have the necessary resources (50%) and that the school did not agree with the recommendation (28%). There are likely many reasons why adherence to school recommendations is more difficult than other types of recommendations. Navigating the school system can be confusing and time consuming for parents. Also, parents are not always sure to what degree schools actually comply with recommendations given that most of them are relying on teacher report to determine what is happening at school. Some parents, especially if their relationship with the school is contentious, may be more negative about the level of adherence. Parents gave various reasons why they were unsure how well the school followed the recommendations,

including staff changes, disagreement between teachers, and general lack of awareness of the level of adherence. These findings point to the importance of working with school personnel to facilitate recommendation implementation, helping parents learn more about educational rights, and how to use these to support their child, or assisting parents with understanding commensurate recommendations outside of school that may be available.

The recommendation for medical assessments had the highest non-adherence rate (27.3%). The most cited barrier was disagreement with this recommendation (43%) followed by being too expensive or not covered by insurance (29%). One parent reported that she disagreed with her husband regarding the need for medication and another reported that they decided to implement other recommendations before considering medication. Other studies have identified family dissension as a reason for non-compliance (Westervelt et al., 2007).

Table 5 presents a comparison of adherence rates by recommendation type from previous research and this study. It is difficult to make a direct comparison since adherence has been measured in different ways across studies and exists on a continuum. Several of the studies thus referenced have considered adherence as a dichotomous variable, asking parents to report either following or not following the recommendations (MacNaughton & Rodrigue, 2001; Moore & Symons, 2009; Pritchard et al., 2014). In contrast other studies have asked parents to report adherence on a scale ranging from none to full adherence as was done in this study (Dreyer et al., 2010; Human & Teglas, 1993; Ibrahim, 2002; King et al., 1997). While it was not always clear how reported adherence rates were calculated, at least one study did indicate that the rates captured

both partial and full adherence reports (Human & Teglassi, 1993). When partial and full adherence are combined this study found higher adherence to school, non-medical, tutoring, and family therapy recommendations than previous research. Adherence to medical/medication referral was within the range of adherence rates from previous findings.

Barriers to adherence. Reported barriers varied across the different types of recommendations. The most cited barriers were “Did not agree” (27.7%) and “Too expensive/not covered by insurance (27.7%).” The categories with the highest partial and non-compliance were recommendations for school and for medical assessment. The most reported barriers to implementing school changes were the school not agreeing with the recommendation (28%) and the school not having the resources (50%). Parents who were given a referral for medical assessment or medication reported several different barriers including that they did not agree with recommendation (43%), it was too expensive or not covered by insurance (29%), they did not understand the recommendation (14%), and their child resisted acting on this recommendation (14%).

Comparison of these findings with those of past research yielded variable results. Parental disagreement with the given recommendation was, overall, 27.7 percent, a statistic close to previous findings that indicated 30 percent of parents had a negative attitude about the recommendation they were given after a pediatric psychological assessment (MacNaughton & Rodrigue, 2001). In contrast a study specific to recommendations given to parents of a child assessed at an ADHD clinic found lower (8.8%) disagreement with the recommendation they were given. Findings regarding

barriers to implementation of school recommendations indicated about 28 percent of parents reported difficulty achieving full adherence because their school did not agree with the recommendation. This is similar to past findings that indicated 37.5 percent of parents experienced disagreement with their children's teachers regarding the recommendations they had been given (Dreyer et al., 2010). This study found lower barriers in terms of recommendations being too time consuming (6.4% for this study versus 13 to 38.8% for previous) and not being able to locate the recommended resource (2.1% for this study versus 28.8 to 39% for previous). These findings may be a factor of the location of the clinic, which is in an area that has abundant resources, or the higher SES characteristics of the sample population.

Outcome. Outcome or improvement in functioning was high, with 82 percent indicating at least a little improvement in functioning. The majority of parents indicated their child was better (42%) or much better (30%). In combination (72%), this is a much higher rate of improvement compared with past research that indicated 57 percent of parents thought their child's PNA had improved school services, and 55 percent thought that it had improved their child's life (Bodin et al., 2013). Research regarding improvement after a psycho-educational assessment found about three-quarters of parents reported improvement (Dreyer et al., 2010). In comparison to these findings, outcome after a PNA, as measured by increase in functioning, seems to be higher. There are likely many reasons for this including the more in-depth nature of PNA and the more personalized recommendations that result. Ongoing research, using the additional data collected in the online survey (Appendix A) will investigate the contribution different

aspects the PNA feedback session may contribute to satisfaction, adherence, and outcome.

Past research has found both a positive relationship between recommendation adherence and outcome, as well as no relationship (Dreyer et al., 2010; Human & Teglas, 1993). Findings from this research indicated a significant, positive relationship between the two, bolstering the assumption that recommendation adherence is associated with improvement in functioning. The exception to this finding was the recommendation for non-medical assessment, with those endorsing partial or non-adherence to this recommendation still experiencing positive outcomes. Similarly, even when parents did not follow medical referral recommendations, some still reported improvement in their child's functioning. Partial adherence to recommendations to make changes at home exceeded full adherence in terms of being associated with positive outcome. It cannot be concluded that partial adherence is more advantageous than full adherence for these recommendation categories given that every participant had varying combinations of recommendation and variable characteristics (e.g., diagnosis, time since assessment, gender). This finding indicates further investigation is warranted regarding the usefulness and effectiveness of these types of recommendations.

In summary this study found that parental adherence to recommendations given, as the result of a PNA assessment, was quite high. Recommendations for school changes and medical assessment were the most difficult to carry out. PNA seemed to lead to higher adherence rates and lower barriers in terms of finding resources and making recommendations that are not too time consuming. Parental and school disagreement

with recommendations was similar to previous findings. Adherence to recommendations for a PNA led to positive outcomes in terms of increased functioning.

Future Research

Due to the complicated nature of school recommendations, future research might investigate adherence across the different types of school recommendations. In addition it would be helpful to understand the limitations of such recommendations from the perspective of school staff. Some school related variables that might be explored in terms of recommendation adherence include differences between children in private versus public school, the effect of having an Individualized Education Plan, and teacher rankings of recommendation adherence. Also the highest non-adherence rate was for medical assessment referrals. This recommendation category encompasses many different types of referrals such as a neurological assessment, a referral to a psychiatrist for psychopharmacological intervention, or a referral for ADHD medication. Due to the wide array of medical referrals that are given, future research should investigate adherence and barriers across the types of recommendations subsumed by this larger category. Across all recommendation types, many respondents reported a barrier of “other”, making it unclear what the actual barrier was. More in depth research is needed to explore what additional types of barriers may exist.

Limitations

Several limitations to this study are significant. First, the sample size was small (n=26) and consisted mainly of affluent, married, well-educated, Caucasian parents. Furthermore, only mothers responded. This population may have reported higher

adherence, had greater means to enact recommendations, and because of their higher education level, had an easier time understanding recommendations and how to interact with the necessary systems. For these reasons it may be inaccurate to generalize these findings to other populations. Ways in which to increase participation are: (a) create a larger incentive for completion of the survey; and (b) discuss the project with potential participants prior to the neuropsychological assessment.

In terms of the limitations of the survey and study methods, the time that elapsed from the time of the assessment to when the survey was completed ranged from several weeks to two years. For those who had recently completed an evaluation, the time frame to fully implement recommendations and evaluate changes in functioning was limited. In contrast, those who were assessed many months prior to completing the survey may have inaccurate recall of the recommendations given and difficulty accurately judging the effect on changes in functioning. Adherence and outcome may vary as time passes. These problems could be addressed by a longitudinal design in which individuals are surveyed at varying intervals following the assessment.

The children included in this study were assessed for a variety of reasons resulting in many different diagnoses. It is possible that recommendation adherence and barriers vary by diagnosis. The severity of difficulties varied across participants, as did the number of comorbid medical and behavioral problems, which may also impact adherence and barriers. Since this was a retrospective survey, parental recall of the information from the assessment and recommendation adherence may have been inaccurate. In addition, the time that had elapsed since the assessment varied across participants. It is

possible that recommendation adherence, barriers, and outcome exist on a continuum that shifts as time passes after the assessment.

The survey was developed specifically for this study and was not tested for reliability or validity. While the questions were based on best practices and surveys from similar research, the validity and reliability of the measure is unknown. Because there is not any formal assessment in existence to measure recommendation adherence and barriers, this was an unavoidable limitation. Even so it makes comparisons with other studies more difficult since each study relies on a different measure.

Nonetheless, the study represents an important step in validating the ecological validity of the PNA to help justify the significant outlay of time, money, and effort to complete these comprehensive evaluations. These results indicate several areas that clinicians might immediately address in practice. For instance, providing thorough education regarding the need for medical assessment and addressing parental disagreement during the feedback session may increase adherence. It may also be advantageous to follow up with parents shortly after the feedback session to further answer questions and address their concerns. In addition, providing parents a referral to a physician that is willing to explain the benefits, risks, and side effects of such interventions might provide a bridge to implementation of such recommendations. In terms of school recommendation, working directly with a child's schools to help implement and increase the understanding of the need for given recommendations may increase adherence. Attending school meetings or continuing to advise parents after the assessment would allow the clinician to facilitate the implementation of alternate

interventions when a school does not have the recommended resources. Or alternately educating parents regarding comparable resources outside the school systems may be helpful. While adherence to recommendation for home changes was high, those that struggled to implement this type of recommendation cited various barriers. The need for personalized recommendations, that address the level of functioning and resources of the family is likely necessary. Referral to a clinician that can assist in making such changes, or providing resources that would guide parents in this process may increase adherence. Forthcoming research regarding the role the PNA feedback session plays in recommendation adherence and outcome will further increase the understanding of the PNA assessment process and efficacy.

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Table 1

Parental Recommendation Adherence Rates Previous Research Summary (% adherence)

Recommendation Type								
Overall Adherence	67			82				
Self-help Behavior Plan				91				76
School		72		78				
Non-psych referral or professional consultation	81	62		88				
Medication/Medical			70		80		67	84
Tutoring		66						
Therapy/Psychological Services	47	73		72	57	53	51	
Family Therapy					31		33	
Notes. Research Description	Phone interview with parents of 4 to 12 year olds 4 weeks after psych assessment	Structured phone interview 4 months after psychoed. Evaluation at private agency	Structured interview with parent and child diagnosed with ADHD at med. check	Structured phone interview 4 to 6 weeks after evaluation at ADHD clinic	Online survey of parents of children with ADHD – recruited online	Retrospective survey – children referred for psychotherapy 1 to 2 years prior	Structured interview 6 to 8 months after hospital discharge (suicidal adol.)	Retrospective online or paper survey of parents with children with ASD
	(MacNaughton & Rodrigue, Teglasi, 1993) 2001)		(Ibrahim, 2002)	(Dreyer et al., 2010)	(Pritchard et al., 2014)	(Joost et al., 1989)	(King et al., 1997)	(Moore & Symons, 2009)

Table 2

Participant Characteristics

	<u>Mean</u>	<u>Median</u>	<u>Range</u>	<u>Std. Deviation</u>
Age (years)	44.7	43	37 to 55	6
Income (dollars)	161,000	137,500	30,000 to 500,000	130,000
		<u>No. of Participants</u>	<u>% of Participants</u>	
Gender				
Male		0	0	
Female		26	100	
Ethnic Background				
Asian		1	3.8	
Black/African American		5	19.2	
White/Caucasian		18	69.2	
Hispanic (any race)		2	7.7	
Marital Status				
Married		21	80.8	
Divorced		3	11.5	
Separated		1	3.8	
Never Married		1	3.8	
Education				
High School		1	3.8	
Some undergraduate		4	15.4	
Completed undergraduate		6	23.1	
Some graduate		2	7.7	
Completed graduate		11	42.3	
Some/completed doctorate		2	7.7	

Table 3

Child Characteristics

	<u>Average</u>	<u>Range</u>	<u>Median</u>
Age at assessment time	8.9	5 to 14	8.5
Grade at assessment time	3.4	K to 10	3
Age at time of survey	10.8	7 to 14	10
Grade at time of survey	5.5	3 to 10	5
	<u>No.</u>	<u>%</u>	
Gender			
Male	19	73.1	
Female	7	26.9	
Ethnic Background			
Asian	1	3.8	
Black/African American	5	19.2	
White/Caucasian	16	61.5	
Other	4	15.4	
Adopted			
Yes	2	7	
No	24	92.3	
Primary Diagnosis			
ADHD	10	38.5	
Reading Disorder	6	23.1	
Math Disorder	1	3.8	
Nonverbal Learning Disorder	1	3.8	
Anxiety	2	7.7	
Intellectual Disability	1	3.8	
Autism Spectrum Disorder	3	11.5	

Table 4

Percent of partial and non-compliant participants endorsing each barrier

	<u>No. of Participants</u>	<u>% of partial and non- compliant participants</u>
Did not agree	13	27.7
Too expensive/not covered	13	27.7
Other	8	17.0
Child resisted	4	8.5
Did not know how to follow	3	6.4
Too time consuming	3	6.4
Did not understand	2	4.3
Could not find resource	1	2.1

Table 5

Percent adherence by recommendation type for past versus current research

	<u>Previous findings*</u>	<u>Somewhat</u>	<u>This study</u> <u>Very much</u>	<u>Total</u>
School	72-78	67	25	92
Non-medical referral	62-88	33	58	92
Tutoring	63	37	63	100
Medication/medical	66-84	36	36	73
Family therapy	33	40	60	100

* Dreyer et al., 2010; Human & Teglas, 1993; Ibrahim, 2002; Joost et al., 1989; King et al., 1997; MacNaughton & Rodrigue, 2001; Moore & Symons, 2009; Pritchard et al., 2014

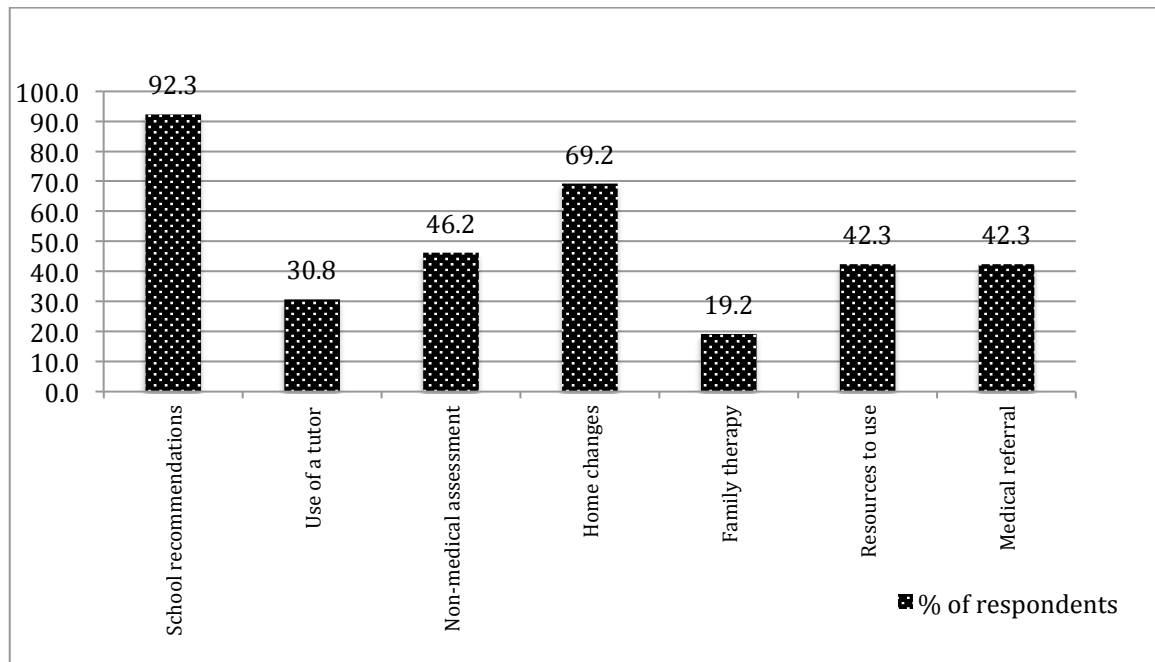


Figure 1. The percentage of respondents who reported being given each recommendation type.

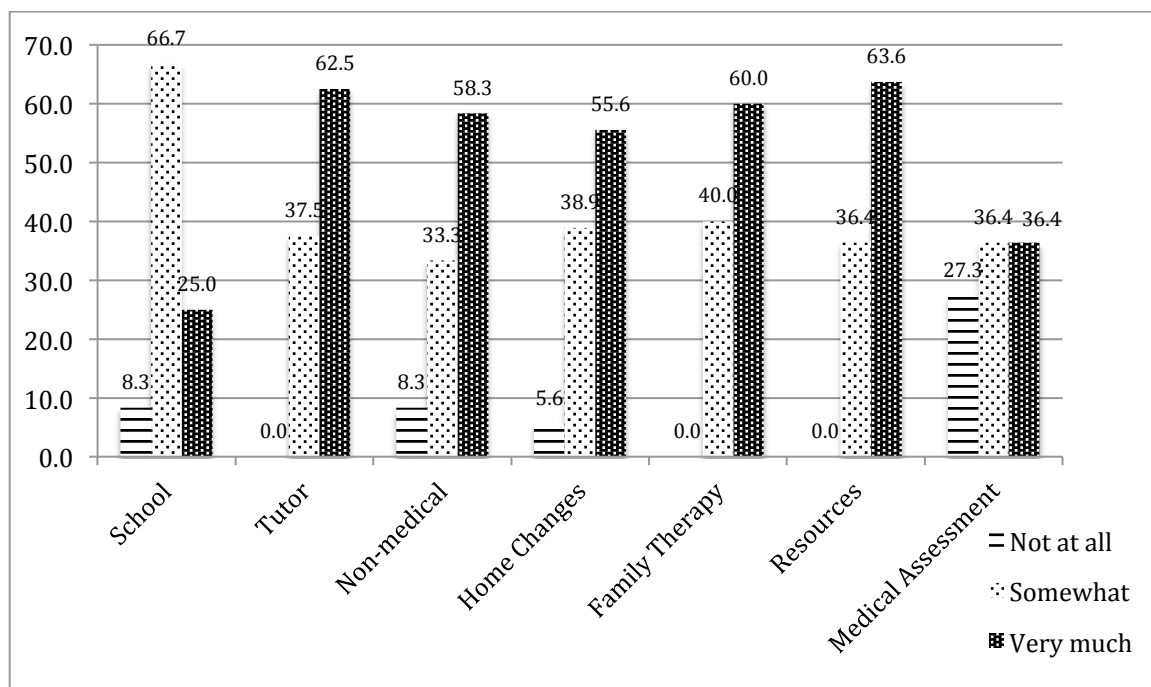


Figure 2. The percentage of participants endorsing each adherence category across recommendation types.

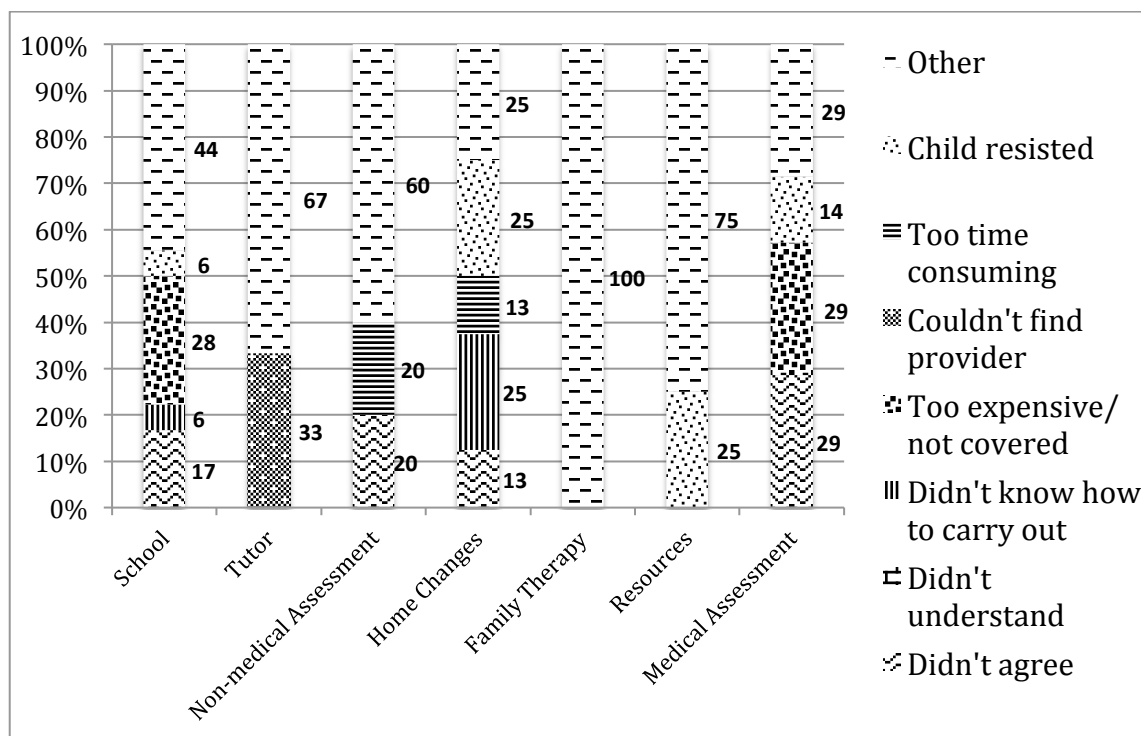


Figure 3. Percent of participants reporting barriers to recommendation adherence by recommendation type.

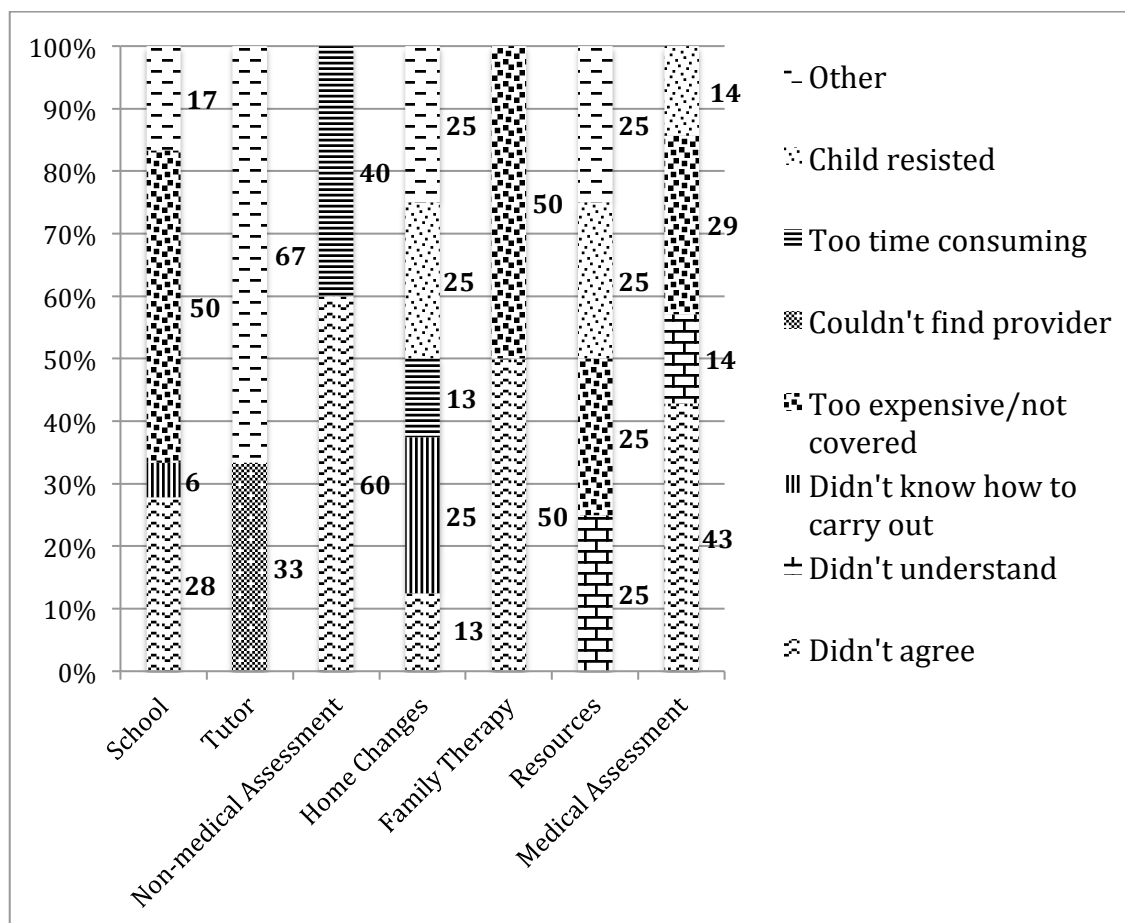


Figure 4. The percent of participants reporting each barrier type by recommendation category with “other” response re-categorized.

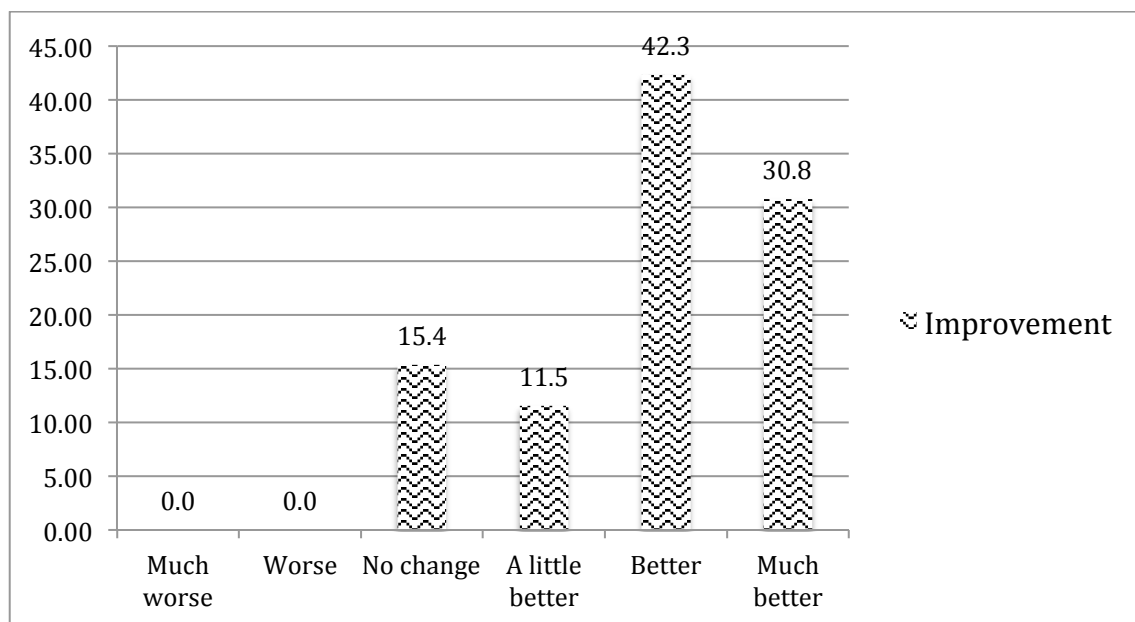


Figure 5. Percent of parents reporting each category of improvement in their child's functioning.

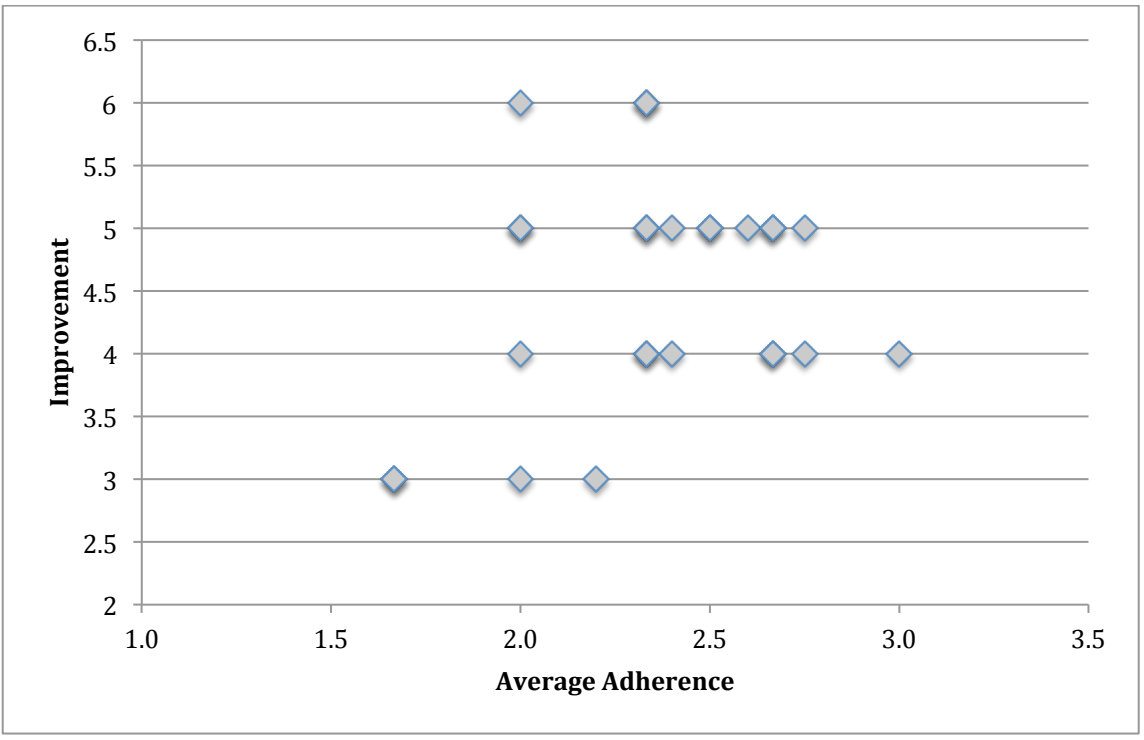


Figure 6. Average adherence across all recommendations versus improvement in functioning.

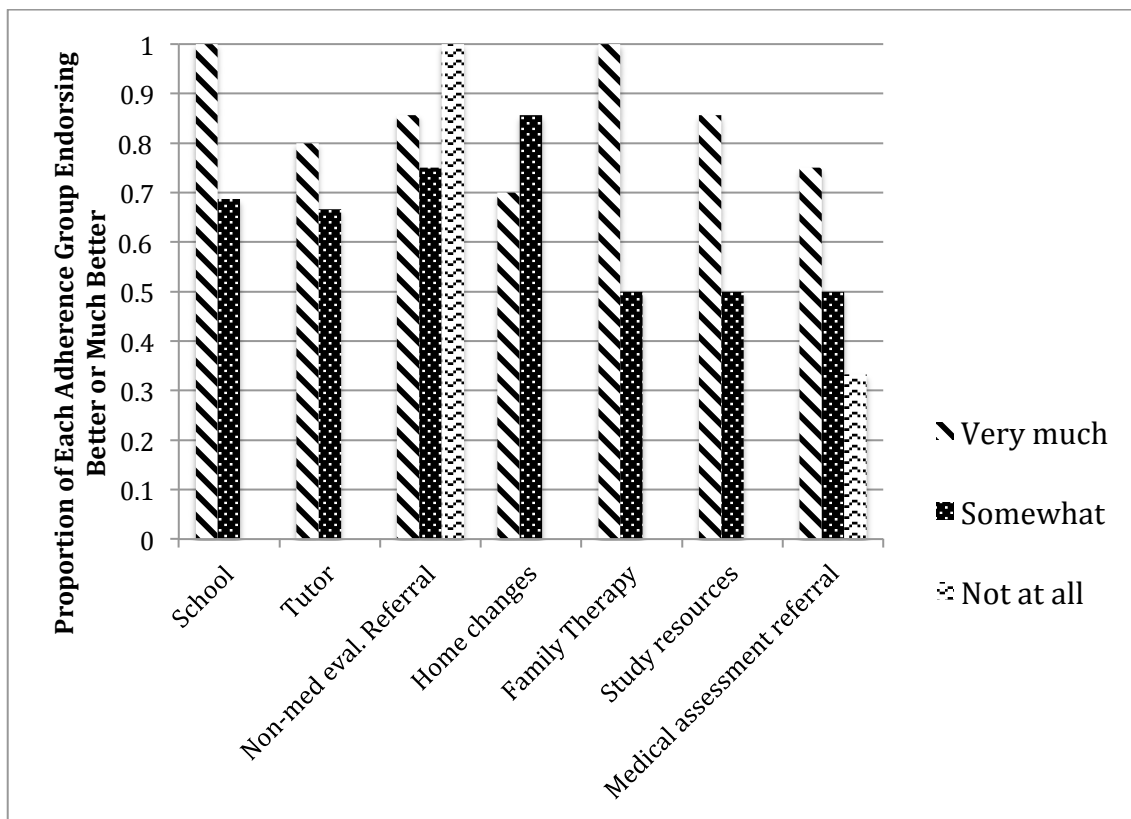


Figure 7. Proportion of participants endorsing each adherence category across recommendation types who reported their children were “Better” or “Much better” after the assessment.

Appendix A

Parent Online Survey

To get started...

Parental Perceptions of the Neuropsychological Assessment Process

By clicking the NEXT button below, to begin the survey, you acknowledge that you have read and agree to the consent information (listed below) and are choosing to participate in this study.

CONSENT INFORMATION/STUDY DETAILS

PURPOSE OF THE STUDY: The purpose of this study is to get feedback from parents who had their child assessed at Widener's Neuropsychology Assessment Center. We hope to use the data we get from this survey to improve our assessment practice. You are being asked to participate in the study because your child was assessed at Widener in the past two years.

DESCRIPTION OF THE STUDY: To participate in this study you will be asked to complete an online survey. This survey will ask questions about your child's assessment at Widener. Participation in this study is optional and answers are confidential. The amount of time required will be between 10-15 minutes. There is no cost to me related to study participation.

RISKS AND DISCOMFORTS: As a participant in this study, you may not remember all of the details of your child's assessment. You should be aware that this may result in discomfort. We ask that you answer the questions the best that you can. We are available to answer any questions.

ALTERNATIVE PROCEDURES: You may choose not to participate in the survey without penalty.

CONFIDENTIALITY: All documents and information pertaining to this research study will be kept confidential in accordance with all applicable federal, state, and local laws and regulations. The data generated by the study will be anonymous and may be reviewed by Widener University's Institutional Review Board, which is the committee responsible for ensuring your welfare and rights as a research participant, to assure proper conduct of the study and compliance with university regulations. If any presentations or publication result from this research, you will not be identified by name. Any information you provide as part of this survey will be kept for future research. Your answers are anonymous and confidential. Data from the study will be stored on a secure computer. Survey answers will only be available to the study investigators via a secured account. You may choose to provide an email address to receive a gift card. This email will be deleted after your gift card has been sent. It will not be connected with your survey answers.

TERMINATION OF PARTICIPATION: You do not have to complete this survey. Participation in this study is optional. Once you complete the anonymous survey your records cannot be identified and cannot be removed from the study.

COMPENSATION: If you complete the study you can choose to receive a \$5 Starbucks gift card. This will be emailed to the email address of your choice.

INJURY COMPENSATION: Neither Widener University nor any government or other agency funding this research project will provide special services, free care, or compensation for any injuries resulting from this research. Treatment for such injuries will be at your expense and/or paid through my medical plan.

QUESTIONS: If you have further questions about this study please contact Allison Blechschmidt at ablechschmidt@mail.widener.edu or Meghan DeVries at mgold@mail.widener.edu. If you have any questions about the rights of research participants, you may call the Chairperson of Widener University's Institutional Review Board at 610-499-4110.

Tell us a little about you...

We know it may have been a while since your child was evaluated at Widener's Neuropsychology Assessment Center. Please try to answer the following questions about your child's evaluation the best that you can.

If you have any questions or concerns feel free to contact us at 610.499.4672.

* What is your current age?

* Which of the following best describes your racial or ethnic background? Please check one:

* What is your marital status?

- Married
 Separated
 Widowed
 Divorced
 Never Married

* What is your highest level of education?

* What is your sex?

* What is your approximate household income before taxes?

* What is your child's current age?

* What was your child's age at the time of his or her assessment?

* What grade is your child in at school?

* What grade was your child in at the time of his or her assessment?

* What is the sex of your child?

* Which of the following best describes your child's racial or ethnic background? Please select one:

* Was your child adopted?

- No
- Yes - adopted from outside the family
- Yes - adopted from inside the family
- Yes - adopted by step-parent
- Other (please specify)

The Feedback Session: Introduction

The feedback session was the appointment you had at our office to go over your child's test results and our recommendations. Our goal for the feedback session is for you and your family to leave the office with a good understanding of the following:

1. The actual test results
2. The relationship between test results and your child's strengths and weaknesses
3. The relationship between test results and any diagnoses
4. A clear understanding of the recommendations
5. A feeling of empowerment to help your child

Please keep these feedback goals in mind as you answer the following set of questions.

For each of the following factors, please indicate:

1. To what degree you believe the factor is important to a successful feedback session
2. To what degree did you personally experience the factor during your feedback session

The Feedback Session

FACTOR: Evaluator trustworthiness

* To what degree do you believe *evaluator trustworthiness* is important to a successful feedback session?

Not at all important Somewhat important Very important

* To what degree did you find your *evaluator trustworthy*?

Not at all trustworthy Somewhat trustworthy Very trustworthy

If *not at all trustworthy*, please explain why not?

The Feedback Session

FACTOR: Not feeling rushed during the feedback session

* To what degree do you believe *not feeling rushed* is important to a successful feedback session?

Not at all important Somewhat important Very important

* To what degree did you *feel rushed* during your feedback session?

Not at all rushed Somewhat rushed Very rushed

If you felt *very rushed* please tell us what caused this.

The Feedback Session

FACTOR: Communication of clear recommendations

* To what degree do you believe *communicating clear recommendations* is important to a successful feedback session?

Not at all important	Somewhat important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* To what degree were *recommendations clearly communicated* to you during your feedback session?

Not at all communicated clearly	Communicated somewhat clearly	Communicated very clearly
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If recommendations were not communicated clearly can you tell us what was not clear or what might have helped?

The Feedback Session

FACTOR: Evaluator warmth and empathy

* To what degree do you believe *evaluator warmth and empathy* are important to a successful feedback session?

Not at all important	Somewhat important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* To what degree did you feel your evaluator was *warm and empathetic* during your feedback session?

Not at all warm and empathetic	Somewhat warm and empathetic	Very warm and empathetic
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If your evaluator was not warm and empathetic please tell us what she/he could have done differently.

The Feedback Session

FACTOR: Good evaluator listening skills

* To what degree do you believe *evaluator listening skills* are important to a successful feedback session?

Not at all important Somewhat important Very important

* To what degree did you feel your *evaluator listened to you* during your feedback session?

Not at all Somewhat Very much

If you feel your evaluator did not listen to you what could she/he have done differently?

The Feedback Session

FACTOR: Use of concrete examples in explaining test results

* To what degree do you believe the *use of concrete examples* is important to a successful feedback session?

Not at all important Somewhat important Very important

* To what degree did your evaluator *use concrete examples* in explaining test results?

Not at all Somewhat Very much

The Feedback Session

FACTOR: Non-judgmental atmosphere

* To what degree do you believe having a *non-judgmental atmosphere* is important to a successful feedback session?

Not at all important Somewhat important Very important

* Was your evaluator *judgmental* during the feedback session?

Not at all judgmental	Somewhat judgmental	Very judgmental
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you felt your evaluator was *very judgmental* please tell us what she/he did to make you feel this way.

The Feedback Session

FACTOR: Delivery of feedback throughout the assessment (e.g. during testing days - prior to the face-to-face feedback session)

* To what degree do you believe *receiving ongoing feedback* throughout the assessment is important?

Not at all important	Somewhat important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* To what degree did you *receive ongoing feedback* during your assessment?

Not at all	Somewhat	Very much
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The Feedback Session

FACTOR: Use of clear and understandable language

* To what degree do you believe the use of *clear and understandable language* is important to a successful feedback session?

Not at all important	Somewhat important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* To what degree did your evaluator use *clear and understandable language* during your feedback session?

Not at all	Somewhat	Very much
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The Feedback Session

FACTOR: Evaluator expertise and knowledge

* To what degree do you believe *evaluator expertise and knowledge* is important to a successful feedback session?

Not at all important	Somewhat important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* To what degree did your evaluator demonstrate *expertise and knowledge* during the feedback session?

Not at all	Somewhat	Very much
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you felt your evaluator did not demonstrate expertise and knowledge please tell us what made you feel so.

The Feedback Session**FACTOR: Clear communication of next steps/action items**

* To what degree do you believe *clear communication of next steps/action items* is important to a successful feedback session?

Not at all important	Somewhat important	Very important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* To what degree did your evaluator *clearly communicate next steps/action items* during the feedback session?

Not at all clearly	Somewhat clearly	Very clearly
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The Feedback Session**FACTOR: Initial referral question was answered**

* To what degree do you believe *answering the initial referral question* is important to a successful feedback session?

Not at all important Somewhat important Very important

* To what degree did your evaluator *answer your initial referral question* during the feedback session?

Not at all answered Somewhat answered Completely answered

The Feedback Session

FACTOR: Feedback delivered directly to both parent(s) and child

* To what degree do you believe the *delivery of feedback to both parent(s) and child* is important to a successful feedback session?

Not at all important Somewhat important Very important

* Did your evaluator *deliver feedback to both you and your child* during the feedback session?

- Yes
- No

The Feedback Session

FACTOR: Use of visual aides (e.g. graphs, brain diagram/model, bell curve chart)

* To what degree do you believe the *use of visual aides* is important to a successful feedback session?

Not at all important Somewhat important Very important

* To what degree did your evaluator *use visual aides* during the feedback session?

Not at all Somewhat A lot

The Feedback Session

FACTOR: Evaluator contact after the formal face-to-face feedback session

* To what degree do you believe *evaluator availability beyond the formal face-to-face feedback session* is important?

Not at all important Somewhat important Very important

* To what degree did your evaluator *make him/herself available beyond the formal face-to-face feedback session*?

Not at all Somewhat A lot

Additional feedback questions

* What type of feedback structure would you prefer?

- The evaluator walks me through the entire report - covering every section and then summarizes findings and shares diagnosis and recommendations
- The evaluator presents a brief overview of findings, focusing on the summary, diagnosis and recommendations
- The evaluator does not discuss the test findings instead focusing solely on diagnosis and recommendations

Other (please specify)

Please share any additional factors that you believe are important to a successful face-to-face feedback session:

The Written Report

Please check any professionals that you shared your child's written report with:

- Teacher
- School Psychologist
- Pediatrician
- Therapist
- Psychiatrist
- Other (please specify)

* Did you read through the written report from your child's assessment?

- Yes
- No (why not?)

* How was the length of your child's written assessment report?

Too long/overwhelming	Just right	Too short/lacking detail
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* How often do you refer back to your child's written assessment report?

Never	Occasionally	Often
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please take this opportunity to share any additional thoughts you have about your child's written assessment report:

Impact of your child's assessment...

* Did the assessment improve your understanding of your child's difficulties?

Not at all Somewhat Very much

If your child received a diagnosis as a result of his or her evaluation please select it below:

Diagnosis #1	<input style="width: 90%;" type="text"/>
Diagnosis #2	<input style="width: 90%;" type="text"/>
Diagnosis #3	<input style="width: 90%;" type="text"/>
Diagnosis #4	<input style="width: 90%;" type="text"/>
Other (please specify)	<input style="width: 90%;" type="text"/>

Recommendations: Introduction

When answering the following questions, please try to recall the recommendations that we made as a result of your child's assessment the best that you can. Recommendations are the activities and changes we gave you during the feedback session and in your written report to address your child's difficulties. These can include such things as school accommodations, therapy for your child, family therapy, use of a tutor, medical and additional assessment referrals

Recommendations

School Recommendations

* Did we recommend that your child's school make specific changes to address your child's needs? (This includes such things as extended time on tests, a separate testing location, preferential seating, a second set of textbooks, specific reading programs, individual instruction, emotional support, and other special education services)

- Yes
 No

Recommendations

School Recommendations

* How well do you feel the school followed the recommendations we made?

Not at all	Somewhat	Very much
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Recommendations

School Recommendations

* We know that these types of recommendations can be difficult to follow. What best describes your experience when considering the school recommendations we made:

- I did not agree with the recommendation
- I did not understand the recommendation
- I did not know how to follow or carry out the recommendation
- My child's school did not agree with the recommendation
- My child's school did not have the necessary resources
- It was too time consuming
- My child resisted acting on the recommendation
- Other (please specify)

Recommendations

Academic Tutor

* Did we recommend the use of an academic tutor, outside of school, to help your child? (e.g. reading tutor, math tutor, study skills/executive coach)

- Yes
- No

Recommendations

Academic Tutor

Please check any additional (non-medical) assessments that we recommended

Speech and Language

Occupational Therapy

Physical Therapy

Other (please specify)

Recommendations

Additional Non-medical Assessments

* How much do you feel you followed the recommendation to get additional non-medical assessment(s) for your child?

Not at all

Somewhat

Very much

What was the outcome of any non-medical assessments your child had?

Recommendations

Additional Non-medical Assessments

* We know that these types of recommendations can be difficult to follow. What best describes your experience when considering the recommendation to have additional non-medical assessments:

- I did not agree with this recommendation
- I did not understand the need for this recommendation
- I did not know how to follow or carry out the recommendation
- It was too expensive/It was not covered by our insurance
- I could not find someone who could provide the service
- It was too time consuming
- My child resisted acting on the recommendation
- Other (please specify)

Recommendations

Home Recommendations

* Did we recommend that you implement changes at home to assist your child? (For example the use of a behavior plan, home organization strategies, planning and time management strategies, etc.)

- Yes
- No

Recommendations

Home Recommendations

* How much do you feel you followed the recommendation to make changes at home?

Not at all

Somewhat

Very much

Recommendations

Home Recommendations

* We know that these types of recommendations can be difficult to follow. What best describes your experience when considering the recommendation to make changes at home:

- I did not agree with this recommendation
- I did not understand the need for this recommendation
- I did not know how to follow or carry out this recommendation
- It was too expensive
- It was too difficult
- It was too time consuming
- My child resisted acting on the recommendation
- Other (please specify)

Recommendations

Family Therapy

* Did we recommend that your family attend family therapy? (i.e. that multiple members of your family attend therapy together in order to resolve conflict or to implement changes)

- Yes
- No

Recommendations

Family Therapy

* How much do you feel you followed our recommendation for family therapy?

Not at all

Somewhat

Very much

Recommendations

Family Therapy

* We know that these types of recommendations can be difficult to follow. What best describes your experience when considering our recommendation of family therapy:

- I did not agree with this recommendation
- I did not understand the need for this recommendation
- I did not know how to follow the recommendation
- It was too expensive/it was not covered by our insurance
- I could not find someone who could provide the service
- It was too time consuming
- My child resisted acting on the recommendation
- Other (please specify)

Recommendations

Study Resources

* Did we recommend specific resources to aid your child in his or her studies or other areas? (This includes such things as audiobooks, apps for studying, study guides, etc.)

- Yes
- No

Recommendations

Study Resources

* How much do you feel you followed our recommendation to use study resources?

Not at all

Somewhat

Very much

Recommendations

Study Resources

* We know that these types of recommendations can be difficult to follow. What best describes your experience when considering the use of study resources:

- I did not agree with this recommendation
- I did not understand the need for this recommendation
- I did not know how to follow the recommendation
- It was too expensive/It was not covered by our insurance
- I could not locate the service/resource recommended
- It was too time consuming
- My child resisted acting on the recommendation
- Other (please specify)

Recommendations

Medical Recommendations

* Did we make any medical recommendations? (This includes a referral for medication, neurological examinations and other types of medical examinations)

- Yes
- No

Recommendations

Medical Recommendations

* How much do you feel you followed our recommendation for additional medical interventions?

Not at all

Somewhat

Very much

What was the outcome of your child's medical assessment?

Recommendations

How could we make it easier to follow the recommendations we give?

Please take this opportunity to share you thoughts regarding the recommendations we made for your child:

Outcome

* Roughly, how much time has passed since your face-to-face feedback session at our office?

* Do you feel the assessment, feedback session, and resulting recommendations led to the improvement of your child's symptoms or difficulties?

Yes

No

Outcome

* Please rate the level of improvement in your child's academic functioning, emotional functioning, and behavior at school and home, as nearly as you can recall, in the time since your child's assessment was completed at Widener:

A little better

Better

Much better

Outcome

* Please rate the change in your child's academic functioning, emotional functioning, and behavior at school and home, as nearly as you can recall, in the time since your child's assessment was completed at Widener:

No change	Worse	Much worse
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If there has been no change or your child's functioning has gotten worse, please share what has changed and what you attribute these changes to:

Survey Completed

Thank you for your time!

Your thoughts and feedback are greatly appreciated and will assist us in improving our services. If you have any further concerns or require any additional help, please contact us at 610.499.4672.

As a token of our appreciation please take a moment to give us your email address so we can send you a \$5 Starbucks gift card. Your email address will be deleted after we send your gift card to ensure your answers remain anonymous.

Email address for your gift card:

Appendix B

Email Requesting Study Participation

Dear parent –

We hope this email finds you well. We are contacting you to ask for your feedback regarding your experience of the assessment that your child had at Widener's Neuropsychology Assessment Center. We are collecting this information as part of a research project. We hope to identify areas that need improvement. We would also like to better understand how your experiences relate to your child's diagnosis (if he or she had one) as well as any changes in your child's functioning. We would greatly appreciate if you would take a few moments to complete a confidential online survey. Please note that you are not required to complete this survey, any information you provide will be anonymous, and your answers are confidential and will be kept separate from your child's assessment records. All survey information will be stored securely.

To thank you for your time we would like to offer you a **\$5 Starbucks gift card** once you complete the survey. After completing the survey, you will be asked for an email address so we can send your gift card. Please note that we will delete your email address after your gift card has been emailed to ensure your survey answers remain anonymous. We greatly appreciate your time and feedback. Your responses will help improve the quality of our services.

If you have any questions please do not hesitate contact us.

Best Regards,

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