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### Professional Manual for the Parent Reaction to Autism Diagnosis Scales (PRADS-2) with Guidance for Tailoring Parent Supports

Kathleen A. Brewer M.A.

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**Professional Manual**  
**for the**  
**Parent Reaction to Autism Diagnosis Scales**  
**(PRADS-2)**  
**with**  
**Guidance for Tailoring Parent Supports**

**Kathleen A. Brewer, M.A.**  
**Mary B. Gruber, Ph.D., BCBA-D**

**The Press at Cal Poly Humboldt**



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AND CONTACT INFORMATION**



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## INTRODUCTION

The Parent Reaction to Autism Diagnosis Scales (PRADS-2) is a 60-item survey, which provides 15 scale scores to measure a parent's specific areas of strengths and difficulties in raising their child with autism. This measure allows researchers to obtain objective data on parent responses, and it allows service providers to tailor specific supports for parents.

Parents have expressed a feeling of crisis when their child receives a diagnosis of a serious condition such as autism spectrum disorder. With the shattering of their existing hopes and dreams for their child's future, the parent feels a deep loss. Along with sadness and grief, the parent is overwhelmed with many new demands and challenges for raising their child. Individual parents will vary in their specific responses and emotions after receiving this shocking news.

Any diagnosis of a disability for a child can bring about a feeling of trauma for a parent, and a feeling of uncertainty about a child's future. The parent may grieve for what the child has lost, as well as speculate about the difficulties that the child and family will face over time. As a parent gains better understanding of the child's diagnosis and gains more confidence and skills in how to support their child, a sense of the possibilities for their child can help replace the sense of anguish.

This reorganization of mental, emotional, and behavioral patterns, along with stronger knowledge, confidence, and skills, is called resolution.

For a parent of a child with a disability, resolution includes a reorganization of thinking, emotional, and behavioral responses, by incorporating understanding of the child's disability into the parents' daily routines and thought processes. These changing responses can be integrated into the lifestyle patterns of the individual and family. With successful resolution, parents can acknowledge the diagnosis, incorporate a new outlook on their life, build awareness and confidence, learn valuable parenting skills, and affirm their identity as a parent of a child with special needs. Thus, a parent-friendly definition of resolution could be to develop new patterns for coping while parenting their child.

Greater resolution is beneficial for parents and families of a child with a disability. Parents in our research who report higher levels of resolution about their child's diagnosis also report higher levels of self-efficacy. With strong self-efficacy, parents are better able to seek the many solutions to issues as they arise when raising a child with special needs. Highly resolved parents have positive beliefs which enable them to analyze and resolve barriers that can impede success in supporting their child. With a degree of resolution, the parent realizes their child will have accomplishments within a unique set of possibilities and can work to help the child achieve success within the child's potential. A more resolved parent can be more able to respond to the complex and changing requirements of raising a child with a disability.

**Needs Addressed by our Measure**

- A researcher studying families of children with autism, may be asking: “How can I measure the many different ways that parents may be feeling and coping in parenting their child with autism? My research team puts in many hours conducting interviews, observations, and interventions. I wish we could also have a solid, objective measure that is easily usable, provides clearly quantified scale scores, has reliability and validity, can be repeated to see changes over time, and can be related to the other variables in our research.”

- A professional service provider for families of children with autism, while preparing to meet with a parent who has received a child’s diagnosis, may be asking: “How can I begin learning about this parent’s strengths and concerns, so that I can start offering hope with tailored supports right away to help this family? How can I make sure I am not missing some important elements for this parent? How many hours of interviewing would I need to do before I can learn which services will be truly meaningful, encouraging, and valuable to this parent and family? I feel a sense of urgency in needing to understand, empathize, and support the parent in this painful situation.”

**Description of our Measure**

The short-form Parent Reaction to Autism Diagnosis Scale (PRADS-2) enables researchers and service professionals working with families to quickly administer a 60-item survey, and objectively score and create a profile along 15 domain scales, which measure an individual parent’s specific areas of resolved strengths and unresolved difficulties.

The 60 items are actual parent statements, and the parent rates each item on a 1-5 rating scale for how much that statement relates to their own experiences. The items include a balanced number of different types of parent comments, as

reported by prior research that used open-ended interviews. Since it has separate resolved and unresolved scales, there are no reverse-scored items. The manual includes the scoring sheets, profile graph template, guidelines for tailoring services, a tailored services worksheet, and a complete example for a parent.

The scales created from the measure provide objective information for researchers who are studying parent responses to a child’s diagnosis. And professional service providers can gain practical information to help identify needed supports specifically tailored for a parent and family.

The PRADS-2 provides a systematic assessment of important aspects of a parent’s experience. It allows for rapid development of empathy and compassion, allows for feedback and discussion with the parent, and allows for collaborating with the parent to select optimal services that will fit with the family’s strengths and concerns. In recognizing and offering supports that are relevant to the family, the family can gain the necessary skills to better support their child.

This manual explains the use of the PRADS-2 for objective research and for practical field application. The full copy of the PRADS-2 measure for parents of children with autism is included as a packet in Appendix A.

We are additionally providing a more general form of our measure which can be used for parents of children with any diagnosis. This measure is called the Parent Reaction to Diagnosis Scale (PRDS-2). It has the same wording as the Parent Reaction to Autism Diagnosis Scale (PRADS-2), except that the word “autism” is replaced with more general terms. The administration, scoring, graphing, and usage guidelines are identical for the PRADS-2 and PRDS-2. The PRDS-2 is included as a packet in Appendix B.

**Reading and Using our Professional Manual**

Our manual describes how you may use our measures accurately, ethically, and effectively, for the benefit of parents and families. To use our measures, you will first need to read our manual from beginning to end.

We have arranged the chapters in our manual in a chronological order, beginning with our research in developing the measure and then progressing through the steps involved in applications in service work.

Note that in Chapter 2, we present our detailed statistical development and validation of the scales. Some readers will want to read this chapter closely before continuing on. Other readers may prefer to glide lightly through this chapter at first, and progress through the rest of the manual. Either way, you may revisit this chapter whenever you wish, to view specific

findings about any variables of particular interest to you.

To glimpse what kinds of skills you can gain in reading our manual, you may wish to peek ahead at some of our sections. For example, in our Summary of Tailored Supports, at the end of Chapter 9, you can see specific details for how this measure can help in crossing the bridge between research and services for parents.

If you meet the professional qualifications stated in this manual for using these measures, you have our permission to print as many copies of the measures, forms, and professional user packets in Appendices A and B as you need over time.

We hope these measures can be beneficial in your research and service work, by aiding in your understanding and support of parents as they raise their child with special needs.

## Chapter 1

### DEVELOPMENT AND DESCRIPTION OF THE PRADS-2

#### The Research Literature

The research literature includes a large group of studies about families and autism. Brewer (2013) has presented an extensive review of the research literature on parent-child attachment and parent resolution, and has followed this by reporting on our research and statistical development of the long-form PRADS measure. Holloway (2015) has reviewed further research studies on parent resolution, and followed this by reporting on our statistical development and validation of the short-form PRADS-2 measure. We are providing the addresses to these in our References list, so that if interested, you may go to them and read our entire literature reviews and research reports directly.

Where relevant in our manual, we are also citing related findings of other research studies conducted by our research team at Humboldt, including Ewen (2003) and Wood (2004) on effects of training parents and caregivers in applied behavior analysis, Casas (2013) on effects of training parents and caregivers in use of visual supports, Kelley (2008) on effects of sibling training and supports, Furuoka (2001) on teachers' preferences for inclusion of children with autism, Moses (2002) on inclusion of individuals with developmental disabilities in the community, and Montano (2014) on parents' experiences and preferences for early behavioral intervention in the home.

Fiske (2017) has presented a valuable, comprehensive review of recent peer-reviewed research studies in her book on *Autism and the Family: Understanding and Supporting Parents and Siblings*. Based on the research findings, her clinical experience, and her own interviews with family members, she recommends ways service providers can better serve families with a child

with autism. Her topics cover the experience of diagnosis, patterns of stress over time, parents and their relationships, sibling support, integrating extended family, the family's culture, key coping strategies, building strong rapport with parents, and guiding parents in the treatment of autism. Fiske stresses that support for parents should be started as early as possible, beginning with establishing rapport and getting to know the parent. To accomplish this, she recommends asking open-ended questions of the parent about their concerns and listening respectfully to understand the parent.

To this end, we are pleased to present our short-form Parent Reaction to Autism Diagnosis Scales (PRADS-2) measure as a valuable, quantitative component in establishing further understanding of the parent's reactions to the child's diagnosis. The PRADS-2 is a brief 60-item survey that provides a clear, comprehensive, and multifaceted measure of the parent's strengths and difficulties from the parent's point of view. Its quantitative scales provide a comprehensive sweep of information to allow the service provider to get to know the parent. The resulting profile can be shared with the parent to allow further discussion about the parent's feelings and consideration of services that can best support the family. The PRADS-2 can be given early when first getting to know the parent, and it can be repeated at future times to measure changes in the parent's profile of scores over time, and to guide adjustment of family services.

#### Sequence of Measures

In our next sections, we describe the three measures which have been developed to study parents' reactions to their child's diagnosis. We first describe the Reaction to Diagnosis Interview (RDI, Pianta and Marvin, 1992, 1993), which was

the precursor to our measures. We next describe our research and development of the long-form Parent Reaction to Autism Diagnosis Scales (PRADS), along with additional concurrent measures. We then describe our development of the short-form Parent Reaction to Autism Diagnosis Scales (PRADS-2).

### **Reaction to Diagnosis Interview (RDI)**

Earlier research on parent adjustment and resolution to raising a child with special needs used the Reaction to Diagnosis Interview (RDI). Pianta and Marvin developed the Reaction to Diagnosis Interview (RDI, 1992) and the Manual for Classification of the Reaction to Diagnosis Interview (MCRDI, 1993) to determine parents' resolution status to their child's diagnosis of a disability.

They designed their Reaction to Diagnosis Interview measure as a structured 20-minute interview, in which parents were asked to recall various aspects of their child's diagnosis. It was comprised of five open-ended questions to obtain information from a parent regarding the situations surrounding the child's diagnosis. The interview was designed to elicit a story narrative from a parent that they used to indicate the parent's resolution status to their child's diagnosis of a disability.

During the RDI interview, parents were asked to recall when they first recognized that their child was having difficulties. They were then asked to describe their initial emotional reactions at the time, how these emotions had since changed in relation to the diagnosis, and how it affected parenting their child. Parents were asked to recall and describe as accurately as they could all aspects of their child's diagnosis, including where the diagnosis took place and who was present while their child was being diagnosed. They were asked what they were thinking and feeling at the time of diagnosis, and what it was like for them to raise a child with special needs.

Finally, they were asked if there was anything further that they might want to expand on or discuss regarding their child.

The RDI protocol also allowed for additional probing with further questions for parent clarification at any time during the interview. The interviewer would ask questions to obtain further information on an area which the person conducting the interview deemed relevant to the parents' resolution. Any areas thought to be relevant were determined by the individual conducting the interview.

Using the RDI, researchers would video record each interview, and then assess for types of parent resolution using the RDI Manual for classification.

The RDI had three categories for the Resolved status: Feeling-Oriented, Action-Oriented, and Thinking-Oriented. It had six categories for the Unresolved status: Overwhelmed, Angrily Preoccupied, Neutralizing, Depressed, Confused, and Distortive.

Their MCRDI manual gives further descriptions of their named categories, along with examples of parent statements representing the elements of the categories to guide their qualitative analysis process.

The purpose of the RDI was to assign a resolution status to a parent as resolved or unresolved, and to place the parent into a category of the RDI. Various elements from other categories of the RDI could also be assigned to a parent. This content analysis was determined by at least two trained coders who reviewed the interview video of the parents and any other observations of the parents which might have been recorded.

The RDI has been used by other researchers studying parent reactions and resolution to a child's diagnosis of a disability, and



we have extensively reviewed these research studies in Brewer (2013) and Holloway (2015).

Oppenheim and colleagues (2007) have carefully explored and elaborated upon the promises and complexities of applying the RDI interview in research and clinical practice to understand parents and to support parent-child attachment.

The interview and subjective probing method of the RDI, however, may naturally miss critical pieces of information about essential aspects of a parent's resolution status. Clients may not disclose all the relevant information in an initial interview, which leaves some areas of concern to be revealed and discussed later after a relationship has been established.

Using an objective, easily scored measure can provide an inclusive sweep of objective information, which can be relevant in deciding which areas to explore further with a parent in a follow-up interview. Such a quantitative measure can be valuable to researchers and service providers in directing them to essential areas of parent resolution which may naturally be missed in a qualitative interview process.

We received written permission from the RDI authors to use the concepts in their qualitative RDI measure and MCRDI categories to construct a quantitative survey reflecting aspects of parent resolution status, resulting in our PRADS and short-form PRADS-2 measures.

These RDI researchers have given us the foundation and inspiration to design and validate our quantitative measure of parents' resolution.

### **Research and Design of the Long-Form Parent Reaction to Autism Diagnosis Scale (PRADS)**

We developed our original long-form Parent Reaction to Autism Diagnosis Scale (PRADS) as a quantitatively scored 98-item

measure, with the scale items constructed to reflect the content areas of the categories of the RDI found in the research and the elements outlined in the MCRDI. When developing the PRADS, we used actual parent statements for the items, which we then organized to reflect the RDI authors' three Resolved categories and their six Unresolved categories.

On the internet platform Survey Monkey, 137 parents of children with autism completed seven different measures, with a total of 214 items. The respondents consisted of 125 (91%) females, 10 (7%) males, and 2 (1%) who did not state their gender. For relationship to the child, 131 (96%) were parents, 3 (2%) were adult relatives, 2 (1%) were guardians, and 1 (1%) did not specify their relationship. In this study, participants are referred to as parents for simplification.

Our long-form PRADS (Brewer, 2013) contained 98 statements that were rated by parents using a five-point response scale, with ratings from 1 (*Not at all like me*) to 5 (*Very much like me*). To maintain balance in representing each of the resolved and unresolved categories within the original RDI, we wrote 48 items representing the Resolved categories, and 48 items representing the Unresolved categories. Within the Resolved category, 16 items apiece related to each of the three Resolved categories of Feeling Oriented, Action Oriented, and Thinking Oriented. Within the Unresolved category, 8 items apiece related to each of the six Unresolved categories of Overwhelmed, Angrily Preoccupied, Depressed, Confused, Neutralizing, and Distorting. In addition to these items, we included one additional item relating to the general overall Resolved status, and one additional item relating to general overall Unresolved status, to evaluate convergent validity of the scales. The items for each of the scales were actual parent comments made during prior interviews with the PRADS authors, and parent responses to open-ended RDI interviews found in research and in the MCRDI (Pianta & Marvin, 1992, 1993).

In order to counterbalance the sequence of items and prevent any recognizable pattern of statements that would reveal the categories of the PRADS, we blocked all of the statements used to represent the elements of the MCRDI into groups of 12 items, consisting of 6 resolved items (2 from each of the three Resolved domains) and 6 unresolved items (1 from each of the six Unresolved domains). Then we placed the items from each block in a random order, resulting in a balance of resolved and unresolved items on each page of the PRADS section within the survey.

We first pilot tested our PRADS measure with several parents and caregivers of children with autism to determine if the length was overwhelming, or if the items created any discomfort or anxiety for the pilot testers. The testers completed the survey with no complaints about excessive length or discomfort in filling out the measure. Specific feedback from each of the testers was used to keep the items on any one page from being too negative or too positive by switching the position of some of the items either within the block or switching items between blocks.

We conducted principle-components factor analyses with orthogonal Varimax rotation on the items within each category domain, to assess construct validity and factor structure within the domains. Five of the original RDI categories revealed more than one factor within them. These emerged within the categories of Feeling Oriented (with 2 factors of Positive Feelings and Working through Emotions), Action Oriented (with 3 factors of Active Research, Participation, and Self-Help Routines), Thinking Oriented (with 2 factors of Broad Perspectives and Focused Thought), Neutralizing (with 2 factors of Unconcerned and Resistant), and Distortions (with 2 factors of Negative Distortions and Positive Distortions). The other four categories of Emotionally Overwhelmed, Angry Feelings, Depressed Feelings, and Confused Feelings each contained a single factor within them.

Our statistical analysis of the PRADS resulted in an objective quantitative measure which created a parent profile along 15 scales, consistent with, and elaborating upon, the nine categories of the RDI for resolution and nonresolution, as a way to identify existing strengths and needed supports for parents and family members of children with a disability.

The PRADS measure provides objective, comprehensive, and inclusive information that can complement the interview process. The facets of parent resolution are represented in the resulting profile created from graphing the quantitative scores on each of the scales. These provide specific information in areas which might not have been elicited and discussed through a qualitative interview process alone. These areas may then be discussed further with the parent in a follow-up interview.

### **Additional Concurrent Measures**

We included five additional measures in our online PRADS survey. These supplementary measures comprised: a Demographic Questionnaire, an Adult Relationship Scale with four factor scales (Griffin and Bartholomew, 1994), a Child-Parent Relationship Scale with three factor scales (Pianta, 1992), a Parenting Self-Efficacy Scale with three factor scales (created by Brewer, 2013), and Emotional Change Scales with three factor scales (created by Brewer, 2013). The complete copies and items for each of these additional measures can be seen in Brewer's (2013) research report. We used these additional measures to examine the correlations between them and each of our PRADS scales, to document the concurrent, convergent, and discriminant validity of our measure.

### **Demographic Questionnaire**

The demographic questions included the participant's identified gender and age level, relationship to the child, partnership status,

whether primary caregiver or not, number of adult caregivers in the home, number of children in the home, number of children with autism, number of children with other developmental disabilities, the child's gender, child's current age, child's functioning level, hours of parent training in applied behavior analysis, use of applied behavior analysis training, other parent training, use of other training, behavioral programs for child, length of time in behavioral programs, weekly hours of behavioral programs, satisfaction with child's behavioral service hours, satisfaction with child's behavioral services, child's school support services, satisfaction with child's school services, child's age when recognized may have a problem, age of child when diagnosed with autism, and length of time since the child's diagnosis. The time measures asked for years and months, and were scaled as total months. The satisfaction measures were answered on a five-point scale, from 1 (*Not at All Satisfied*) to 5 (*Completely Satisfied*). These demographic questions are shown in Appendix C of Brewer (2013).

### **Adult Relationships Measure**

Griffin and Bartholomew's (1994) Adult Relationships Scale measures participants' close relationship styles with others. It consists of 17 items, which are rated on a five-point scale, from 1 (*Not at all like me*) to 5 (*Very much like me*). Four factors emerged from our factor analysis based on the responses of the parents in our study: Closeness versus Distance (9 items), Anxiety Alone (4 items), Valuing of Independence (2 items), and Acceptance of Dependents (2 items). These 17 items, their factor loadings, and their alpha reliability coefficients can be seen in Table 1 of Brewer (2013).

### **Child-Parent Relationships Measure**

Pianta's (1992) Child-Parent Relationship Scale-Short Form measures parents' perceptions of their attachment with their child. It consists of

15 items, which are rated on a five-point scale from 1 (*Definitely Does Not Apply*) to 5 (*Definitely Applies*). Three factors emerged from our factor analysis of the items based on the responses by the parents in our study: Child-Parent Conflict (7 items), Child-Parent Closeness (6 items), and Child-Parent Sharing (2 items). These 15 items, their factor loadings, and their alpha reliability coefficients can be seen in Table 2 of Brewer (2013).

### **Parenting Self-Efficacy Measure**

Brewer's (2013) Self-Efficacy for Parenting a Child with Autism Scale measures how confident parents feel using various skills while parenting a child with autism. It consists of 13 items, which are rated on a five-point scale, from 1 (*Not at All Confident*) to 5 (*Completely Confident*). Three factors emerged from our factor analysis of the items rated by the parents in our study: Confidence in Managing Behaviors (5 items), Confidence in Teaching New Skills (5 items), and Confidence in Advocating for Services (3 items). These 13 items, their factor loadings, and their alpha reliability coefficients can be seen in Table 3 of Brewer (2013).

### **Emotional Changes Measure**

In our PRADS research, we also developed and included a measure for initial emotions, current emotions, and emotional change. The parents were asked to rate how much they experienced each of 22 emotion words, both for their initial emotional responses at the time their child received a diagnosis of autism, and also for their current responses at the time when they filled out the measure. We gathered the emotion words from parent statements found in research using the RDI, and from our prior interviews with parents of children with autism. The participants rated the degree to which they experienced each of the 22 emotions, using a five-point response scale with ratings from 1 (*Not at all*) to 5 (*Extremely*).

Factor analysis of the parents' responses on the emotion items revealed three emotional scales: Distressed Emotions (12 items), Positive Emotions (6 items), and Detached Emotions (4 items). The 22 emotion items, their factor loadings, and their alpha reliability coefficients can be seen in Table 4 of Brewer (2013), for both initial emotions and current emotions. We then obtained Emotion Change scores by subtracting the Initial Emotion rating from the Current Emotion rating for each parent on each emotion measure. Thus, positive change scores represented increases in the emotion, and negative change scores represented decreases in the emotion over time.

The development of the long-form PRADS scales, along with their significant relationships with the concurrent variables are presented in Brewer (2013).

### **Design of the Short-Form Parent Reaction to Autism Diagnosis Scale (PRADS-2)**

After developing and validating our longer-form PRADS measure, with 98 items, we then condensed and validated our shorter-form PRADS-2 measure, with 60 items.

In creating the short-form PRADS-2, we selected four items from each of our PRADS long-form scales. Our selected items were those that appeared to best represent the universe of parent comments within each domain, so as to maintain content validity. Principle-components factor analyses with orthogonal Varimax rotation were conducted on the short-form items within domains, and the patterns of resulting factor scales were compared to those of the long-form items to assess construct validity and consistency of the factor structure.

We examined the correlations between each of the short-form and long-form scales and confirmed that each short-form scale correlated more highly with its corresponding long-form scale than with the other long-form scales. This

confirmed that each short-form scale best represents its specific, corresponding long-form scale, rather than the other long-form scales.

Our development of the short-form items resulted in 15 separate domains, with four items in each domain. The measure provides seven Resolved scales, including two feeling-oriented scales of Positive Feelings and Working through Emotions, three action-oriented scales of Active Research, Participation and Helping, and Self-Help Routines, and two thinking-oriented scales of Broad Perspectives and Focused Thought. The measure provides seven Unresolved scales, including Emotionally Overwhelmed, Angry Feelings, Depressed Feelings, Confused Feelings, Neutralizing Unconcerned, Neutralizing Resistant, and Negative Distortions. The measure also provides a separately identified domain scale of Positive Distortions.

The PRADS long-form scales exhibited high internal reliability, as well as content, construct, convergent, concurrent, discriminant, face, and representational evidence for validity. In our creating and evaluating the PRADS-2 short-form scales, these same psychometric attributes were examined and confirmed (Holloway, 2015).

After statistically validating the short-form scales, we created a balanced sequence of the 60 items for the short-form survey. This counterbalancing was done by creating four blocks with 15 items apiece, with exactly one item from each of the 15 domains in each block. Within each block, we arranged the sequence of the short-form items to match the sequence of those items from the long-form measure, which had been created by blocking and then randomizing the order of the items within the blocks. The positions of a few of the short-form items were then interchanged to ensure that resolved and unresolved items were distributed evenly within the blocks and no patterns of the scales could be determined.

The PRADS-2 is an easily scored assessment which enables researchers and service providers working with families to quickly and effectively measure the parent's or caregiver's reactions and adjustments to their child's diagnosis of autism spectrum disorder. The resulting profile plotted from the scoring form provides a multifaceted view of the parent's resolved strengths and unresolved concerns. Using the profile as a starting point, and considering parent input, appropriate supports and services can be designed which are meaningful and beneficial to the parent and family.

### **Description of Test Materials and Use**

The PRADS-2 is comprised of 15 domain scales with 4 items within each scale, for a total of 60 items. This brief measure takes about 20 to 30 minutes to complete. An Informed Consent sheet is presented prior to the survey form. A Scoring Sheet and Profile Graphing Form are included within this manual to help with the administration and easy scoring of the measure. Additionally, we provide a Services Worksheet to help design supports and services tailored for the individual parent.

The PRADS-2 can help researchers and service providers to understand the individual parents' responses while parenting a child with

special needs. The resolution process is multidimensional, with each parent having varying areas of resolved strengths and unresolved challenges. The PRADS-2 measure can be a valuable resource in research when studying parent resolution to a child's diagnosis. The parent's scores can also assist service providers in the family's local community to identify meaningful services for optimal family support.

The PRADS-2 uses continuous scales to show parent resolution in the various domains. Thus, the parents are not placed into single domain categories or labeled as Resolved or Unresolved, as this does not reflect the complexity of the resolution process. When placing parents into single categories, important aspects of the parent's resolution status can be missed. Using a quantifiable measure and creating a profile of degrees along each of the continuous domain scales gives additional information regarding the parents' resolved strengths in raising a child with a disability, as well as areas of concern with any unresolved issues. These identified areas of concern can then be addressed with specifically tailored family supports. The measure is designed for service providers to share the profile with the parents, allowing parents and family members to collaborate with the professionals in deciding on needed supports that would be relevant to them.

## Chapter 2

### STATISTICAL DEVELOPMENT AND VALIDATION OF SCALES

#### Selection of Short-Form Items

To create the PRADS short form (PRADS-2), we selected four items from each of our PRADS long-form scales. These scales included seven Resolved domains of Positive Feelings, Working Through Emotions, Active Research, Participation and Helping, Self-Help Routines, Broad Perspectives, and Focused Thought. They also included seven Unresolved domains of Emotionally Overwhelmed, Angry Feelings, Depressed Feelings, Confused Feelings, Neutralizing Unconcerned, Neutralizing Resistant, and Negative Distortions. The scale of Positive Distortions was also included as a special case.

Within each scale, we selected the four items that appeared to best represent the universe of parent comments within that domain. To maintain content validity, we did not simply pick the four items with the strongest factor loadings, as the selected items would be too similar, and some types of parent comments in that domain would no longer be represented.

We then created scale scores for each participant on each short-form scale, by summing the ratings on the items, then dividing by the number of items in the scale, and expressing the scale score, with accuracy to the hundredths place. Thus, the scores for all the scales are expressed on the same 1-5 measurement scale which was used in the item ratings, thus aiding in interpretation. Because of the separate Resolved and Unresolved scales, there are no reverse-scored items on any of the resolved or unresolved scales.

During subsequent analyses, we tested other combinations of four items within scales, and the results confirmed that the originally selected four items for the scales provided the best

reliability and validity outcomes for the scales. Therefore, we retained these originally selected items for our 15 scales.

#### Special Cases for the Short-Form Scales

Three special cases were deliberated upon in creating the short-form scales. These involved the development of the Self-Help Routines scale, the Unconcerned and Resistant Neutralizing scales, and the Negative and Positive Distortions scales.

Regarding the Self-Help Routines items, three items within the Resolved Action Oriented domain of the long-form PRADS had formed a separate factor. These three items reflected caregivers' self-help activities. In developing the short-form PRADS, we examined correlations between the long-form Self-Help scale and each of the other PRADS items. The highest correlation was with the item "I have supportive phrases I tell myself to get through the day", which was a part of the long-form Thinking Oriented scale. When this item was included in the factor analysis of the short-form Action Oriented scale items, it loaded highly (.731) on the short-form Self-Help factor, thus creating a solid Self-Help Routines scale with four items. Because self-help is an important element involved in the welfare of caregivers and those they care for, it is valuable that we include it as a scale measure.

Regarding the Neutralizing items, the eight items reflecting the Neutralizing domain in the long-form PRADS formed two separate factors, with four items within each. We labeled the first factor Neutralizing Unconcerned, and we labeled the second factor Neutralizing Resistant. The Unconcerned and Resistant factors showed different patterns of correlations with the other

variables. Thus, we included the two separate scales of Unconcerned and Resistant, with four items in each, in the short-form PRADS, to measure these two distinct types of neutralizing.

Regarding the Distortion items, the eight items for distorting statements in the long form of the PRADS formed two separate factors, with four items in each, reflecting Negative Distortions and Positive Distortions. The Negative and Positive Distortions scales showed different patterns of correlations with the other variables. Since the Negative Distortions scale correlated positively with the Unresolved Total scale,  $r(135) = .775$ ,  $p < .001$ , and did not correlate significantly with the Resolved Total scale, it was included with the Unresolved scales. The RDI interview authors had included both negative and positive distorting comments within their Unresolved Distorting category, but our data showed that the Positive Distortions scale correlated positively with the Resolved Total scale,  $r(135) = .347$ ,  $p < .001$ , and correlated negatively with the Unresolved Total scale,  $r(135) = .303$ ,  $p < .001$ . For these reasons, the Positive Distortions scale was not included in either the Resolved or Unresolved Total scores, but it was kept as a separate variable.

Thus, the short form of the PRADS is a balanced measure, consisting of 15 scales, with seven Resolved scales, seven Unresolved scales, and one independent Positive Distortions scale. Each scale has four items, making 60 items in the PRADS short form.

### **Short-Form Scale Items and Factor Loadings**

The items within each of the 15 scales, along with the item factor loadings and the Cronbach alpha reliability coefficients for each scale, are shown in Tables 1-6. We conducted principal components factor analysis with Varimax rotation on the items within each domain, to assess construct validity and consistency of the factor structure. The factor loadings are shown for each item within each short-form scale.

Table 1 presents the Resolved items within the Feeling Oriented domain, which formed the two factor scales of **Positive Feelings** and **Working through Emotions** in the long form. Factor analysis of the selected short-form items resulted in the same two separate factors that were shown for the long-form items.

Table 2 presents the Resolved items within the Action Oriented domain, which formed the three factor scales of **Active Research, Participation and Helping**, and **Self-Help Routines** in the long form. Factor analysis of the short-form items resulted in the same three factors.

Table 3 presents the Resolved items within the Thinking Oriented domain, which formed two factor scales of **Broad Perspectives** and **Focused Thought** in the long form. Factor analysis of the short-form items resulted in the same two factors.

Table 4 presents the Unresolved items within each of the distressed domains of **Emotionally Overwhelmed, Angry Feelings, Depressed Feelings, and Confused Feelings**. The items were written in the long form to match the content of the four separate domains. Factor analysis of the short-form items within each domain resulted in a single factor for each of these domains, consistent with the scales in the long form.

Table 5 presents the Unresolved items within the Neutralizing domain, which formed two separate factor scales of **Neutralizing Unconcerned** and **Neutralizing Resistant**, consistent with the factors in the long form.

Table 6 presents the items within the Distortion domain, which was made up of two separate factor scales of **Negative Distortions** and **Positive Distortions**, consistent with the scales in the long form.

Table 1

*The Short-Form Resolved Feeling Oriented Items, showing the Factors, Item Numbers and Items, Factor Loadings, and Alpha Reliability, with N = 137*

Feeling Oriented Domain ( $\alpha = .682$ ) Factor Scales and Items	Factor Loadings
Positive Feelings Scale ( $\alpha = .691$ )	
60. I have found joy in raising my child.	.790
30. I feel more positive now about my child's diagnosis of autism.	.776
1. I feel a strong emotional connection to my child with autism.	.622
45. I am proud of myself for how well I am helping my child.	.589
Working through Emotions Scale ( $\alpha = .666$ )	
4. I worked through a lot of emotions about my child's diagnosis.	.831
20. Being able to express myself and talk to others about my emotions helps me to cope with my child's autism.	.534
33. I feel that by addressing my emotions after my child's diagnosis, I am better able to support my child.	.539
46. I felt a need to grieve after my child's diagnosis.	.534



Table 2

*The Short-Form Resolved Action Oriented Items, showing the Factors, Item Numbers and Items, Factor Loadings, and Alpha Reliability, with N = 137*

Action Oriented Domain ( $\alpha = .787$ ) Factor Scales and Items	Factor Loadings
<b>Active Research Scale (<math>\alpha = .741</math>)</b>	
3. I sought answers immediately when I realized that my child was having problems.	.791
18. When my child was diagnosed with autism, I researched everything I could.	.778
57. I take charge of getting my child appropriate services.	.695
37. I try to stay current with new interventions so that I can actively help my child.	.501
<b>Participation and Helping Scale (<math>\alpha = .722</math>)</b>	
48. It is important that I actively participate in helping my child make progress.	.764
35. I work with all of the professionals in my child's life to understand my child's changing needs.	.717
24. I continue to do what I have to do to help my child each day.	.674
6. I actively participate in interventions and programs for my child.	.637
<b>Self-Help Routines Scale (<math>\alpha = .634</math>)</b>	
38. I have created self-help routines to help me get through my day.	.873
59. I have supportive phrases I tell myself that help me get through each day.	.731
22. I have created routines that help me to meet my child's needs.	.645
10. I schedule special time for myself to relax, rejuvenate, and restore my well-being.	.422

Table 3

*The Short-Form Resolved Thinking Oriented Items, showing the Factors, Item Numbers and Items, Factor Loadings, and Alpha Reliability, with N = 137*

Thinking Oriented Domain ( $\alpha = .676$ ) Factor Scales and Items	Factor Loadings
 Broad Perspectives Scale ( $\alpha = .673$ )	
40. Thinking positively about my child's future helps me to help my child.	.742
14. I think my child makes a positive contribution to our family.	.700
55. My personal beliefs have helped me to come to terms with my child's diagnosis.	.694
28. Observing what my child does helps me to understand my child better.	.637
 Focused Thought Scale ( $\alpha = .586$ )	
29. I stay focused on learning everything I can about autism to help me support my child.	.818
43. It is important for me to have information about autism.	.791
12. I believe that the more I plan for the possibilities of each day, the more prepared I am to help my child.	.532
52. I think it is important for me to acknowledge my success in helping my child.	.402

Table 4

*The Short-Form Unresolved Overwhelmed, Angry, Depressed, and Confused Items, showing the Factors, Item Numbers and Items, Factor Loadings, and Alpha Reliability, with N = 137*

Unresolved Total Items ( $\alpha = .849$ ) Factor Scales and Items	Factor Loadings
<b>Emotionally Overwhelmed Scale (<math>\alpha = .714</math>)</b>	
47. I am overwhelmed when caring for my child.	.894
41. I feel that I am in a continual state of crisis.	.864
9. Every day I experience the same overwhelming emotions I had when my child received a diagnosis.	.800
19. I worry about other people judging me as a parent of a child with autism.	.318
<b>Angry Feelings Scale (<math>\alpha = .712</math>)</b>	
58. I am constantly angry that my child has autism.	.823
5. It is important to me that someone be held responsible for my child having autism.	.815
42. I want others to be as angry as I am about my child's situation.	.715
27. I am angry with the professionals who diagnosed my child.	.567
<b>Depressed Feelings Scale (<math>\alpha = .719</math>)</b>	
11. I am stuck in sadness about my child having autism.	.780
36. I feel isolated and alone since my child's diagnosis.	.752
49. I feel powerless to help my child.	.748
21. I do not have much hope for my child's future.	.666
<b>Confused Feelings Scale (<math>\alpha = .709</math>)</b>	
34. I am so confused about autism that I don't know what to do to help my child.	.760
54. I just cannot get myself organized and focused enough to help my child.	.727
8. Sometimes I think everything will be okay and then it just becomes too much to handle.	.721
23. I get so confused and at a loss when I try to talk about my child's autism.	.713

Table 5

*The Short-Form Unresolved Neutralizing Unconcerned and Resistant Items, showing the Factors, Item Numbers and Items, Factor Loadings, and Alpha Reliability, with N = 137*

Neutralizing Scales Factor Scales and Items	Factor Loadings
Neutralizing Unconcerned Scale ( $\alpha = .623$ )	
56. I believe my child's diagnosis has had no effect on our family.	.739
26. My child's diagnosis of autism has never bothered me.	.736
13. I have never felt strong emotions about my child's diagnosis of autism.	.729
44. I feel I don't need to do anything more to help my child.	.481
Neutralizing Resistant Scale ( $\alpha = .529$ )	
17. Someone else noticed my child was having problems before I did and told me.	.707
32. I waited to get my child diagnosed because I did not think there was a problem.	.676
2. I really believe that my child's diagnosis of autism is incorrect.	.645
53. I avoid thinking about my child's autism.	.537

Table 6

*The Short-Form Negative and Positive Distortion Items, showing the Factors, Item Numbers and Items, Factor Loadings, and Alpha Reliability, with N = 137*

Distortion Scales Factor Scales and Items	Factor Loadings
Negative Distortions Scale ( $\alpha = .508$ )	
15. Since receiving the diagnosis, I feel that I am the only one who can help my child.	.723
51. I feel that everything about my child's autism is negative.	.678
25. I blame myself for causing my child's autism.	.616
39. I feel that my child's autism has been harder for me as the parent than for my child.	.514
Positive Distortions Scale ( $\alpha = .552$ )	
7. My child's having autism has been a wonderful blessing for our family.	.731
31. My child was given autism to help me with my own personal growth.	.706
50. I believe my child's brilliance will make a huge difference in the world someday.	.650
16. Without my child having a diagnosis of autism, my life would not have a purpose.	.515

### **Creation of Resolved and Unresolved Total Scales**

The Resolved Total score was calculated for each participant by summing each participant's scores on each of the items in the Positive Feelings, Working through Emotions, Active Research, Participation and Helping, Self-Help Routines, Broad Perspectives, and Focused Thought scales, and then dividing by the number of answered items in the domain, with accuracy to the hundredths place. The Unresolved Total score was calculated by summing each participant's scores on each of the items in the Emotionally Overwhelmed, Angry, Depressed, Confused, Neutralizing Unconcerned, Neutralizing Resistant, and Negative Distortions scales, and then dividing by the number of answered items in the domain, with accuracy to the hundredths place. Thus, the Resolved Total and Unresolved Total scales are expressed on the same 1-5 scale as for the original items and for the scale scores. The Positive Distortions scale was not included in calculating the Resolved or Unresolved Total scales, but was kept as a separate variable, which is also expressed on the same 1-5 scale.

### **Cronbach Alpha Reliability Coefficients**

Table 7 shows the means, standard deviations, and alpha reliability coefficients for each of the scales. The Cronbach alpha reliability coefficients or internal consistency of the items were high for the Resolved Total scale ( $\alpha = .856$ ) and for the Unresolved Total scale ( $\alpha = .849$ ). The alpha reliability coefficients for the 15 domain scales ranged from .508 to .741. If we had selected only items with the highest factor loadings for the short-form scales, the alpha coefficients for the scales would have been higher, but content validity would have been lower. This would cause some of the types of parent comments in the domain to no longer be represented in the scale, and each scale would no longer represent the breadth of the original domain content. Therefore, we retained these

selected items to maintain optimal content validity in the scales.

### **Standard Error Values**

Table 7 also shows the standard error of the mean (SEM) and the standard error of measurement (SEm) values for each scale. The SEM values are less than 0.09 of a raw score unit on each of the 5-point scales, and the SEm values are less than 0.57 of a raw score unit on each of the scales.

### **Correlations of Short-Form with Long-Form Scales**

Table 7 also presents the correlations of each short-form scale with its corresponding long-form scale. The correlations between the short-form scales and their corresponding long-form scales were high and significant, all at the  $p < .001$  level. The correlations of the short-form and corresponding long-form scales were .960 for the Resolved Total scale, .954 for the Unresolved Total scale, and between .613 and 1.00 for the domain scales. The correlations between the short and long forms were 1.00 for Unconcerned, Resistant, Negative Distortions, and Positive Distortions scales, because there were only four items in their corresponding long forms, so their short and long forms contained identical items. Each short-form scale correlated most highly with its corresponding long-form scale, and less highly with the other long-form scales.

### **Comparison of Resolved Total and Unresolved Total Means**

The participants' short-form Resolved Total mean score of 3.82 was significantly higher than their Unresolved Total mean score of 1.75,  $F(1, 136) = 997.29, p < .001, \eta^2 = .880$ . Thus, the parents scored significantly higher on resolution than nonresolution. In addition to having statistical significance and a large effect size of .880, this difference can be considered to have

Table 7

*The Short-Form Scales, showing Each Scale's Mean Score, Standard Deviation, Alpha Reliability, Standard Error of the Mean (SEM), Standard Error of Measurement (SEm), Number of Items in its Original Long-Form Scale, and Correlation of Each Short-Form Scale with its Corresponding Long-Form Scale, with N = 137*

Short-Form Scale	Mean Score	Standard Deviation	Alpha Reliability	SEM	SEm	Long Form Items	Correlation with its Long Form
Resolved Total	3.82	0.50	.856	0.04	0.19	48	.960 ***
Positive Feelings	3.94	0.79	.691	0.07	0.44	10	.896 ***
Working through Emotions	3.27	0.97	.666	0.08	0.56	6	.911 ***
Active Research	4.33	0.76	.741	0.06	0.39	7	.936 ***
Participation and Helping	4.53	0.58	.722	0.05	0.31	6	.613 ***
Self-Help Routines	2.78	0.90	.634	0.08	0.54	3	.940 ***
Broad Perspectives	4.01	0.76	.673	0.07	0.44	9	.855 ***
Focused Thought	3.91	0.76	.586	0.06	0.49	7	.807 ***
Unresolved Total	1.75	0.48	.849	0.04	0.19	44	.954 ***
Emotionally Overwhelmed	2.05	0.89	.741	0.08	0.45	8	.929 ***
Angry Feelings	1.39	0.65	.712	0.06	0.35	8	.877 ***
Depressed Feelings	1.91	0.83	.719	0.07	0.44	8	.903 ***
Confused Feelings	1.88	0.75	.709	0.06	0.41	8	.918 ***
Neutralizing Unconcerned	1.49	0.62	.623	0.05	0.38	4	1.00 ***
Neutralizing Resistant	1.54	0.65	.529	0.06	0.45	4	1.00 ***
Negative Distortions	2.02	0.76	.508	0.06	0.53	4	1.00 ***
Positive Distortions	2.18	0.81	.552	0.07	0.54	4	1.00 ***

*Note.* Each short-form scale correlates more highly with its corresponding long-form scale, than with the other long-form scales. The correlations are 1.00 for the neutralizing and distortions scales, because their long and short forms contained the same four items.  
\*\*\* Significant correlations at  $p < .001$ .

practical significance for the parents, with a mean for the Resolved items close to 4 (*Mostly like me*) and the mean for the Unresolved items close to 2 (*Slightly like me*) on the 1-5 rating scale. The difference between the Resolved and Unresolved Total means in the long-form measure was also significant at the  $p < .001$  level and had a similar effect size of .868.

To examine what proportion of the parents scored as more Resolved than Unresolved, and what proportion of the parents scored as more Unresolved than Resolved, we calculated difference scores by taking each parent's Resolved Total score minus the parent's Unresolved Total score. Thus, a positive difference score indicated a higher Resolved Total score than Unresolved Total score, while a negative difference score would indicate a lower Resolved Total score than Unresolved Total score.

Researchers using the RDI interview had categorized most parents as Unresolved. However, the 137 parents in our data had difference scores ranging from 0.00 to +3.64, with a mean difference score of +2.07. Fully 135 (99%) of the parents scored higher on the Resolved Total scale than they did on the Unresolved Total scale, two (1%) scored exactly the same on the Resolved and Unresolved scales, and none (0%) of the parents scored higher on the Unresolved Total scale than the Resolved Total scale.

### Profile of Scale Means

The means and standard deviations for each of the short-form scales are shown in Table 7, and a profile graph of the scale means is presented in Figure 1. Within-subjects analysis of variance showed that there were significant differences among the scale means,  $F(14, 123) = 319.53, p < .001, \eta^2 = .701$ . Contrasts showed that the participants' means on each of the short-form Resolved scales were significantly higher than their means on each of the Unresolved scales, at

the  $p < .001$  level, thus showing the same pattern as that shown for the long-form scales.

Among the Resolved scales, contrasts showed that the means for Participation and Helping (4.53) and Active Research (4.33) were significantly higher than those for Broad Perspectives (4.01), Focused Thought (3.91), and Positive Feelings (3.94), which in turn were significantly higher than Working through Emotions (3.27), which in turn was significantly higher than for Self-Help Routines (2.78), at the  $p < .001$  level. Except for the Self-Help Routines mean of 2.78, the parents' means for the Resolved scales were all above 3.00 on the 1-5 response scale.

Among the Unresolved scales, contrasts showed that the means for Emotionally Overwhelmed (2.05), Negative Distortions (2.02), Depressed (1.91), and Confused (1.88) were each significantly higher than for Resistant (1.54), Unconcerned (1.49), and Angry (1.39), at the  $p < .001$  level. The parents' means for the Unresolved scales were all relatively low, being near or below 2.00 on the 1-5 response scale.

The short-form scale means were all within .5 or half of a score unit from their corresponding long-form scale means. Both the short-form and long-form means showed the same pattern of contrasts, in which each of the Resolved scale means were significantly higher than each of the Unresolved scale means at the  $p < .001$  level.

### Correlations of Resolved Total Scores with Demographic Measures

Table 8 presents the correlations between the short-form Resolved and Unresolved Total scores and the demographic measures. Correlations that are starred are statistically significant, while correlations that are bolded indicate variables that are significantly correlated for both the short form and long form.



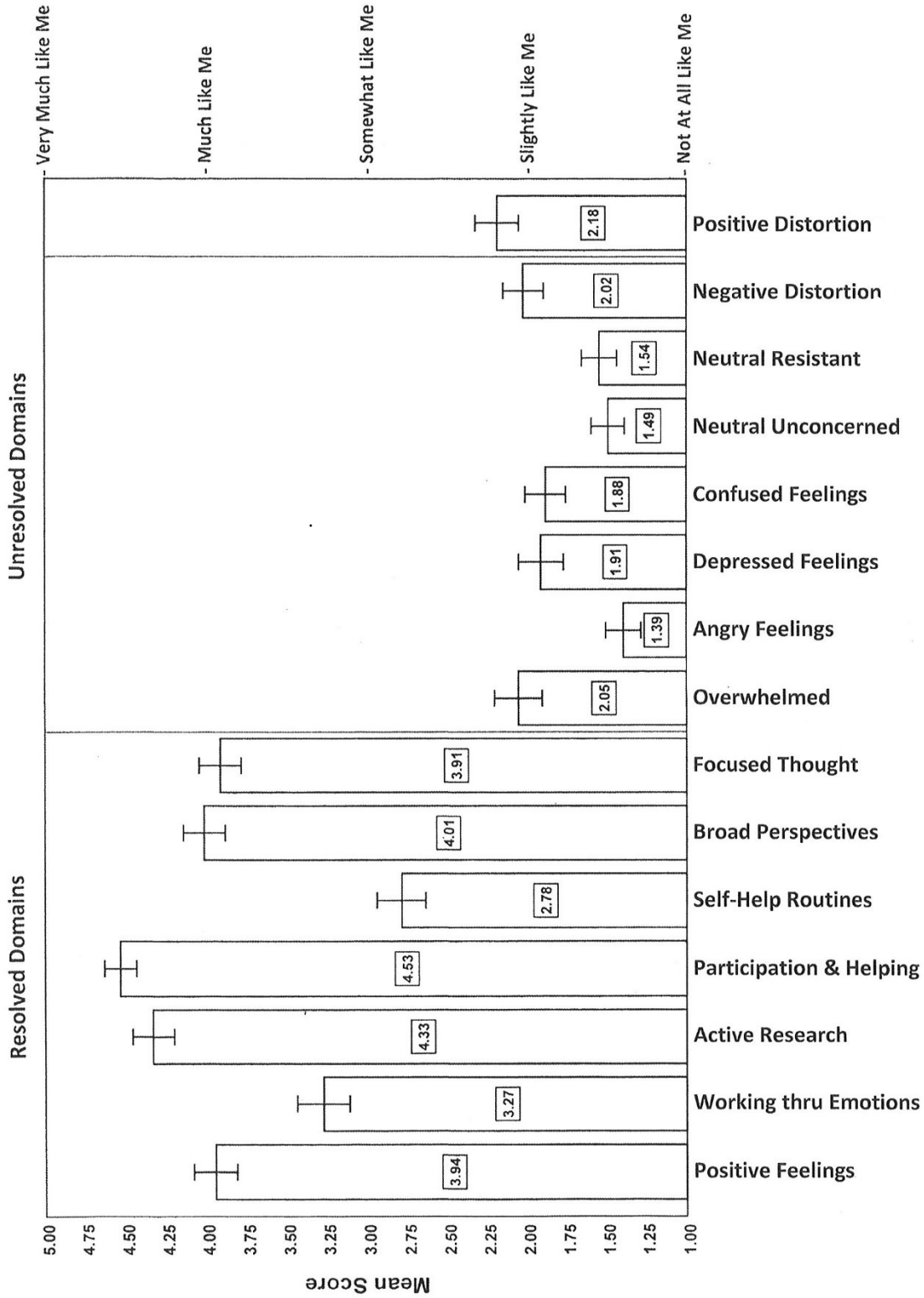


Figure 1. Mean scores for the 137 parents on each of the Resolved and Unresolved scales. Lines above and below the bar tops show the 95% confidence intervals for the means. The parents' means on each of the Resolved scales are significantly higher than their means on each of the Unresolved scales, at the  $p < .001$  level.

Table 8

*Correlations of the Resolved and Unresolved Total Scores with Demographic Measures*

Demographic Measure	Resolved Total Score	Unresolved Total Score
Participant Age Level	.056	<b>-.283 **</b>
Child Age in Years	-.035	<b>-.206 *</b>
Autism Functioning Level	-.002	<b>-.239 **</b>
Parent ABA Training	.116	-.067
ABA Training Hour Levels	.107	-.109
ABA Training Usage	.120	-.125
Parent Other Training	.093	-.052
Parent Other Training Usage	.102	-.083
Years of Child Behavioral Treatment	<b>.213 *</b>	-.160
Satisfaction with Behavioral Treatment	<b>.323 ***</b>	<b>-.357 ***</b>
Satisfaction with Behavioral Hours	<b>.188 *</b>	<b>-.252 **</b>
School Services	<b>.221 *</b>	-.061
Satisfaction with School Services	<b>.242 **</b>	<b>-.352 ***</b>
Child Age when Noticed Problem	<b>-.212 *</b>	-.059
Child Age when Diagnosed	<b>-.192 *</b>	-.005
Years Since Diagnosis	.044	<b>-.206 *</b>

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 109-137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.

The participants' Resolved Total scores showed significant positive correlations with the child's years of behavioral treatment, with their satisfaction with the child's behavioral treatment, with satisfaction with the child's behavioral treatment hours, with the child receiving school services, and with satisfaction with the school services.

The Resolved Total scores showed significant negative correlations with the child's age when the participant first noticed the child may have a problem, and with the child's age when diagnosed with autism.

Thus, these correlations indicate that the more highly Resolved parents tended to have had their child in behavioral treatment for a longer time, were more likely to have school services for their child, and they were more satisfied with their child's behavioral treatment program, behavioral treatment hours, and school services. They also noticed that their child may have a problem at an earlier age, and had their child diagnosed at a younger age.

### **Correlations of Unresolved Total Scores with Demographic Measures**

As shown in the second column of Table 8, the participants' Unresolved Total scores showed significant negative correlations with the parents' age, with their child's age, with their child's autism functioning level, with their satisfaction with the child's behavioral treatment, with their satisfaction with the child's behavioral treatment hours, with satisfaction with school services, and with the time that has elapsed since the child's diagnosis.

Thus, these correlations indicate that the more highly Unresolved parents tend to be younger, have a younger child with autism, identify the child as having a lower functioning level, are less satisfied with their child's behavioral treatment, behavioral treatment hours, and school services; and have received their child's diagnosis more recently.

### **Correlations of Resolved Total Scores with Relationship, Self-Efficacy, and Emotion Measures**

The correlations between the short-form Resolved Total scores and the relationship, self-efficacy, and emotion measures are presented in the first column of Table 9.

**For the relationship measures**, the participants' Resolved scores showed significant positive correlations with Adult Closeness, with Child-Parent Closeness, and with Child-Parent Sharing.

Thus, these correlations show that the more highly Resolved parents tended to experience more closeness in their adult relationships, and more closeness and more sharing with their child.

**For parenting self-efficacy**, the Resolved scores showed significant positive correlations with Total Parenting Self-Efficacy, along with Confidence in Managing Behaviors, Confidence in Teaching Skills, and Confidence in Advocating for Supports.

Thus, the more highly Resolved participants tended to be more confident in parenting a child with autism, including managing behaviors, teaching skills, and advocating for supports for their child.

Table 9

*Correlations of the Resolved and Unresolved Total Scores with Relationship, Self-Efficacy, and Emotion Measures*

Scale Measure	Resolved Total Score	Unresolved Total Score
<b>Adult Relationships</b>		
Adult Closeness	<b>.233 **</b>	<b>-.335 ***</b>
Worry Alone	-.066	<b>.341 ***</b>
Valuing of Independence	.046	-.010
Accepting of Dependents	.118	<b>-.484 ***</b>
<b>Child-Parent Relationship</b>		
Child-Parent Conflicts	-.163	<b>.428 ***</b>
Child-Parent Closeness	<b>.379 ***</b>	<b>-.198 *</b>
Child-Parent Sharing	<b>.169 *</b>	-.129
<b>Parenting Self-Efficacy</b>		
Total Self-Efficacy	<b>.303 ***</b>	<b>-.524 ***</b>
Managing Behaviors	<b>.234 **</b>	<b>-.432 ***</b>
Teaching Skills	<b>.263 **</b>	<b>-.375 ***</b>
Advocating for Supports	<b>.239 **</b>	<b>-.478 ***</b>
<b>Initial Emotions</b>		
Distressed Emotions	.117	<b>.358 ***</b>
Positive Emotions	.020	-.141
Detached Emotions	.042	<b>.312 ***</b>
<b>Current Emotions</b>		
Distressed Emotions	-.160	<b>.851 ***</b>
Positive Emotions	<b>.446 ***</b>	<b>-.530 ***</b>
Detached Emotions	-.134	<b>.565 ***</b>

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.

**For the emotion measures,** the Resolved scores showed no significant correlations with Initial Emotions experienced when receiving the child's diagnosis. The Resolved scores did show a significant positive correlation with their Current Positive Emotions.

Thus, the more highly Resolved parents, regardless of their initial emotions experienced at diagnosis, tended to experience more positive emotions at the current time.

In addition to measuring Initial and Current Emotions, we calculated Emotion Change scores by subtracting the Initial Emotion rating from the Current Emotion rating for each participant on each emotion measure. Thus, positive change scores represented increases in the emotion, and negative change scores represented decreases in the emotion over time. The participants' Resolved Total scores showed a significant positive correlation with the Positive Emotions Change scores, and they showed a significant negative correlation with the Distressed Emotions Change scores.

Thus, relative to the less highly Resolved participants, the more highly Resolved participants experienced greater increases in positive emotions and greater decreases in distressed emotions from the time of diagnosis to the current time. These significant correlations of change scores with the short-form Resolved scale were also significant with the long-form Resolved scale as well.

### **Correlations of Unresolved Total Scores with Relationship, Self-Efficacy, and Emotion Measures**

The correlations between the short-form Unresolved Total scores and the relationship, self-efficacy, and emotion measures are presented in the second column of Table 9.

**For the relationship measures,** the participants' Unresolved scores showed a significant negative correlation with Adult Closeness, a positive correlation with Worry about Being Alone, a negative correlation with Acceptance of Dependents, a negative correlation with Child-Parent Closeness, and a positive correlation with Child-Parent Conflicts.

Thus, these correlations indicate that the more highly Unresolved participants tend to experience less closeness, more worry about being alone, and less comfort with others depending on them in their adult relationships; and they also tend to experience less closeness and more conflicts in their relationship with their child.

**For parenting self-efficacy,** the Unresolved scores showed significant negative correlations with Total Parenting Self-Efficacy, and with Confidence in Managing Behaviors, Confidence in Teaching Skills, and Confidence in Advocating for Supports.

Thus, the more highly Unresolved participants tended to be less confident in parenting a child with autism, including managing behaviors, teaching skills, and advocating for supports for their child.

**For the emotion measures,** the Unresolved scores correlated positively with Initial Distressed Emotions, and with Initial Detached Emotions at the time of diagnosis. The Unresolved scores also correlated positively and strongly with Current Distressed Emotions and with Current Detached Emotions, and negatively with Current Positive Emotions.

Thus, the more highly Unresolved participants experienced more distress and detachment when their child was diagnosed, and they continued to experience more distress and detachment and less positive emotions in the current time.

Now that we have presented the correlations for the Resolved and Unresolved Total scores with the other variables, we are next presenting the correlations for each of the 15 scales with the other variables.

### **Correlations of the Resolved Scales with Demographic Measures**

Correlations of the seven short-form Resolved scales with the demographic measures are shown in Table 10, along with their significance levels.

The significant correlations in Table 10 show that the parents scoring more highly in the **Positive Feelings** domain tended to have greater satisfaction with their child's behavioral treatment program, behavioral treatment hours, and school services.

Parents scoring more highly on **Active Research** tended to have obtained more hours of training in applied behavior analysis, had noticed earlier that their child may have a problem, and had their child diagnosed at an earlier age.

Parents scoring more highly on **Participation and Helping** tended to have more hours of training in applied behavior analysis, were more likely to be using applied behavior analysis skills in parenting their child, were more likely to have other training and be using other parenting methods with their child, had their child receiving more years of behavioral treatment, were more likely to have their child receiving services in the school, noticed earlier that their child may have a problem, and had their child diagnosed at an earlier age.

Parents scoring more highly on **Broad Perspectives** tended to rate their child as having a higher level of functioning, and they were more satisfied with their child's behavioral treatment program and with their child's school services.

Parents scoring more highly on **Focused Thought** tended to have their child receive behavioral services for a longer time, noticed earlier that their child may have a problem, and had their child diagnosed at an earlier age.

### **Correlations of the Resolved Scales with Relationship, Self-Efficacy, and Emotion Measures**

The correlations of the seven short-form Resolved scales with the relationship, self-efficacy, and emotion measures are shown in Table 11.

The significant correlations in Table 11 show that the parents scoring more highly in the **Positive Feelings** domain tended to experience more closeness and greater acceptance of dependents in their adult relationships, as well as experiencing more closeness, more sharing, and fewer conflicts with their child. They also showed higher total parenting self-efficacy, along with greater confidence in managing behaviors, teaching skills, and advocating for supports for their child. They experienced greater current positive emotions, and fewer current distressed and detached emotions. On the emotion change scores, the parents scoring higher on Positive Feelings showed a greater increase in positive emotions and a greater decrease in distressed emotions from the initial to the current time.

The parents scoring more highly on **Working through Emotions** tended to experience greater closeness in their adult relationships. They reported having had greater initial distressed and detached emotions, and fewer positive emotions at the initial time of diagnosis. On the emotion change scores, these parents who scored highly in Working through Emotions achieved greater increases in positive emotions and greater decreases in distressed and detached emotions from the initial to the current time.

Table 10

*Correlations of the Resolved Scales with Demographic Measures*

Demographic Measure	Positive Feelings	Work thru Emotions	Active Research	Participation	Self-Help	Perspectives	Focused Thought
Participant Age Level	.110	-.129	.039	.068	.087	.069	.044
Child Age in Years	.041	-.105	-.073	-.043	.048	.089	-.113
Autism Functioning Level	.159	-.170	-.062	-.129	.005	<b>.230**</b>	-.041
Parent ABA Training	.098	.052	.142	<b>.270***</b>	.016	-.146	.147
ABA Training Hour Levels	.053	.068	<b>.196*</b>	<b>.239**</b>	.010	-.212*	.173*
ABA Training Usage	.082	.067	.138	<b>.276***</b>	.050	-.155	.129
Parent Other Training	.050	-.036	.160	<b>.229**</b>	.023	-.038	.101
Other Training Usage	.087	-.015	.151	<b>.209*</b>	.014	-.008	.082
Years Child Behavioral Treat	.073	.122	.195*	<b>.222**</b>	.103	.014	<b>.238**</b>
Satisfaction Behavioral Treat	<b>.342***</b>	.187*	.150	.247**	.107	<b>.267**</b>	.188*
Satisfaction Behavioral Hours	<b>.190*</b>	.111	.070	.193*	.038	.158	.131
School Services	.122	.124	.094	.268**	.195*	.173*	.042
Satisfaction School Services	<b>.350***</b>	.176	.076	.101	.098	<b>.268**</b>	.005
Child Age Noticed Problem	-.148	-.049	<b>-.235**</b>	<b>-.217*</b>	-.083	-.063	<b>-.195*</b>
Child Age when Diagnosed	-.020	-.069	<b>-.279***</b>	<b>-.274***</b>	-.074	.059	<b>-.254**</b>
Years since Diagnosis	.056	-.064	.026	.057	.085	.078	-.024

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 109-137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.

Table 11

*Correlations of the Resolved Scales with Relationship, Self-Efficacy, and Emotion Measures*

Scale Measure	Positive Feelings	Work thru Emotions	Active Research	Participation	Self-Help	Perspectives	Focused Thought
<b>Adult Relationships</b>							
Adult Closeness	<b>.297***</b>	<b>.264**</b>	.058	.227**	-.009	<b>.169*</b>	.037
Worry Alone	-.144	.079	-.170*	-.176*	.043	-.034	.031
Valuing of Independence	.024	-.073	.119	.030	.044	-.052	.137
Accepting of Dependents	.226**	.045	.127	.106	-.042	<b>.204*</b>	-.113
<b>Child-Parent Relationship</b>							
Child-Parent Conflicts	<b>-.380***</b>	-.064	-.041	-.154	.103	<b>-.269***</b>	.034
Child-Parent Closeness	<b>.544***</b>	.108	.128	.264**	.096	<b>.433***</b>	.162
Child-Parent Sharing	<b>.327***</b>	.012	-.008	-.029	.031	<b>.273**</b>	.140
<b>Parenting Self-Efficacy</b>							
Total Self-Efficacy	<b>.434***</b>	.024	.191*	.162	.158	<b>.309***</b>	.098
Managing Behaviors	<b>.365***</b>	-.013	.141	.086	.103	<b>.298***</b>	.083
Teaching Skills	<b>.400***</b>	-.013	.152	.096	.129	<b>.298***</b>	.134
Advocating for Supports	<b>.270***</b>	.108	.180*	<b>.239**</b>	.161	.122	.005
<b>Initial Emotions</b>							
Distressed Emotions	.160	<b>-.458***</b>	.052	.135	.080	-.221**	.090
Positive Emotions	.127	<b>-.327***</b>	<b>.204*</b>	-.067	.017	.163	.039
Detached Emotions	-.124	<b>.368***</b>	-.136	.045	.076	-.136	.000
<b>Current Emotions</b>							
Distressed Emotions	<b>-.585***</b>	.156	.054	-.017	-.011	<b>-.479***</b>	.126
Positive Emotions	<b>.658***</b>	-.016	<b>.249**</b>	<b>.184*</b>	<b>.203*</b>	<b>.523***</b>	.231**
Detached Emotions	<b>-.313***</b>	.026	-.093	-.142	.123	<b>-.212*</b>	.017
<b>Emotion Change Scores</b>							
Distressed Emotion Change	<b>-.365***</b>	<b>-.326***</b>	-.004	-.153	-.094	<b>-.211*</b>	.019
Positive Emotion Change	<b>.455***</b>	<b>.333***</b>	.011	.240**	.172*	<b>.294***</b>	.166
Detached Emotion Change	-.127	<b>-.364***</b>	.076	-.139	-.008	.000	.010

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.



The parents scoring more highly on **Active Research** tended to report experiencing more positive emotions both initially and currently, compared to other parents. The parents scoring more highly on **Participation and Helping** tended to have greater confidence in their advocating for supports for their child, and they tended to score higher on current positive emotions. Parents scoring more highly on **Self-Help Routines** and parents scoring more highly on **Focused Thought** also tended to experience higher current positive emotions.

The parents scoring more highly on **Broad Perspectives** showed greater closeness and acceptance of dependents in their adult relationships, and they also showed greater closeness, greater sharing, and fewer conflicts in their relationship with their child. These parents showed greater total parenting self-efficacy, with greater confidence in managing behaviors and teaching skills for their child. They tended to experience fewer initial distressed emotions, fewer current distressed and detached emotions, and greater current positive emotions. On the emotion change scores, the parents scoring higher in Broad Perspectives showed greater increases in positive emotions and greater decreases in distressed emotions, from the initial to the current time.

### **Correlations of the Unresolved Scales with Demographic Measures**

The correlations of the short-form Unresolved scales with the demographic measures are shown in Tables 12 and 13.

The significant correlations in Table 12 show that the parents who scored as more **Emotionally Overwhelmed** tended to be younger, have a younger child, rate their child's functioning level as lower, be less satisfied with their child's behavioral treatment and school services, and received their child's diagnosis more recently.

Parents scoring higher in **Angry Feelings** tended to rate their child's functioning level as lower, and they were less satisfied with their child's school services. Parents scoring higher in **Depressed Feelings** tended to have a younger child, rated their child as having a lower functioning level, and were less satisfied with their child's behavioral treatment program, behavioral treatment hours, and school services. Parents scoring higher on the **Confused** scale tended to be younger, have a younger child, be less satisfied with their child's behavioral treatment program, behavioral treatment hours, and school services, and have received their child's diagnosis more recently.

The significant correlations in Table 13 show that the parents who scored as more **Neutralizing Unconcerned** tended to rate their child's functioning level as higher, had fewer hours of training and usage of applied behavior analysis, and had fewer years of behavioral treatment for their child. Parents scoring higher on **Negative Distortions** tended to be younger, have a younger child, rate their child's functioning level as lower, were less satisfied with their child's behavioral treatment program, behavioral treatment hours, school services, and had received their child's diagnosis more recently.

In contrast, the parents scoring higher on **Positive Distortions** tended to be more satisfied with their child's behavioral treatment program, and they also noticed earlier that their child might have a problem.

### **Correlations of the Unresolved Scales with Relationship, Self-Efficacy, and Emotion Measures**

The correlations of the short-form Unresolved scales with the relationship, self-efficacy, and emotion measures are shown in Tables 14 and 15.

Table 12

*Correlations of the Unresolved Overwhelmed, Angry, Depressed, and Confused Scales with Demographic Measures*

Demographic Measure	Overwhelmed	Angry Feelings	Depressed Feelings	Confused Feelings
Participant Age Level	<b>-.245**</b>	-.164	-.124	<b>-.356***</b>
Child Age in Years	<b>-.257**</b>	-.065	<b>-.186*</b>	<b>-.261**</b>
Autism Functioning Level	<b>-.186*</b>	<b>-.348***</b>	<b>-.212*</b>	-.149
Parent ABA Training	-.196*	-.045	-.051	-.188*
ABA Training Hour Levels	-.135	.023	-.025	-.157
ABA Training Usage	-.152	-.042	-.030	-.175*
Parent Other Training	-.037	.016	-.020	-.177*
Other Training Usage	-.036	.006	-.064	-.105
Years Child Behavioral Treat	-.140	.008	-.085	-.194*
Satisfaction Behavioral Treat	<b>-.246**</b>	-.182	<b>-.332***</b>	<b>-.387***</b>
Satisfaction Behavioral Hours	-.154	-.103	<b>-.272**</b>	<b>-.252**</b>
School Services	.011	-.002	-.097	-.030
Satisfaction School Services	<b>-.275**</b>	<b>-.253**</b>	<b>-.355***</b>	<b>-.269**</b>
Child Age Noticed Problem	-.128	-.023	-.125	-.046
Child Age when Diagnosed	.008	-.053	-.103	.041
Years since Diagnosis	<b>-.261**</b>	-.049	-.154	<b>-.274**</b>

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 109-137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.

Table 13

*Correlations of the Neutralizing and Distortion Scales with Demographic Measures*

Demographic Measure	Neutralizing Unconcerned	Neutralizing Resistant	Negative Distortions	Positive Distortions
Participant Age Level	-.081	-.108	<b>-.174*</b>	-.040
Child Age in Years	.139	.015	<b>-.216*</b>	-.089
Autism Functioning Level	<b>.187*</b>	-.106	<b>-.215*</b>	.083
Parent ABA Training	<b>-.193*</b>	.003	.019	.060
ABA Training Hour Levels	<b>-.218**</b>	-.051	.062	-.002
ABA Training Usage	<b>-.205*</b>	.015	.024	.068
Parent Other Training	-.043	-.047	-.007	.054
Other Training Usage	-.025	-.063	-.082	.108
Years Child Behavioral Treat	<b>-.193*</b>	-.022	-.083	-.097
Satisfaction Behavioral Treat	-.065	-.172	<b>-.212*</b>	<b>.213*</b>
Satisfaction Behavioral Hours	-.006	-.113	<b>-.204*</b>	.091
School Services	-.144	.105	-.113	-.046
Satisfaction School Services	-.001	-.163	<b>-.196*</b>	.133
Child Age Noticed Problem	.142	.026	-.132	<b>-.186*</b>
Child Age when Diagnosed	.172	.023	-.074	-.024
Years since Diagnosis	.080	.006	<b>-.189*</b>	-.068

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 109-137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.

Table 14

*Correlations of the Unresolved Overwhelmed, Angry, Depressed, and Confused Scales with Relationship, Self-Efficacy, and Emotion Measures*

Scale Measure	Overwhelmed	Angry Feelings	Depressed Feelings	Confused Feelings
<b>Adult Relationships</b>				
Adult Closeness	<b>-.257**</b>	-.167	<b>-.186*</b>	<b>-.304***</b>
Worry Alone	<b>.344***</b>	<b>.210*</b>	<b>.254**</b>	<b>.382***</b>
Valuing of Independence	-.029	-.054	-.041	-.086
Accepting of Dependents	<b>-.416***</b>	<b>-.321***</b>	<b>-.393***</b>	<b>-.387***</b>
<b>Child-Parent Relationship</b>				
Child-Parent Conflicts	<b>.525***</b>	<b>.187*</b>	<b>.339***</b>	<b>.442***</b>
Child-Parent Closeness	<b>-.248**</b>	-.018	<b>-.209*</b>	<b>-.266**</b>
Child-Parent Sharing	-.103	-.095	-.142	<b>-.212*</b>
<b>Parenting Self-Efficacy</b>				
Total Self-Efficacy	<b>-.535***</b>	<b>-.323***</b>	<b>-.412***</b>	<b>-.599***</b>
Managing Behaviors	<b>-.468***</b>	<b>-.292***</b>	<b>-.328***</b>	<b>-.493***</b>
Teaching Skills	<b>-.380***</b>	<b>-.380***</b>	<b>-.317***</b>	<b>-.467***</b>
Advocating for Supports	<b>-.454***</b>	<b>-.248**</b>	<b>-.363***</b>	<b>-.497***</b>
<b>Initial Emotions</b>				
Distressed Emotions	<b>.315***</b>	<b>.338***</b>	<b>.422***</b>	<b>.333***</b>
Positive Emotions	-.071	<b>-.241**</b>	<b>-.230**</b>	-.086
Detached Emotions	.166	<b>.345***</b>	<b>.345***</b>	<b>.220**</b>
<b>Current Emotions</b>				
Distressed Emotions	<b>.813***</b>	<b>.714***</b>	<b>.801***</b>	<b>.704***</b>
Positive Emotions	<b>-.430***</b>	<b>-.474***</b>	<b>-.541***</b>	<b>-.463***</b>
Detached Emotions	<b>.471***</b>	<b>.470***</b>	<b>.437***</b>	<b>.380***</b>

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.

Table 15

*Correlations of the Neutralizing and Distortion Scales with Relationship, Self-Efficacy, and Emotion Measures*

Scale Measure	Neutralizing Unconcerned	Neutralizing Resistant	Negative Distortions	Positive Distortions
<b>Adult Relationships</b>				
Adult Closeness	-.128	-.125	<b>-.316***</b>	.075
Worry Alone	.019	.123	.142	-.007
Valuing of Independence	.038	.074	.072	-.062
Accepting of Dependents	-.096	<b>-.174*</b>	<b>-.330***</b>	.118
<b>Child-Parent Relationship</b>				
Child-Parent Conflicts	-.049	.102	<b>.255**</b>	-.104
Child-Parent Closeness	.059	.023	-.139	<b>.225**</b>
Child-Parent Sharing	.153	-.002	-.125	.119
<b>Parenting Self-Efficacy</b>				
Total Self-Efficacy	.122	<b>-.173*</b>	<b>-.311***</b>	<b>.241**</b>
Managing Behaviors	.156	<b>-.203*</b>	<b>-.210*</b>	<b>.218**</b>
Teaching Skills	.137	-.071	<b>-.242**</b>	<b>.248**</b>
Advocating for Supports	.031	-.142	<b>-.324***</b>	.097
<b>Initial Emotions</b>				
Distressed Emotions	<b>-.466***</b>	.131	<b>.390***</b>	<b>-.278***</b>
Positive Emotions	<b>.427***</b>	<b>-.254**</b>	-.123	<b>.284***</b>
Detached Emotions	<b>-.290***</b>	<b>.320***</b>	<b>.247**</b>	-.153
<b>Current Emotions</b>				
Distressed Emotions	<b>-.307***</b>	<b>.206*</b>	<b>.679***</b>	<b>-.345***</b>
Positive Emotions	<b>.278***</b>	<b>-.257**</b>	<b>-.377***</b>	<b>.625***</b>
Detached Emotions	.066	<b>.204*</b>	<b>.450***</b>	-.136

*Note.* Bolded correlations indicate variables that correlate significantly in both the short-form and long-form.  $N = 137$ .

\* Significant correlation at  $p < .05$  level.

\*\* Significant correlation at  $p < .01$  level.

\*\*\* Significant correlation at  $p < .001$  level.

The significant correlations in Table 14 show that the **Emotionally Overwhelmed**, **Angry**, **Depressed**, and **Confused** scales had similar patterns of correlations with the other variables. Higher scores on these Unresolved feelings scales were associated with the parents' lower closeness, more worry about being alone, and lower acceptance of dependents in their adult relationships, as well as more conflicts and less closeness in their relationship with their child. Higher scores on these scales were associated with the parents' experiencing lower total parenting self-efficacy, along with lower confidence in managing behaviors, teaching skills, and advocating for supports for their child. Higher scores on these scales were also associated with greater initial distressed emotions, and they were strongly associated with greater current distressed and detached emotions and lower current positive emotions.

The significant correlations in Table 15 show that parents who scored higher on the **Neutralizing Unconcerned** scale expressed less initial distressed and detached emotions, less current distressed emotions, and higher initial and current positive emotions. Parents who scored higher on the **Neutralizing Resistant** scale showed lower acceptance of dependents in their adult relationships, lower total parenting self-efficacy, lower confidence in managing behaviors, lower initial and current positive emotions, greater initial and current detached emotions, and greater current distressed emotions. Parents who scored higher on **Negative Distortions** showed less adult closeness, less accepting of dependents, more conflicts with their child, lower parenting self-efficacy, less confidence in managing behaviors, teaching skills, and advocating for supports, greater initial and current distressed and detached emotions, and less current positive emotions.

In contrast, parents who scored higher on **Positive Distortions** experienced greater closeness with their child, greater total parenting self-efficacy, greater confidence in managing

behaviors and teaching skills to their child, less initial and current distressed emotions, and greater initial and current positive emotions.

### **Agreement in Correlation Patterns between the Short and Long Form**

The pattern of significant and non-significant correlations of the scales with other variables was similar, but not identical, for the short form and long form. Of the 582 correlations, regarding agreements, 215 (37%) were significant in both the short and long forms, and 318 (55%) were non-significant in both the short and long forms. Regarding disagreements, 25 (4%) were significant in the short form but non-significant in the long form, and 24 (4%) were non-significant in the short form but significant in the long form. Thus, regarding the pattern of significant and non-significant correlations, 533 (92%) of the 582 correlations showed agreement between the short and long forms.

### **Relationship of Two Central Items with the Resolved and Unresolved Measures**

To evaluate convergent validity, we included two items in the long form which summarized the definitions of resolution and nonresolution given by Pianta and Marvin (1993).

The item "Since my child received a diagnosis of autism, I have been able to accept it and move forward" was worded to summarize the central concept of resolution. The parents' ratings on this item were positively correlated with their short-form Resolved Total scores,  $r(135) = .302$ ,  $p < .001$ , and these ratings were also negatively correlated with their short-form Unresolved Total scores,  $r(135) = -.448$ ,  $p < .001$ .

The other item "My feelings have stayed the same since my child was first diagnosed with autism" was worded to summarize the central concept of nonresolution. The parents' ratings on this item were negatively correlated with their short-form Resolved Total scores,  $r(135) = -.178$ ,

$p = .038$ , and these ratings were positively correlated with their short-form Unresolved Neutralizing Unconcerned scores,  $r(135) = .321$ ,  $p < .001$ . This pattern of correlations is the same as the pattern with the long-form measures.

### Chapter 3

#### PSYCHOMETRIC PROPERTIES OF THE PRADS-2

Like the long-form PRADS, the short-form PRADS-2 exhibits internal reliability and several forms of evidence for validity.

**Internal reliability**, or consistency of items within scales, is shown with good Cronbach alpha coefficients of .856 for the Resolved Total scale, .849 for the Unresolved Total Scale, and coefficients between .508 and .741 for the domain scales, as shown in Table 7.

**Response validity** was checked for this research sample by examining and finding no eccentrically fixed patterns of responding across the sequence of item ratings for any of the individual parents. The resolved and unresolved items are interspersed in a counterbalanced and randomized sequence to help neutralize effects of possible acquiescence, nay-saying, and other patterned biases.

**Content validity** was carefully maintained when selecting items to include in the short-form PRADS-2, as we did not merely pick the four items with the strongest factor loadings, but rather items were chosen to ensure that all types of parent comments within that domain were represented.

**Construct validity** is confirmed by the factor structure of the items within and between each of the domain scales, with solid item factor loadings given for each scale, as shown in Tables 1-6.

**Convergent validity** is shown in significant correlations of the resolved and unresolved scales with two extra items worded to summarize the central concepts of resolution (“Since my child received a diagnosis of autism I have been able to accept it and move forward”) and nonresolution (“My feelings have stayed the

same since my child was first diagnosed with autism”), and also in significant correlations of the scales with specific Initial Emotions, Current Emotions, and Emotion Change scores which have been theorized to be a central element of resolution, as shown in Tables 9, 11, 14, and 15.

**Concurrent validity** is indicated in the significant correlations of the resolution scales with other concurrent measures of similar constructs which they have been predicted to relate to, including the parents’ Satisfaction with Behavioral and School Services, the attachment scales for Adult Relationships and Child-Parent Relationships, the Parenting Self-Efficacy scales, and the Initial and Current Emotion scales, as shown in Tables 8-15.

**Discriminant validity** is shown in the different patterns of correlations between specific scales and the other variables in the study, as shown in Tables 8-15. These tables show significant correlations between specific scales and other variables that measure similar constructs, along with low or nonsignificant correlations between the scale and variables that measure separate constructs. For example, the Working through Emotions scale correlates significantly with initial emotion and emotion change scores, but not with action variables; while the Participation and Helping scale correlates significantly with action variables such as ABA training and usage and early detection and diagnosis, but correlates less strongly with emotion scores.

**Face validity** is indicated by the survey items, which were originally chosen from actual parent statements, appearing to be clearly relevant to parents’ experiences, as confirmed by personal comments typed at the end of the survey by 69 of the participants.



**Representational validity** is indicated by having the relatively abstract theoretical construct of resolution translated to a concrete, objectively scored measuring instrument with practical usefulness for both research and application.

### **Terms for Validity**

The current *Standards for Educational and Psychological Testing* (AERO, APA, & MCME, 2014) manual states that the traditional **two-word terms** relating to validity should be interpreted, not as specifying different types of validity, but rather as specifying different types of **evidence** for validity. Their formal standards do not require avoiding these traditional terms, however. Thus, for conciseness and clarity, we are using the traditional **two-word terms**, and we are clearly stating how our procedures and statistical findings provide each type of **evidence** relating to the validity of our measure.

## Chapter 4

### ETHICAL STANDARDS AND ETHICAL QUALITIES OF THE PRADS-2

#### Ethical Standards for Testing

The current *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 2014) manual presents ethical standards for ensuring the rights of test takers and the responsibilities of test users. We have carefully incorporated and upheld these standards in writing this users' manual.

The *Standards* (2014) specify that test takers have rights to information prior to testing, rights to be protected from unauthorized use of test results, rights to access their test results, and rights to fair and accurate score reports.

Respectively, this measure includes a paragraph prior to the survey form that informs the parent of the purpose and use of this survey. The cover page of the survey form has an informed consent and parent rights section stating that the parent can specify whether they do or do not authorize certain other individuals to view their scores. This manual provides a description of how to score the parent's responses, along with a scoring sheet, a graphing template, and an illustration of a filled-in scoring sheet and profile graph for an example parent. This manual also provides a description of how the service provider can share and discuss the profile of scores with the parent in a clear, accurate, and supportive way.

The *Standards* (2014) specify that test users have the responsibility for meeting the training, credentials, or experience requirements that are specified in the test manual.

Respectively, our manual states that those who wish to use this measure in research work should obtain formal approval for their research from their Research Review Committee and should follow the ethical guidelines of their

profession. Those who wish to use this measure in service work should be professional service providers for families of children with serious diagnoses, should know what services are available for families in their community, and should also follow the ethical guidelines of their profession. The users should know how to administer and score assessments, as well as interpret the scores.

The *Standards* (2014) also specify that test users have the responsibility for studying the materials provided in the manual prior to use, for clearly understanding the intended uses for the scores, for carefully avoiding scoring errors, for avoiding misinterpretations of the scores, for considering other relevant information about the person or setting when interpreting scores, and for offering accommodations for test takers with disabilities.

Respectively, this manual provides important materials for the user to study prior to using the measure. The manual clearly states the intended uses for the scores, which are to measure parent's perceived strengths and difficulties in coping with their child's diagnosis, and to use the parent's profile of scores to identify specific services that may be of benefit to them. The manual provides the scoring sheet, graphing template, and an illustration for an example parent, to assist the user in accurately calculating scores for individual parents, and we recommend that the user check their scoring for possible errors before presenting them. To help the user avoid misinterpreting the parent scale scores, the manual especially cautions the user to avoid using the measure to place the parents into diagnostic categories, and our scale labels are carefully worded to avoid such misinterpretations, for example "depressed feelings" rather than "depression". The manual

points out that other relevant information, including the values, culture, and ecology of the family, can be important while considering specific services that may be appropriate for the family, as is illustrated in the section on interpretations and possible services for an example parent. For accommodations for test takers with disabilities, our manual points out that the parent may have unlimited time to complete the survey. The parent may answer the survey in pen-and-paper form or on a computerized form. The user may orally read each item aloud and have the parent orally state their rating of the item, or they may conduct this using sign language. The printed questions can be enlarged to be more visible for a parent, and the parent can choose the settings that would be best for them as well, such as in the user's office or the family home. The items may be translated and answers recorded by a professional who is expert in the parent's preferred language, provided the professional also follows the ethical guidelines.

The *Standards* (2014) specify that test users have the responsibility for specifying how long the records will be kept and to whom and under what conditions the records may be released, for protecting the privacy of the test taker unless a specific disclosure is agreed upon or legally authorized, and for providing a timely report of the results to the test taker and others entitled to receive this information.

Respectively, this manual provides a Parent Rights and Informed Consent form stating how long the records will be kept and under what conditions the records may be released, how the privacy of the parent will be protected, and how the parent can specify whether they do or do not authorize certain other individuals to view their scores. This manual also provides a Scoring Sheet, Profile Graphing Form, and Services Worksheet to facilitate accurate and timely reporting.

The *Standards* (2014) further specify that test users have the responsibility for obtaining

permission before altering the copyrighted test, and for respecting the conditions of the test copyright.

Respectively, we point out that researchers and service professionals have permission to use our measure in a way that is consistent with our manual's procedures, consistent with the *Standards* (2014), and consistent with their research and professional guidelines. If you wish to alter our measure in any way, however, you will need to obtain our written permission.

### **Ethical Standards for Cultural Competence**

The Behavior Analyst Certification Board's current *Ethics Code for Behavior Analysts* (BACB, 2020) presents professional standards that support their four core principles of: benefitting others; treating others with compassion, dignity, and respect; behaving with integrity; and ensuring competence. Here we highlight how these core principles relate to responsible behavior when providing services to families with diverse cultures.

The *Ethics Code* (2020) specifies that responsible professionals acquire knowledge and skills related to multicultural competence and diversity. Responsible professionals evaluate their own cultural biases and their ability to address needs of individuals with culturally diverse backgrounds. They do not discriminate against others. They behave toward others in a respectful, equitable, and inclusive manner, regardless of age, disability, ethnicity, gender identity, immigration status, marital or relationship status, national origin, race, religion, sexual orientation, or socioeconomic status.

Respectively, we recommend that if you will be serving families with cultures that are currently unfamiliar to you, it is essential to obtain information, training, or consultation about the typical traditions, values, family systems, and customs of the family groups you will be serving.

It is also especially beneficial to ask individual parents about their specific views and preferences when collaborating with them, so that you can help tailor supports that will be compatible with their family's cultural values.

### **Ethical Qualities of the PRADS-2 Measure**

The value of any measure includes the ethical qualities involved in its use. In developing the PRADS-2, ethical applications for the use of the measure were forefront in carrying out our research design. It was important to us that the use of the measure provide valuable data for researchers, as well as being a tool for service providers to help in the creation of a service package for families.

The PRADS-2 measure is respectful of families and what they may be experiencing in raising a child with autism. It contains a set of 60 items making up 15 domain scales of resolution and nonresolution relating to parenting a child with special needs. The 60 items are actual parent statements of their own experiences in raising a child with special needs, which were gathered from previous research and actual prior parent interviews by the PRADS researchers. Using actual parent statements makes the scales relatable for parents or caregivers taking the measure. Pointing out that these statements were made by other parents in similar parenting situations offers the parent a sense that they are not alone in their parenting experiences. Each parent gives their own specific set of responses, thus helping service providers in designing supports tailored for the family.

For researchers, the PRADS-2 is a quantifiable measure that is objectively scored so as not to be subject to speculative interpretation. The order of the 60 items has been carefully counterbalanced so that the sequencing does not reveal any pattern of domain scales to the parent that may bias their responding. A profile is created which shows the parent's current resolved strengths and unresolved concerns.

Thus, parents are not placed into categories of Resolved or Unresolved, and the profile of scores better represents the facets of the parent's current resolution status. The graphed profile created in scoring the measure, as well as individual answers to the scale items, offers useful information for researchers using a follow-up interview measure. Having the PRADS-2 as a foundation for a subsequent interview provides comprehensive information on many aspects of resolution and reduces subjectivity by the researchers in choosing what topics may be explored in an interview for further information and clarification.

The purpose of the PRADS-2 is clear. It was developed as an assessment of strengths and needs for parents of a child with autism. It is not a clinical tool that puts parents into diagnostic categories; rather the measure provides a visual profile of the 15 domain scales which show areas of strength and areas of difficulty. The domain scales are carefully worded so that a parent will not feel labeled or judged. The wording of the domain scales also eliminates any misunderstanding that the measure is designed for clinical diagnostic purposes. However, the measure can be used as a guideline for possible referrals for professional follow-up for any serious areas of concern that might be found.

The PRADS-2 is also not intended to be used as a normative or standardized measure. Our research sample of 137 parents, who completed all the 214 items in the seven measures in our online research survey, were internet-connected and actively responsive. They may not be representative of all parents of children diagnosed with autism. Thus, it is important for the user to not consider our participants' mean scores as norms, or what a "normal" parent "should" be feeling. Correspondingly, there are no cutoff points on the scales to separate what might be considered as "normal" versus "non-normal" scores. Instead, we use a personal and practical focus. Resolved scores around 1-2 (*Not at all like me and Slightly like me*), and Unresolved scores

around 4-5 (*Much like me* and *Very much like me*), may indicate parent feelings in areas where support services might help, provided that the parent agrees that they would appreciate assistance in these areas.

Ethical use of the PRADS-2 is an important aspect of working with families. We have clearly explained that the users of the PRADS-2 need to be familiar with all aspects of this manual in order to effectively administer the measure in a way that respects the family culture and ecology, identifies supports and services that the family agrees will be beneficial, and engages the parent respectfully and collaboratively throughout the process.

The PRADS-2 should only be used by researchers or by agencies providing direct services to families as well as the child. This measure is an assessment that can be used to design tailored services for parents and families.

Consistent with ethical principles, the manual has been written to show how the measure can be used with a strength-based approach in working with families, and further provides suggestions on how to provide feedback in respectful and positive ways. Sharing the Profile Graphing Form with the parent, the administrator can provide feedback in a supportive way to help engage the family in designing supports that the family will find helpful. Respecting the culture of the family will create a positive relationship with the family for the future. The first part of the Profile Graph shows domain scores in areas of strength, which can be encouraging for families who are not yet confident or comfortable with their child's diagnosis. This positive approach can be helpful when next discussing areas that may need additional supports if the parents see these as areas of need.

Thus, the PRADS-2 is developed as a strength-based measure to be used in a way that is respectful of the parents. Whenever using this measure for research or service work, the Resolved scale scores should always be included in addition to the Unresolved scale scores.

We intend our measure to be a voluntary survey, which is not compulsory and not a requirement for obtaining services. Whether used in research or service work, the parent can choose to give consent or to decline to fill out the measure. The parent can decide to stop filling it out at any time. The parent can also postpone answering it and may decide to answer it later. The parent may also refrain from answering all the questions. The parent should be informed that there is no penalty for declining to take the measure, and no penalty for missing responses on some items. There are no right or wrong answers. When used in service work, make it clear that the purpose of the measure is to indicate which of the available services may be most helpful to the parent; but that answering it is not a requirement for receiving services.

The information provided by this measure is personal and confidential and should not be shared outside the agency or person administering the measure, except when given express written permission by the individual taking the PRADS-2 measure. Thus, the parent's responses, scores, and services worksheets are to be kept confidential, unless the parent signs a release of information form for sharing the test information with specific other parties.

We wish to point out that the copyrighted measures contained in this manual must not be altered or used in any other way outside the specifications of this manual, without first obtaining our express written permission.

## Chapter 5

### APPLICATIONS OF THE PRADS-2

The PRADS-2 is designed for use by those conducting research relating to parent resolution when raising a child with autism, as well as by professionals who work directly with families of children with autism. The purposeful design of the measure allows for use in a variety of settings. The measure can be valuable for researchers conducting studies of parents of children with autism. It can be a valuable tool for gaining useful information prior to an interview in a research study, or as part of the intake process by agencies and individuals working with families of children with special needs.

The objective design of the PRADS-2 is comprehensive and uses actual parent statements regarding experiences parenting a child with autism. Understanding that the items are actual parent statements may make it easier for parents taking the assessment to relate to the items and recognize that they are not alone in their feelings or experiences. The ease of use of the measure makes it helpful for those individuals and agencies providing direct services to children and their families to target needed services to support those families.

The measure reflects the degree of parent experiences found in the domains in the RDI Reaction to Diagnosis Interview, a research tool of parent experiences used in the past. The graphed profile template, designed for the PRADS-2, makes it easier to interpret the scores and to help parents understand how their experiences relate to their resolution status. A services worksheet is also included to help with interpreting the results and designing supports and services for the family.

#### Use in Research

The PRADS-2 is useful in research as a

psychometrically sound measure of multiple facets of parent resolution. The design of the PRADS-2 enables researchers to do quantitative analysis using an objective measure that is cleaner and less cumbersome than a qualitative interview process, aiding in objectivity, reliability, validity, and ease of use for research studies. The statistical analysis for validation of the PRADS-2 in research is included in this manual. Researchers can further explore relationships of parents' PRADS-2 scales with other variables of interest to them.

Research with families of children with special needs often includes parent interviews, as well as formal and informal parent-child observations. When conducting interviews with parents, or when doing research on parenting a child with a disability, having the information from the PRADS-2 can be helpful in establishing relevant information for subsequent follow-up and clarification. Parents may not express all their feelings and concerns in an initial interview session, and the PRADS-2 measure gives an objective profile of parent responses and feelings, which may help start or direct the conversation to gain useful and meaningful information in a subsequent interview.

The PRADS-2 also gives parents the opportunity to provide additional comments about their experiences in raising their child, and these additional comments can again provide valuable information to researchers when conducting research and follow-up interviews. Using the profile graph, as well as looking at individual item responses and the written parent comments, allows the researcher to follow through with questions that explore areas shown to be important for the parent, and which might not be demonstrated within an interview alone.

The PRADS-2 is a self-report measure that can give insight into the parents' responses toward raising a child with special needs. It can be a valuable tool in supporting research that explores parent-child dynamics in parenting a child with special needs.

### **Use in Professional Practice**

The PRADS-2 is a tool that can aid in the design of needed supports for parents of children with disabilities. When first meeting with the parent, the PRADS-2 gives the service coordinator a comprehensive sweep of information to get to know the parent. The resulting graphed profile of parent strengths, as well as unresolved areas where the parents could use extra support, provides service providers with a foundation to determine needed supports for families. The service provider, in sharing the individual profile with the parent, can begin the process of designing supports by first helping parents understand their areas of resolved strengths.

Parents need to recognize their own successes in raising their child, prior to considering any unresolved challenges indicated by the profile graph and item responses which may indicate distress for the parent. The PRADS-2 scale provides a profile of domain scores that indicate an individual parent's areas of resolved strengths and areas of unresolved difficulties. This profile is useful to help pinpoint specific, individualized supports which may be of benefit to parents as they work toward resolution in parenting their child with special needs.

Service providers, who work directly with the children and families, are generally the ones connecting these families with the various supports in their community. Supports are valued when the family agrees that they would be helpful. The PRADS-2 measure offers a starting point in identifying needed services. It is best to have an idea of specific services which you think will support the family, and which the parents might

value, before meeting with them to share the profile. It is beneficial for service providers to have filled out a tentative draft of the Services Worksheet before meeting with the parent to share the profile.

An important aspect in supporting a family is knowing what types of services are available in the community to fit their identified needs. In offering the various services, it is useful to clearly explain parent strengths from the resolved areas of the profile form, then explain any areas of concern, and next to include the parents in identifying possible services they feel will be beneficial in creating a services package. Use respectful and caring language, and be aware that what you write into your Services Worksheet draft, you will also be sharing with the parent.

The profile graph from the PRADS-2 is designed for ease of use to identify strengths and identify needed services for families of children with special needs. The measure may be used as an assessment tool at intake for early identification of needed parent supports. It can also be administered periodically at later times, to view changes in the parent's responses to parenting their child, and to aid in making any needed changes or adjustments in the service package.

The PRADS-2 may be useful as part of the routine intake practice of an agency, and it may help parents gain more confidence and feel less self-conscious during the intake process. Informing parents that the items in the measure are comments made by other parents raising a child with special needs can help those parents of newly diagnosed children feel that they are not isolated in their own feelings or experiences. The parents of children with a more recent diagnosis typically need more additional support, as they generally feel less confident in their parenting skills. The benefits of an intake procedure include assessing for family needs, which aids the family in making needed adjustments more quickly, which may help not only the child affected, but

the entire family. By understanding how a parent is adjusting to raising a child with special needs, the specific supports and services the family needs can be started earlier, thus helping the parents acclimate to supporting their child and family, while gaining confidence in their own parenting skills. Any referrals for needed professional services and community resources can be made during early critical times for families.

The measures in this manual are designed to give service providers a current snapshot of parent resolution. The PRADS-2 can be repeated as parent responses change over time, to guide adjustments and changes to services. The resolution and grief process is fluid and is affected by many factors, including appropriate family supports. A change in the resolution profile is expected, as parents adjust to their child's successes, and are confronted with many transitions and changes to their child's needs as they get older. Thus, the PRADS-2 can be useful as an ongoing tool to periodically assess parent's responses to parenting their child, which allows practitioners to discuss with the parent the usefulness of the current services and provides for possible adjustments and changes to family supports and services as needed.

### **Inclusion of Other Adult Caregivers**

Within the child's family, there may be several adults with the potential to provide significant caregiving for the child. These may include parents, stepparents, partners, adult siblings, and extended family members, such as grandparents, aunts, and uncles. For simplicity, we are using the term "parent" in this manual, although we recognize that some adult caregivers in the child's family may be related in different ways. These other adults in the child's family can be recognized and invited to fill out the measure as well, to learn about their points of view, to consider supports for them, and to consider ways the adult caregivers can coordinate their support for the child and for each other. As the various

adults in the family may differ in when and how they learned of the child's diagnosis, the service provider may ask them to respond to the items according to their own responses after they themselves learned of the diagnosis.

### **Future Evaluation Research**

The bridge between research and service is ideally a two-way relationship. After conducting our research with parents of children with autism, statistically developing and validating this measuring instrument, correlating it with other measures, and creating the detailed forms for scoring, graphing, and tailoring services, we invite future researchers to conduct research to evaluate the efficacy of using our developed measure with parents and families.

For evaluating PRADS-2 usage as an independent variable, researchers may use a group design, where some parents are given the measure, while other parents are not. Or they may use a staggered design, where some parents are given the measure at their very first meeting along with follow-up interview at their next meeting, while other parents are not given these until later meeting times. Tracking outcome measures at times before and after the PRADS-2 use could show if there are positive changes associated with the particular timing of the PRADS-2 use for each parent.

Outcome measures could include the service provider's confidence ratings of their ability to understand and help the family, at times when they have not, versus when they have, used the PRADS-2 for becoming acquainted with parents.

Outcome measures could also include the parent's ratings of rapport with the service coordinator, their satisfaction with the services provided to their family, their confidence and active engagement in parenting their child, and their scores on the PRADS-2 scales taken at a later time.



Researchers may also use their own preferred designs in research that includes this measure. For example, they may correlate the PRADS-2 scale scores with other variables of interest. They may also measure parents' PRADS-2 scale scores before and after parent trainings or other interventions that they wish to evaluate, to view effects of their specific intervention on parents' specific PRADS-2 scores as dependent measures.

Thus, the PRADS-2 can be used as an independent variable, correlated variable, or dependent variable, depending on the research design. Researchers and service providers may also explore using the more general PRDS-2 as a measure for parents of children with other diagnoses.

## Chapter 6

### ADMINISTRATION OF THE PRADS-2

#### Population of Interest

Respondents who are asked to answer the PRADS-2 should be the adult parents or caregivers in the family of a child who is diagnosed on the autism spectrum. We are also including an additional generalized form called the Parent Reaction to Diagnosis Scale (PRDS-2). It is identical to the PRADS-2, except that the words relating to autism are replaced with more general terms, so that it can be used for caregivers of a child having any diagnosis.

#### Professional Qualifications

Professionals who are experienced and qualified in working with families, as well as in administering and scoring assessments, and in designing or supervising services, may use this assessment. Users should read this entire manual carefully prior to using the measure.

In research studying parent and family adjustment to a child's diagnosis of a disability, researchers should first obtain formal approval for their research through their Research Review Committee, and should take care to follow the ethical guidelines of their profession.

In service work, this measure should only be used by professionals in agencies providing direct services to the parents and families, as well as the child. The users should take care to follow the ethical guidelines of their profession.

Since the information obtained with this measure is outside the scope of services provided by school personnel, we are not including school personnel among the professionals qualified to use this assessment with parents. We respect the valuable work of school personnel in serving their students and consulting with parents. However,

we want to ensure that the school system will not use our measure to make evaluative judgments of a student's parents or family. School personnel are welcome, however, to read our manual to see ideas for verbally supporting parents who may describe difficulties they are having.

Whoever administers the assessment should be prepared to help the parent to process any strong or difficult emotions that may arise. The parent may feel vulnerable when reflecting on raising their child with special needs. Expressing compassion and reminding the parent that the survey items are statements made by other parents who have a child with special needs may help the parent recognize that they are not alone in their emotional responses, and this may help the parent feel more comfortable and supported. Thus, these items may help foster the parent's mindfulness about their own feelings, along with fostering feelings of connectedness and shared experience with other parents.

#### Administration Setting

When used for research purposes, the survey can be administered individually or in a group setting, with parents spaced apart for confidentiality. In addition, researchers may present the survey in an online format for their research participants to fill out on the computer.

When used in an office, the measure should be administered in a comfortable environment which offers plenty of light and few distractions. The surface that is used should be flat and offer enough space and support so that the test materials are easy to handle while answering the questions.

Parents might be more comfortable answering the forms in a private setting, as some

of the parent statements may elicit strong emotional responses. It is permissible for parents to complete the measure at home, if that would be a more comfortable setting, and if the provider is comfortable providing that option. All materials should be returned to the administrator for scoring.

For safety during a pandemic, or during any difficulty in traveling or meeting in person with the parent, the survey may be mailed or emailed to the parent, and the parent may mail or email their completed consent form and survey responses back to the administrator. The administrator and parent may also meet virtually together on the phone or online, with the administrator reading the survey items aloud, and marking the parent's responses to them.

If the parent wears reading glasses or lenses, these should be worn when answering the survey. If there is difficulty in viewing or reading the materials, the survey can be read aloud to the parent and their responses can be marked by the administrator. The questions may be translated and answers recorded by a professional who is expert in the parent's preferred language, provided this professional also follows the ethical guidelines.

### **Administration Procedures**

The complete PRADS-2 and the more general PRDS-2 forms are included in this manual in Appendices A and B, and they can be photocopied or printed for each parent. The measures can also be uploaded to an online survey site for participants to answer online.

After welcoming and establishing rapport with the parent, you may invite the parent to fill out the survey about their experiences in raising their child.

The parent should be provided with the Parent's Rights and Informed Consent form, for them to read and decide whether to give their consent to take the survey. It is good to have two

copies of the consent form, one for you to keep, and one to offer to the parent, in case the parent would also like to keep a copy.

You may inform the parent that the survey allows parents to express their reactions to their child's diagnosis, and that it can be used to help identify supports of benefit to parents. You should offer to answer any questions the parent may have about the measure. If the parent gives consent, then you may proceed with the survey.

The parent should be informed that the statements in the measure are *actual parent statements* about their experiences raising a child with a disability. These items have been garnered from previous parent interviews and research relating to parenting a child with special needs.

Each parent responds differently when raising any child. The parents are asked to rate how much each statement corresponds with their own personal experience in raising their child. The parent should be assured that there are no right or wrong answers to the statements, and the parents should be encouraged to respond as accurately as they can to the items.

If there is more than one child with a disability in the family, the parent may be asked to focus on only *one* of the children when answering the measure to allow the parent to keep a consistent focus. The parent may answer the measure at a later time for any additional children who may also benefit from services.

The measure typically takes about 20 to 30 minutes to complete, but some parents may take longer, and there is no time limit. Parents should be given ample time to answer the questions and not feel rushed.

The measure is most helpful if the measure is fully filled out with no missing responses. Be sure to inform the parent, however, that there is no penalty if a parent chooses to not answer an item or to not fill out the questionnaire.

When the parent returns the form to you, if you note that a parent did not answer any item, you may remind the parent that there are no right or wrong answers to the items, and you may encourage them to circle their best estimate for how much each item applies to their experiences.

Be careful to not suggest specific answers to the parent, however. Also be careful to respect the parent's choice to not answer all the items if the parent prefers this. An item with a missing response may indicate a sensitive area, which may be brought up and discussed in the future.

The scoring instructions state how best to create scale scores when there are missing responses. The entire scoring process creates a profile of 15 domain scores, showing the parent's strengths and areas in which additional supports may be needed.

### **Maintaining Confidentiality**

The information provided by the measure is personal and confidential and should not be shared, except when given express written permission by the individual taking the measure.

The agency should have procedures in place that ensure confidentiality for all clients. The agency should inform the parent about their specific procedures for protecting their privacy. The agency may use procedures such as shredding outdated documents, keeping parent files in a locked cabinet, and allowing the parent to review files and content for accuracy.

A copy of the scoring sheet and profile graph can be kept in the parent file to show the scores and areas of change if the parent retakes the measure. The newer information can be used to determine the parent's current responses to parenting their child, and can be used to adjust supports or plan for further supports.

Any time parents are referred to another agency for supports or services, the parents should

first sign your agency's Release of Information form for each specific referral.

### **Use of Our Measures**

The assessments are quickly scored and graphed for a visual representation of the parent's scores on each of the domain scales. Thus, parents are *not* placed into diagnostic categories. Instead, the resulting graph creates a profile of the parent's scores on each of the scales, offering a more comprehensive understanding of the parent's experiences within each of the domain areas. We earnestly stress that our measure should not be used to place parents into any clinical or diagnostic categories. By not placing parents into a single domain category, important aspects of the parent's resolution status can be better understood.

Using our measure to create a profile of scores along each of the quantitative scales gives a comprehensive sweep of information about the parent's resolved strengths and unresolved concerns in raising a child with a disability. The resulting graph helps to easily identify the parent's resolved strengths and unresolved concerns, which are then used to design supports and services which may prove beneficial to the family.

Service providers, when sharing these results with the family, can elicit responses and listen to the parent's own comments about their areas of confidence and areas of concern. The parent's scores, along with their additional written comments at the end of the measure, can then be used to identify potential supports and services that may help the parent in addressing unresolved areas. You can encourage the parent to identify the services that interest them and which might support them in their areas of concern.

We have worded our Parent's Rights and Informed Consent form to be useful in both research and service work. If you are using our measure as one element within a broader research study, you will also need to include an Informed

Consent form that applies to the other elements of your research study as well.

Qualified users have our permission to print out and use a paper copy of our copyrighted PRADS-2 and PRDS-2 measures, and all forms included in the Appendix packets, or to use these measures on an online survey site, as long as the forms are identical to what we have provided, with the same wording, in the same order of the items in the measure, unedited, and includes our names as creators of the measure. Scoring is to be conducted using the methods provided in this manual.

## **Chapter 7**

### **SCORING AND GRAPHING INSTRUCTIONS**

We are providing two versions of the scoring instructions. Both methods result in the same scale scores.

The first version is especially useful for researchers who are conducting research with a group of parents. It provides concise instructions for computing the scale scores for each participant. The researcher can enter the item responses for each parent into the data file, and then enter computing commands in the format used by the researcher's statistical program, resulting in the scale scores for each participant being computed and added into the data file.

The second version is especially useful for service providers who are working with individual parents. It provides a scoring sheet which guides the test user to manually enter the individual's item responses and then easily calculate the individual's scores for each of the scales.

**INSTRUCTIONS FOR SCORING THE PRADS-2 SCALES**  
**FOR RESEARCHERS**

Kathleen A. Brewer, M.A., and Mary B. Gruber, Ph.D., BCBA-D

California State Polytechnic University Humboldt

For a scale score, we add the respondent's ratings on each of the items in the scale, and then divide by the number of items in the scale, keeping two digits past the decimal point. This gives the parent's average rating on the scale items. It also expresses the scale score on the same 1-5 scale as the original rating scale, thus facilitating interpretation.

The item numbers for each of the Resolved scales are listed below:

Positive Feelings: Items 1, 30, 45, and 60.  
Working through Emotions: Items 4, 20, 33, and 46.  
Active Research: Items 3, 18, 37, and 57.  
Participation and Helping: Items 6, 24, 35, and 48.  
Self-Help Routines: Items 10, 22, 38, and 59.  
Broad Perspectives: Items 14, 28, 40, and 55.  
Focused Thought: Items 12, 29, 43, and 52.

The item numbers for each of the Unresolved scales are listed below:

Emotionally Overwhelmed: Items 9, 19, 41, and 47.  
Angry Feelings: Items 5, 27, 42, and 58.  
Depressed Feelings: Items 11, 21, 36, and 49.  
Confused Feelings: Items 8, 23, 34, and 54.  
Neutralizing Unconcerned: Items 13, 26, 44, and 56.  
Neutralizing Resistant: Items 2, 17, 32, and 53.  
Negative Distortions: Items 15, 25, 39, and 51.

The item numbers for the Positive Distortions scale are listed below:

Positive Distortions: Items 7, 16, 31, and 50.

For each scale score, we add the respondent's ratings on each of the four items in that scale, and then divide by four, keeping two digits past the decimal point.

For the Resolved Total score, we add the respondent's scores on each of the seven Resolved scale scores, and then divide by seven, rounding to two digits past the decimal point.

For the Unresolved Total score, we add the respondent's scores on each of the seven Unresolved scale scores, and then divide by seven, rounding to two digits past the decimal point.

As a researcher, you can enter the item responses for each parent into your data file. You can then enter the computing commands in the format used by your statistical program, resulting in the scale scores for each parent being computed and added into your data file.

If not all of the items in a scale were answered, and you are conducting research with a group of parents, the most conservative and stable treatment of missing responses is to substitute the group's item mean for that parent's missing item, prior to calculating the scale and total scores.

If not all of the items in a scale were answered, and you are working with just one parent at the time, the parent's scale score is best calculated via prorating, by adding the parent's ratings on the answered items, and then dividing by the number of answered items.

We hope these measures can be beneficial in your research or service work. If you have further comments or questions about these measures, you may contact us at [mbg2@humboldt.edu](mailto:mbg2@humboldt.edu).



**SCORING SHEET FOR THE PRADS-2**  
**FOR AN INDIVIDUAL PARENT**

**Parent ID:** \_\_\_\_\_

For a scale score, we enter and add the parent's ratings on each of the items in the scale, and then divide by the number of answered items in the scale, keeping two digits past the decimal point. This gives the parent's average rating on the scale items. It also expresses the scale score on the same 1-5 scale as the original rating scale, thus facilitating interpretation.

**RESOLVED Feeling-Oriented Scales:**

**1. Positive Feelings Scale:**

- \_\_\_\_\_ Item 1. I feel a strong emotional connection with my child.
- \_\_\_\_\_ Item 30. I feel more positive now about my child's diagnosis of autism.
- \_\_\_\_\_ Item 45. I am proud of myself for how well I am helping my child.
- \_\_\_\_\_ Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**2. Working through Emotions Scale:**

- \_\_\_\_\_ Item 4. I worked through a lot of emotions about my child's diagnosis.
- \_\_\_\_\_ Item 20. Being able to express myself and talk to others about my emotions helps me to cope with my child's autism.
- \_\_\_\_\_ Item 33. I feel that by addressing my emotions after my child's diagnosis, I am better able to support my child.
- \_\_\_\_\_ Item 46. I felt a need to grieve after my child's diagnosis.

$$\text{Working through Emotions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**RESOLVED Action-Oriented Scales:**

**3. Active Research Scale:**

- \_\_\_\_\_ Item 3. I sought answers immediately when I realized that my child was having problems.  
\_\_\_\_\_ Item 18. When my child was diagnosed with autism, I researched everything I could.  
\_\_\_\_\_ Item 37. I try to stay current with new interventions so that I can actively help my child.  
\_\_\_\_\_ Item 57. I take charge of getting my child appropriate services.

$$\text{Active Research Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**4. Participation and Helping Scale:**

- \_\_\_\_\_ Item 6. I actively participate in interventions and programs for my child.  
\_\_\_\_\_ Item 24. I continue to do what I have to do to help my child every day.  
\_\_\_\_\_ Item 35. I work with all the professionals in my child's life to understand my child's changing needs.  
\_\_\_\_\_ Item 48. It is important that I actively participate in helping my child make progress.

$$\text{Participation and Helping Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**5. Self-Help Routines Scale:**

- \_\_\_\_\_ Item 10. I schedule special time for myself to relax, rejuvenate, and restore my well-being.  
\_\_\_\_\_ Item 22. I have created routines that help me to meet my child's needs.  
\_\_\_\_\_ Item 38. I have created self-help routines to help me get through my day.  
\_\_\_\_\_ Item 59. I have supportive phrases I tell myself that help me get through each day.

$$\text{Self-Help Routines Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**RESOLVED Thinking-Oriented Scales:**

**6. Broad Perspectives Scale:**

- \_\_\_\_\_ Item 14. I think my child makes a positive contribution to our family.
- \_\_\_\_\_ Item 28. Observing what my child does helps me to understand my child better.
- \_\_\_\_\_ Item 40. Thinking positively about my child's future helps me to help my child.
- \_\_\_\_\_ Item 55. My personal beliefs have helped me to come to terms with my child's diagnosis.

$$\text{Broad Perspectives Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**7. Focused Thought Scale:**

- \_\_\_\_\_ Item 12. I believe that the more I plan for the possibilities of each day, the more prepared I am to help my child.
- \_\_\_\_\_ Item 29. I stay focused on learning everything I can about autism to help me support my child.
- \_\_\_\_\_ Item 43. It is important for me to have information about autism.
- \_\_\_\_\_ Item 52. I think it is important for me to acknowledge my success in helping my child.

$$\text{Focused Thought Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

- Place a dot by any of the above Resolved items which the parent rated low (1 or 2).

**RESOLVED TOTAL SCORE:**

For the Resolved Total Score, we add the parent's scores on each of these seven Resolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\begin{aligned} \text{Resolved Total Score} &= \frac{(\text{PFS} + \text{WES} + \text{ARS} + \text{PHS} + \text{SRS} + \text{BPS} + \text{FTS})}{7} \\ &= \frac{(\quad + \quad + \quad + \quad + \quad + \quad)}{7} = \frac{\quad}{7} = \boxed{\quad . \quad} \end{aligned}$$

**UNRESOLVED Overwhelmed, Angry, Depressed, and Confused Scales:**

**8. Emotionally Overwhelmed Scale:**

\_\_\_\_\_ Item 9. Every day I experience the same overwhelming emotions I had when my child received a diagnosis.

\_\_\_\_\_ Item 19. I worry about other people judging me as a parent of a child with autism.

\_\_\_\_\_ Item 41. I feel that I am in a continual state of crisis.

\_\_\_\_\_ Item 47. I am overwhelmed when caring for my child.

$$\text{Emotionally Overwhelmed Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**9. Angry Feelings Scale:**

\_\_\_\_\_ Item 5. It is important to me that someone be held responsible for my child having autism.

\_\_\_\_\_ Item 27. I am angry with the professionals who diagnosed my child with autism.

\_\_\_\_\_ Item 42. I want others to be as angry as I am about my child's situation.

\_\_\_\_\_ Item 58. I am constantly angry that my child has autism.

$$\text{Angry Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**10. Depressed Feelings Scale:**

\_\_\_\_\_ Item 11. I am stuck in sadness about my child having autism.

\_\_\_\_\_ Item 21. I do not have much hope for my child's future.

\_\_\_\_\_ Item 36. I feel isolated and alone since my child's diagnosis.

\_\_\_\_\_ Item 49. I feel powerless to help my child.

$$\text{Depressed Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**11. Confused Feelings Scale:**

\_\_\_\_\_ Item 8. Sometimes I think everything will be okay and then it just becomes too much to handle.

\_\_\_\_\_ Item 23. I get so confused and at a loss when I try to talk about my child's autism.

\_\_\_\_\_ Item 34. I am so confused about autism that I don't know what to do to help my child.

\_\_\_\_\_ Item 54. I just cannot get myself organized and focused enough to help my child.

$$\text{Confused Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**UNRESOLVED Unconcerned, Resistant, and Negative Distortions Scales:**

**12. Neutralizing Unconcerned Scale:**

- \_\_\_\_\_ Item 13. I have never felt strong emotions about my child’s diagnosis of autism.
- \_\_\_\_\_ Item 26. My child’s diagnosis of autism never bothered me.
- \_\_\_\_\_ Item 44. I feel I don’t need to do anything more to help my child.
- \_\_\_\_\_ Item 56. I believe my child’s diagnosis of autism has had no effect on our family.

$$\text{Neutralizing Unconcerned Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**13. Neutralizing Resistant Scale:**

- \_\_\_\_\_ Item 2. I really believe that my child’s diagnosis of autism is incorrect.
- \_\_\_\_\_ Item 17. Someone else noticed my child was having problems before I did and told me.
- \_\_\_\_\_ Item 32. I waited to get my child diagnosed because I did not think there was a problem.
- \_\_\_\_\_ Item 53. I avoid thinking about my child’s autism.

$$\text{Neutralizing Resistant Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**14. Negative Distortions Scale:**

- \_\_\_\_\_ Item 15. Since receiving the diagnosis, I feel that I am the only one who can help my child.
- \_\_\_\_\_ Item 25. I blame myself for causing my child’s autism.
- \_\_\_\_\_ Item 39. I feel that my child’s autism has been harder for me as the parent than for my child.
- \_\_\_\_\_ Item 51. I feel that everything about my child’s autism is negative.

$$\text{Negative Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

- Place a dot by any of the above Unresolved items which the parent rated highly (4 or 5).

**UNRESOLVED TOTAL SCORE:**

For the Unresolved Total Score, we add the parent’s scores on each of these seven Unresolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\begin{aligned} \text{Unresolved Total Score} &= \frac{(\text{EOS} + \text{AFS} + \text{DFS} + \text{CFS} + \text{NUS} + \text{NRS} + \text{NDS})}{7} \\ &= \left( \frac{\quad + \quad + \quad + \quad + \quad + \quad}{7} \right) = \frac{\quad}{7} = \boxed{\quad . \quad} \end{aligned}$$

**15. Positive Distortions Scale:**

The Positive Distortions Scale is calculated separately from the Resolved and Unresolved scales.

- Item 7. My child's having autism has been a wonderful blessing for our family.
- Item 16. Without my child having a diagnosis of autism, my life would not have a purpose.
- Item 31. My child was given autism to help me with my own personal growth.
- Item 50. I believe my child's brilliance will make a huge difference in the world someday.

$$\text{Positive Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad .}$$

**Missing Responses**

If there are some missing responses, you may remind the parent that there are no right or wrong answers to the questions, and you may encourage them to fill in their best estimate for how much each item applies to their experiences. Be careful not to suggest specific answers to the parent, however. Also, be careful to respect the parent's choice to not answer all the items if the parent prefers this.

If there are still some missing responses, you may use prorating to calculate the parent's scale score, by adding the parent's ratings on the answered items, and then dividing by the number of answered items in that scale.

For example, if a parent did not answer Item 45 on the Positive Feelings scale, you may calculate a Positive Feelings scale score by adding the responses on the other three items and then dividing by three instead of four. This gives the parent's average rating on the items that they did answer.

**Positive Feelings Scale - Example with a missing response:**

- 4   Item 1. I feel a strong emotional connection with my child.
- 3   Item 30. I feel more positive now about my child's diagnosis of autism.
- n   Item 45. I am proud of myself for how well I am helping my child.
- 5   Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4 - 1} = \frac{12}{3} = \boxed{4.00}$$

**GRAPHING THE PARENT'S PROFILE  
OF SCORES ON THE PROFILE FORM**

After calculating a parent's scale scores, you can graph the parent's profile on the profile template form, shown in Figure 2. The vertical axis shows the scale score values from 1 to 5. A blank column is shown above each of the 15 scale labels. Within each column, draw a colored line at the height of the parent's score, and write the parent's score value above the line, as shown in the example in Figure 3.

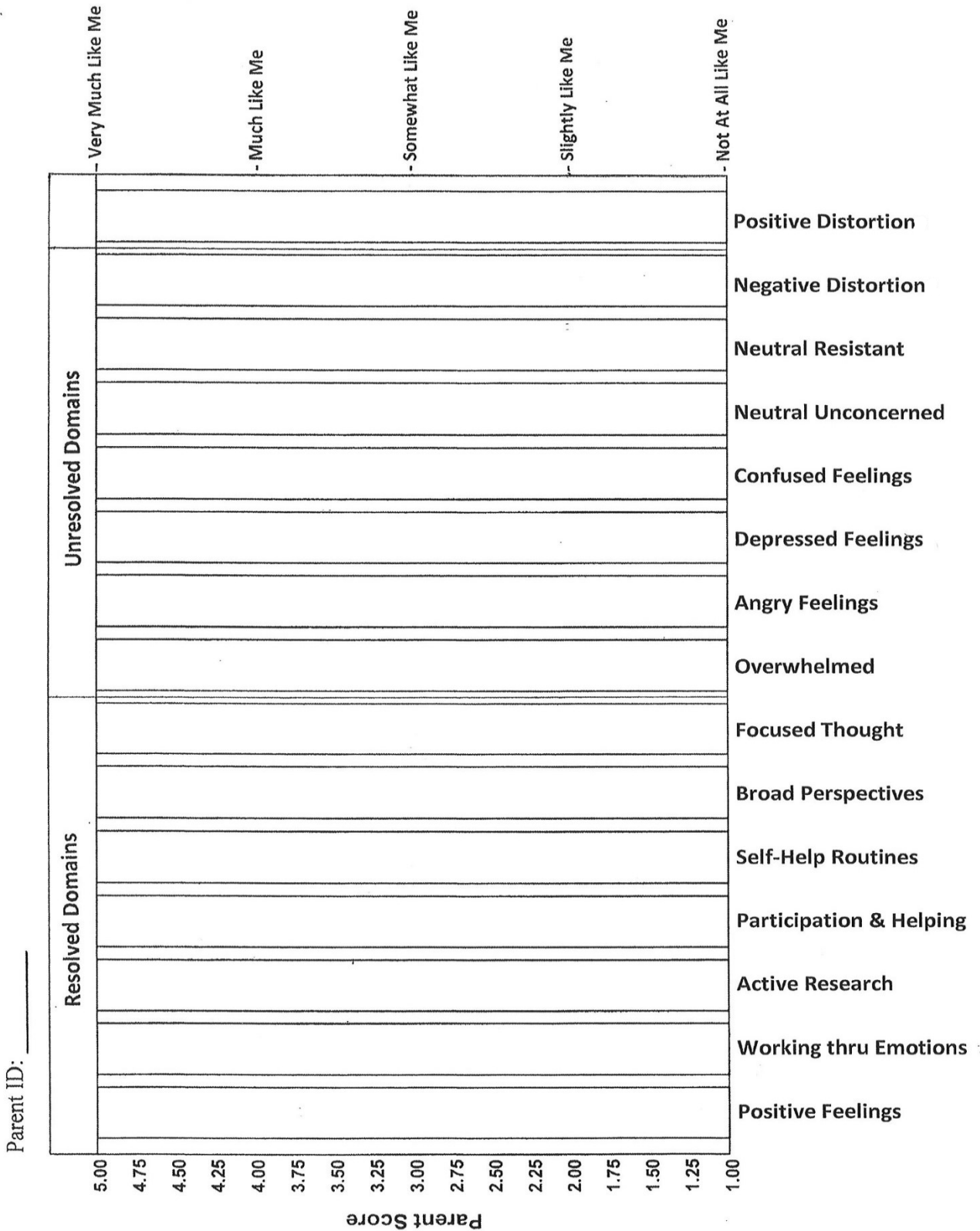


Figure 2. Profile graph form for showing the profile of scores for an individual parent.



Parent ID: 070

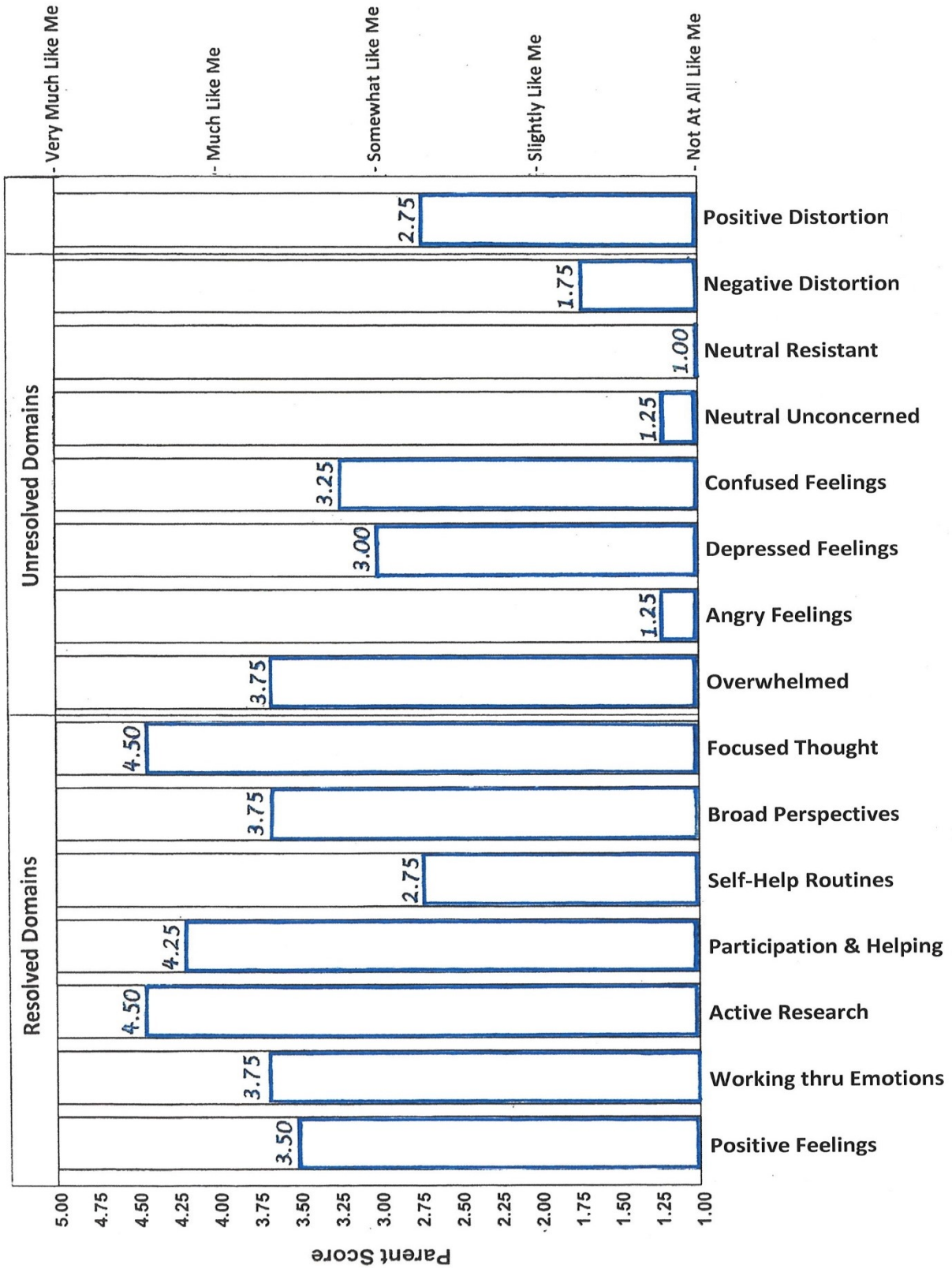


Figure 3. Profile graph form showing the profile of scores for the example Parent #070.

## Chapter 8

### GENERAL SUPPORTS FOR PARENTS

With the parent's profile of scale scores, we next consider both general and specific supports for the family.

First, in this chapter, we discuss broad categories of supports that can be helpful for many families of a child with special needs.

Then, in our next chapter after this one, we focus more closely and precisely on tailoring specific supports for individual parents, depending upon their specific scale scores.

General supports that can be beneficial to any family of a child with special needs include parent training, team collaboration, parent support groups, educational services, sibling training and support, respite services, community inclusion, internet resources, assessment over time, preparing for unexpected events, and planning for the child's future.

#### Parent Training

Having a child with special needs requires more parenting skills than most parents are initially equipped to offer a child. When a parent is ready, parent training can be very beneficial in helping parents gain useful skills that can benefit their child, and increase their own confidence as a parent.

In surveying parents of children receiving in-home behavioral services, Montano (2014) found that these parents gave high ratings on the benefits of their child's in-home behavioral programs. When the parents were asked for their preferences for changes in their children's services, the parents' highest rated preferences were for more parent training on how to manage challenging behaviors and teach new skills to

their child, and for more instructional materials to allow them to use further specific methods in assisting their child.

In studies in which caregivers were given training sessions in applied behavioral methods (Casas, 2013; Ewen, 2003; Wood, 2004), the participants rated their training very highly, and they showed increased confidence and ability in using these new methods for relating positively with their child, for coping with problematic behaviors, and for teaching their child new skills.

Offering parents opportunities to take classes specific to their child's abilities can aid the parent's confidence to become more involved with the other team members working with their child. Using behavioral skills training and inviting parents to participate as a supportive trainee in sessions with their child can help the parent develop proficiency.

Offering information and parent training about their child's diagnosis is beneficial, but many parents of a newly diagnosed child are not yet ready to process everything. There can be a lot of new and complex information that the family needs to learn and understand to better support their child. Tailoring the level of information given to parents, and knowing which type of information is needed, can help parents to feel less overwhelmed.

Parents may need to grieve and process their emotional and mental responses to a child's diagnosis before they can start to understand the information and materials provided to them. Compassion toward the parent includes gently discussing their emotional concerns with them, and carefully offering basic information prior to proceeding to more complex information.

All children develop at their own pace, including children with autism, and knowing this may reassure parents as they learn new techniques to help their child. Identifying a child's developing strengths and abilities can reassure parents as they use their newly acquired skills to help their child learn.

Parents gain greater confidence when they recognize their child's successes. Being able to see how they themselves contributed to the child's achievements can inspire parents to continue learning new skills that enable them to help their child make progress. Share in the parent's celebration of their own contributions to their child's successes.

### **Team Collaboration**

It is helpful for parents to know that they are members of a team working collaboratively to help their child. Encourage parents to express their opinions and concerns with the other team members, and be sure to respectfully listen, respond to, and value their input. Encourage the parents to work with the entire team to help the other team members to better understand their child. Encourage parents to ask questions of the other team members when they do not understand an intervention or support. And encourage team members to show parents techniques they can use when the parent is with the child.

Parents whose children have a more recent diagnosis of autism may need additional support in understanding any information that is available regarding their child's diagnosis. Encourage team members to offer the parents helpful information which is worded for parents to understand. Have them invite the parents to express their opinions and to ask questions about anything they are uncertain about. Recommend that the service providers include the parents in the child's program, when possible, by modeling simple, supportive ways the parent can work with their child.

### **Respite Services**

Parenting a child with autism can be effortful and exhausting. Some local and state agencies offer respite services, which enables parents to have time away from the stress of parenting, to rest and participate in activities which they enjoy. These services generally have a set number of hours periodically, and are paid by a third party, which helps reduce the family's burden. If these types of services are available in your area, and if the agency has workers who are qualified to provide care at the level the child needs, you can explain to the parents how respite works and help arrange for contact between the agency and the parent. Respite can be a valuable resource for parents of children with special needs.

### **Parent Support Groups**

Parent support groups can be created by parents who have children with a similar disability. Parent groups can offer several types of support for families. For instance, more experienced members can give a newer parent empathy, encouragement, and suggestions about how they have dealt with similar difficulties. This type of support and information offered can be of benefit to both the parent and their child. In turn, experienced parents can value the opportunity share their knowledge to help and support other parents in these areas.

When referring a parent to a support group, make sure that the group is welcoming to new parents. Some support groups may be comprised of parents with children within a certain age range, and others may have a different agenda than what the parent needs. Some parent groups focus on giving comfort and support, while others focus on fundraising for a cause, or on research and training. It can help to describe to the parent which types of parent groups are available, so that the parent can decide which group may be a good fit for them.

Encouraging parents to seek out other families whose child shares the same diagnosis helps parents to understand that they are not alone in their situation. This may help decrease distress and increase self-efficacy. Parents who have a child with a more recent diagnosis can gain much needed support from more experienced parents as they navigate changing responses to their child's diagnosis.

### **Educational Services**

An important area, which many parents identify as stressful and difficult, is working with schools to get appropriate supports and educational services for their child. Laws governing special education in schools and other educational settings include broader federal laws such as Civil Rights laws, as well as the specific federal laws in the Individuals with Disabilities Education Act (IDEA). In addition, each state has their own laws on special education for that individual state. Combined, these laws require school districts to provide children having special needs with an appropriate education which offers them a challenge as well as a meaningful benefit. This process can be complex, as each child requires different supports, services, and scientifically proven instructional techniques to help the child learn and achieve success along with other children in their age group.

Special education planning includes designing educational supports and goals for the Individualized Education Program or IEP document, which is created for an individual child by the IEP team. The parent is an integral part of the IEP team and may need additional support managing the special education procedures to understand how best to help their child at school. Connecting families to special education advocates, who understand the process of providing appropriate education for children with special needs, can help a parent with the anxiety and confusion that can arise while navigating the special and general education systems.

Important issues with getting children in appropriate placements include teachers who may vary in their willingness to include children with autism in their classrooms, and the variations of specific services offered by the school district. Furuoka (2001) identified four factors which predicted teachers' greater willingness to have children with autism in their classroom. These factors include the teacher's own perceived effectiveness in handling difficulties that might occur in the classroom, their perceived feasibility to adapt the classroom activities to include the child with autism, having additional training specific to teaching children with autism, and having a classroom aide who is qualified to assist the child.

Helping parents to identify teachers who are more willing to include a child with autism will benefit the child, as well as relieve parent anxiety. Parents may need to observe classrooms and talk with teachers before they agree to a placement or teacher during the IEP process, and an experienced advocate can help with these activities. A special education advocate can help families navigate the IEP process, help find an appropriate placement, help the family to ascertain that all of their child's needs are being met through the IEP goals, supports, and services, and help the family participate with the team to create an IEP which will benefit their child.

### **Sibling Training and Support**

Parents have also expressed concerns that the other children in their family may not be getting the attention and support that they need, when so much of the family's resources and parent attention are given to the child with autism. Connecting siblings to their own support systems can be valuable to these siblings, as well as the other family members. Many communities have sibling support groups that aim to benefit the brothers and sisters of a child with special needs. These support groups give siblings an opportunity to be with a group of children who understand the experiences of being a sibling of a child with

special needs. Children can express frustration and other emotions in the group, where they are accepted without judgement. This allows the sibling to relax and recognize that they are not the only one with difficult feelings about a child with special needs in the family. Having peers who are understanding and accepting helps to reduce possible feelings of stress a sibling might have. Finding the right supports, not only for the child with a disability, but for their typical developing siblings, may be a service the family would find valuable.

Siblings of children with autism have expressed difficulties in relating to their brother or sister with special needs, as well as dealing with the sibling's problematic behaviors, and dealing with negative responses of friends or other people to their sibling. Opportunities for sibling training may be something that families are interested in. This type of training can offer benefits for the whole family. For example, Kelley (2008) reported that after siblings of children with autism received training to better understand autism, to use basic positive reinforcement, and to foster play skills, the siblings tended to report greater closeness among their family members, the parents tended to report giving more equal time among their children, and the children with autism tended to show fewer problematic behaviors. The family can include the siblings in deciding what types of supports the siblings would find beneficial, and whether participating in some type of training or support group might be something they are interested in.

Professionals working with the family may find ways to include siblings in some of the therapies that a child is receiving. Providers can model and teach simple techniques to siblings, which they can use when interacting or playing with their brother or sister. Modeling straightforward and easy techniques to siblings and actively shaping their skills, can help the siblings connect to their brother or sister, and create more natural opportunities for the child with autism to learn new social and play skills.

## **Community Inclusion**

Parents often report experiencing difficulties participating in family activities in the community. They express reluctance in taking their child to public places due to unforeseen behaviors of the child, and fear of negative public perception of their parenting. Families of children with autism may often give up on public outings and community activities, opting to stay home. They report this type of social isolation as another form of hardship they endure. Parents describe the increasing isolation and the loss of contact with friends and relatives as painful. Isolation can increase feelings of sadness and anxiety. Finding ways to help families integrate more comfortably into community situations can be a valuable service to help alleviate social isolation.

Support persons trained in behavioral techniques can assist the child with autism to navigate difficult social situations and learn new adaptive skills for public settings. Home behavioral supports can include programs in which the child is carefully introduced to community situations, and when in the community they are taught to identify and safely approach community helpers such as public safety officers in case they find themselves in a dangerous situation alone. Family members can be encouraged to participate in community-oriented skills programs to learn constructive ways to help their child adapt to unfamiliar community situations. Parent training for specific skills to help the child in the community can aid the parent in gaining the confidence needed for taking their child out into the community safely.

Pleasant contact experience with developmentally disabled persons is associated with subsequent favorable and welcoming attitudes toward their inclusion in the community. Moses (2002) found that pleasant interactions between community members and individuals with developmental disabilities is associated with how positively the community members favor community inclusion and continuing contact with

individuals with special needs. Parent and sibling training could be instrumental in fostering continuing positive interactions within the community. Many programs are starting to create enjoyable community events specifically with special needs families in mind, such as sensory screening of films and special activities in parks and other community settings. Sharing the information and dates for these community events can be important in helping those families who feel isolated.

### **Internet Resources**

The internet provides avenues of support for many families. Groups that offer information about various disabilities have been created on different social networks that offer help to parents. These can include groups for a specific diagnosis such as autism.

Encourage parents to look for valid information available on the internet relating to their child and family needs. You may show the parents sound internet resources specific to their needs. Books for parents of children with special needs are also available on the internet.

During a pandemic or any time when in-person meetings are not safe or possible, you may continue meeting with the parent through telephone or an online virtual meeting site to provide continuing, individualized support.

### **Preparing for Unexpected Events**

Not everything can be anticipated or prepared for when designing services for families. Global and local crises can have a large impact on families of members with special needs. Stress increases when a parent is not able to anticipate their child's needs or has concerns about safety and the availability of scarce or distant resources, which can include educational, therapeutic, and medical resources during emergencies.

Communicating frequently and supportively with the families is important during times of crisis, using whatever modes are safe and available, including telephone and internet. You can reassure the family that services can be adjusted in flexible and creative ways when unforeseen events occur. You may provide information that is available about the current crisis, tailored for a child's level, which the parent can share with their child.

Assure parents that self-care is important during a time of crisis. Discuss ways the parent can take time to relax and care for themselves. A secondary caregiver should be designated in case the parent is not available. Encourage parents to stay connected with others through many options available, including telephone and online communications. Parents can be guided to create and maintain routines to help the family with the unpredictability of the crisis and help decrease their stress.

Support the parents in contacting essential persons providing services to their child, such as teachers, school aids, home therapists, medical persons, and other service providers. Many educational services are now provided over the internet. Offer the parent information for any behavioral or other training which might be available locally and from internet resources to help them support their child.

Parents should discuss any changes with their child, and you may discuss what school, home therapies, and other services will look like during the crisis. Children should be told if the changes will be temporary or permanent. Parents should also know that discontinuing or altering formal therapy or homeschool during a crisis can be okay. You may guide them in finding creative ways for fostering less-structured, incidental learning activities instead.

Making sure a child feels comforted and secure is a priority during a crisis. Consider activities that the whole family can enjoy together to help reduce stress and frustration. Parents can encourage their child to discuss how they are feeling, as well as encourage them to ask questions about anything they need to have answered. Parents need to be honest with their child, but also careful with how they word their answers, since overemphasis of the crisis can increase a child's stress levels. Children need to be comforted and encouraged when unexpected things happen.

Not every need can be anticipated, but letting parents know that you are available to answer questions and offer parent support is valuable during a time of crisis.

### **Assessment over Time**

Resolution is a fluid process. A parent of a child with special needs can pass through many stages of distress throughout their child's life. As a child grows older, the child's needs can become more complex, requiring responses beyond the parent's emerging skillset. The child's supports and services may need to be periodically updated. A parent can again become overwhelmed with emotions while trying to understand how best to continue helping their child as their child's needs change. Parents may experience distress and confusion regarding new information they will need to learn and process for their child's changing needs and continued success.

Our measure offers a snapshot of current parent resolution to help understand a parents' response to their child's diagnosis. Since parent responses can change and the child's needs can also change, administering the measure at a later date can assist in updating family services by pinpointing newer areas of difficulty, as well as newly developed strengths that may not have existed when the parent answered the measure previously.

### **Planning into the Future**

It is helpful to collaborate with the parent on planning for upcoming major transitions, including early intervention, educational phases, increasing independent living skills, entering adulthood, obtaining employment, and planning for the parents' elder years and beyond.

Discussion among family members should include the preferences of the adult with autism, as well as the preferences and commitments of grown siblings and other adult relatives and caregivers. Interdependent relationships which the child has built with supportive individuals and programs within the community will be valuable for the child as the parents get older. This lessens the burden upon the parents and gives them confidence that their child will continue to be successful when they are no longer alive or able to take care of an adult child. Maintaining these relationships will help with the child's transition and wellbeing when the parents are gone. There are important legal issues to consider for the child when parents approach the end of their lives, including housing, independence, finances, safety, and guardianship or conservatorship of the child. These issues are a source of great stress for many parents of children with autism. Helping facilitate early and continuing conversations among family members and helping to obtain legal professional counsel can be valuable in determining continuing services for families as they prepare for the future.

## Chapter 9

### TAILORING OF SERVICES TO THE PARENT'S RESPONSES

Individual parents will vary in their responses to their child's diagnosis, with differing areas of concerns and differing areas of strengths. In this section, we are presenting suggestions for ways you can tailor supports for parents, based on their scores on each of the 15 specific scales.

For parents who have *high* scores in *Resolved* domains, the graphed profile form effectively shows these positive strengths, so that the parents can see how well they are managing. Sharing the positive strengths in the Resolved scales before looking at possible concerns in other scales, helps demonstrate to the parent that they do show areas of strength in raising their child, thus helping to increase parent confidence in their ability to learn the necessary skills to offer their child additional support. For *low* scores in *Resolved* domains, the parent can be offered services to help them develop strengths in these areas.

For parents who have *high* scores in *Unresolved* domains, it is essential to show compassion, and to explain that it is common for parents to have difficult responses to their child's diagnosis. Parents whose child has had a more recent diagnosis will tend to score higher in the unresolved domains. Emphasizing that it is common for parents to have problems adjusting to their child's diagnosis can help to support the parent's confidence. Pointing out that the PRADS-2 uses actual parent statements demonstrates that other parents have experienced many of the same feelings. This lets the parent know that they are not alone in their struggle with having a child with a disability. The grief process is not finite when you are the parent of a child with special needs. Unexpected distress can be repeated many times over the parent's lifetime. Parents need to know that there are supports available to help them during times of extreme

stress. The parent's *low* scores in *Unresolved* domains show additional areas of strength, which should be pointed out to them during the follow-up interview.

The design of the profile graph is useful by visually highlighting the parent's strengths and areas of difficulty. The profile graph and scoring sheet help service providers design and offer services that are specific to the parent's needs, and that foster further development of the parent's strengths. These tailored supports can be beneficial to the child and family.

Below are suggestions for each domain, which include several types of services or activities that may offer some assistance and support for a specific area of need. Each community has its own set of possible services, so the list of available services will vary. You can propose possible resources on the services worksheet, and if the parent expresses interest, you can connect the family to these services in the community. Practical aspects, such as financial assistance, transportation, and childcare needs should be considered when sharing possible resources. You may also suggest activities that can be done at home that will offer a benefit to them and to their family's wellbeing. Carefully consider and respect the family ecology, values, culture, and preferences when suggesting, discussing, and arranging supports for the parent.

#### Services and Supports for Each of the Resolved Domains

For high scores in any Resolved domains (around 4-5), be sure to acknowledge the parent's successes and strengths with parenting their child. Give praise when sharing their strengths. Listen to the parent's narrative about their child. Comment on the child's successes and share in the



parent's joy. Parents should be given the opportunity to see how well they are parenting their child and should be encouraged to feel proud of their accomplishments. The profile graph can provide a visual confirmation of these strengths.

For medium scores (around 3), you may ask the parent whether they may value supports in those areas, and discuss these with them.

Lower scores in Resolved domains (around 1-2), indicate areas of concern or difficulty for the parent. A low score on any single item in any of the resolved domains may also indicate a specific concern for the parent. Allow parents to further describe their own concerns in relation to these domains or individual items. Compassionately discuss their situation with them and suggest resources and supports that may be helpful for them in these areas.

Our measure contains seven Resolved domains: Positive Feelings, Working through Emotions, Active Research, Participation and Helping, Self-Help Routines, Broad Perspectives, and Focused Thought.

### **Positive Feelings**

For a parent who scores high in Positive Feelings, you can congratulate the parent for the pleasure they have experienced in raising their child. Share in their enjoyment and ask questions about their child's successes. Parents of children with special needs can enjoy talking about a child's accomplishments large and small. Often what others outside the family unit see as small is a huge achievement for a family and worth celebrating.

For parents who score low in Positive Feelings, you can acknowledge that having a child with special needs can be difficult, and often parents need to work through very painful and complicated emotions while still finding ways to help the child. When a parent fails to find joy in raising their child, it can be discouraging.

Reassure the parent that sadness and other painful emotions are natural for all parents. These emotions can get intense, and may come and go more frequently in parents of children with special needs.

You might ask the parent to discuss just one thing that their child has done that has made them proud or happy. Share with the parent any successes that the child has had that you are aware of. Ask about the child's favorite things and encourage the parent to find a fun activity that the parent can share with the child that involves this favorite thing. Suggest to the parent that they make a regular play date with their child to spend time in an enjoyable shared activity. If the parent likes to write, creating an ongoing list of any positive experiences with the child can help increase the parent's positive views. You may also point out reasons for the parent to feel proud, including positive aspects of the parent's or child's actions.

Connecting the parent with other families, who have a child with the same disability and age level, for play dates may help a parent to find additional encouraging support from other parents. Suggest to the parent, if they show an interest, to contact a local parent support group, for parents who have children with the same disability, for additional support and encouragement from other parents who have been through similar feelings. Offer the parent the contact information for any group that you suggest.

### **Working through Emotions**

Parents often feel a need to grieve when their child has received a diagnosis of autism or other disability. Parents can cycle through a lot of emotions before affirming that they are the parent of a child with special needs. Parents who score high in this domain should be congratulated on their accomplishment of dealing with a difficult situation. Encourage them to share how they have been able to acknowledge and cope with difficult emotions.

Some parents scoring low in this domain may have a child with a newer diagnosis. Giving parents of a newly diagnosed child the opportunity to talk and share their emotions can be very beneficial in helping them to process their grief. Reassure them that feelings of grief are natural, and parents of children with special needs often find themselves distressed and overwhelmed. Parents may find it difficult to express these emotions. If the parent likes to write, journaling can help sort out emotions and it can be a way to express feelings privately. Listening to the parents and encouraging them to acknowledge their emotions is an important part of the grief process.

Offer the parent information on any parent support groups that might be relevant for them. Connecting parents who have children with a newer diagnosis to other more experienced parents can be helpful. Parent support groups generally offer a safe environment in which parents can express their feelings to other parents who have been through a similar emotional process. Grief counseling, whether it is private or in a group with other parents, can assist a parent to work toward emotional well-being.

### **Active Research**

Parents who score high in this domain by actively researching information about their child's disorder may appreciate any additional informational resources you can offer and share with them, to help them continue with their research. These parents may want to share their information with you as well, and praising their efforts and encouraging them to talk about this information can be beneficial in fostering them to continue to do research, and seek further information about their child's diagnosis.

Parents who do research may appreciate receiving some additional training in advanced techniques to help them understand how they can better help their child. Additionally, if the parent has an interest, conferences or seminars relating

to their child's diagnosis may be available. The parent may have done research on more recent types of interventions and supports that might be appropriate for their child's program, now or in the future. Respectfully listen to their ideas about the interventions or supports and the type of research they have done. Offer to help the parent to obtain further current information on evidence-based treatments.

If a parent scores low in this Active Research domain, they may be confused about how to find information regarding their child's diagnosis. Parents with a newly diagnosed child may not know what kinds of questions to ask. Provide easily understandable materials about their child's condition initially, and then provide additional and more complex information as they gain confidence and a better understanding of their child's diagnosis. Give the parents enough time and opportunity to review any new information, and encourage them to ask questions about aspects that interest them.

Ask the parent questions about their child and show your interest. Encourage the parent to talk about their child's condition and to ask you for any clarifications they might need. Invite them to contact you with any additional questions they may have. As the parent becomes more confident in understanding their child's condition, you can offer them additional information that is relevant to the child's changing needs. Ask the parent what kinds of information they would like and their preferences for the types of information given. Provide the parents with other materials where they can learn additional information when they feel more comfortable and confident.

### **Participation and Helping**

A parent scoring high in the Participation and Helping domain is often highly involved with their child's programs and progress. Encourage parents to continue their participation by offering them current information or parent training in advanced techniques to help their child. Listen to

their ideas about what other types of interventions or supports they have researched that might be beneficial to their child, and help the parent to obtain additional current information about evidence-based treatments and how they can continue to help their child. Point out any additional positive gains that you know of regarding their child. Congratulate the parents on their contributions to their child's success. Encourage them to continue working with their child's team, and to share any new information.

A parent scoring lower in this area may not know how to work with their child, or how to ask for help in learning techniques that might benefit their child. They may be afraid they don't have the skills needed to appropriately help their child.

Participating with the professionals in their child's life might be intimidating for some parents. Empower the parent by listening to their opinions and by inviting them to ask questions of other team members so that they can learn to actively participate in their child's interventions. Find training opportunities, such as behavioral skills training, for the parent and encourage them to attend. Model to the parent how they can work with their child and encourage them to do so. Praise them for their efforts and encourage other professionals on the team to be more proactive in working with the parents as well.

Parents should be encouraged to ask questions of other team members, and they should be encouraged to use newly learned skills with their child, to gain confidence in their techniques and abilities. Share with them that other parents have found parent training specific to their child's diagnosis to be helpful. Parent training can benefit the parent by increasing their confidence in working with their child, teaching their child new skills, and intervening appropriately when the child is exhibiting problematic behaviors. Parent training benefits not only the child, but also helps the parents feel that they are an active part of the team working collaboratively together to teach their child.

## **Self-Help Routines**

All caregivers need to take care of themselves. Parenting a child with special needs takes great energy physically and emotionally. Parents who score highly in their use self-help routines can experience more general well-being and should be praised and encouraged to continue to do so.

Caregivers who are overwhelmed will often forget to prioritize for their own needs and well-being. Parents who score low in this domain may need gentle reminders that they should take care of themselves if they are to take care of their child. Empathize with the parent. It is very tiring to parent a child with special needs.

If paid respite care is available through a local or state agency, you can assist the parent to arrange for respite hours. Explain what respite is and what is available to the parent. Respite is usually for a certain number of hours per month, and you can encourage parents to use this time for themselves.

Remind parents of activities that they enjoyed previously, and encourage them to resume these activities, even in a limited way. Not every support offered or discussed with the family needs to be provided from groups specifically established for helping families with special needs. You can encourage parents to resume enjoyable activities they engaged in prior to their child's diagnosis. Some self-care activities for parents may include activities such as hiking, meditation, spiritual groups, yoga, tai-chi, journaling, dancing, favorite sports, and artistic endeavors such as writing, painting, photography, needlework, and scrapbooking. There are various community groups, local businesses, and even college classes that support these activities.

Explain that small things such as posting encouraging statements around the house helps to remind parents that they are doing a good job. Using lists and a calendar to keep life on track is

beneficial in supporting well-being. Mindfulness activities such as yoga, meditation, tai-chi, prayer, and journaling can all aid in a sense of calm and focus. If mental health services are available to the family, interventions such as cognitive behavioral therapy can be therapeutic in aiding a parent to pursue specific self-help and wellness activities.

### **Broad Perspectives**

Broad perspectives involve the parent positively viewing the child within wider perspectives, including the family, the future, personal beliefs, and observing the child to better understand the child's patterns of behavior. A parent's broad perspective of their child is related to their personal beliefs and includes the positive views of a child as a valued member of the extended family, who makes their own meaningful contribution to the family ecology. The parent focuses positively on their child's potential by making plans for the child's future. The parent may observe their child to gain a better understanding of the child's behaviors and needs, and to think of effective ways to better help them. The parent may want to discuss their observations with you and share various anecdotes about their child and family.

For parents scoring high in this area, show respect for their positive views of their child within wider perspectives. Encourage the parent to share. Show the parent that you are actively listening, and praise the parent for the many ways the child has been included and valued in the family or community.

Parents scoring low in the domain of Broad Perspectives may need gentle guidance in learning how to include their child in the family and cultural structure. Discuss with the parent various situations where the child has been a part of the family or greater culture, and suggest ways in which the child might be further included. If it is an activity the parent might enjoy, suggest

journaling and writing their observations and thoughts about their child.

Services relating to broad perspectives could include parent training specific to the child's observed interests and behavior patterns, discussing ways to further include the child in family or group activities, resources that may be available when the child gets older, and helping the parent plan for their child's possible changing needs and transitions in the future. It is helpful to maintain rapport by asking about and respecting the perspectives and values of the child's family and culture.

Parents of children with special needs may or may not be comfortable taking a child to public festivities due to noise and crowds. However, there may be extended family occasions and other community events that can be organized where it might be easier for the parent to include their child. Ask the parent if they have observed something that the child really enjoys. Is there a way to use this highly preferred activity as the focus of a family or group centered event? Encourage the parent to think about their child's future, and ask how you can help them make plans. Suggest available resources that might help the parent to better understand the various options for their child's changing needs.

Parents may be fearful about their child's future when they are no longer around to help their child, and they may be unable to express these fears. Empathize and encourage parents to share their plans for their child's future. If a parent is unable to clearly state goals and ideas for their child, offer to help look at possible future supports, and some that could start at a sooner time for a child's transition. Connect the family with the resources they need to start investigating possible services that will benefit their child in the future, which will continue when a parent is unable to take care of their child. Connecting families to services can help reduce the parent's anxiety about their child's future.

**Focused Thought**

If a parent scores high in this domain, compliment them on how well they are focusing and planning ways to help their child. The parent would probably appreciate further information about their child's diagnosis. If any trainings are available for advanced techniques to better understand and work with their child, ask the parent if they would like to participate in the training.

For parents scoring low in this area, offer them current information about their child's diagnosis. Encourage parents to plan ways to help their child and offer to model interventions and supports they can use to work with their child. Praise the parent and help them to recognize their efforts. If any training for advanced techniques are available, ask the parent if they would like to participate in the training. Encourage them to positively acknowledge themselves for their planning and successes.

**Services and Supports for Each of the Unresolved Domains**

For comfortably low scores (around 1-2) in any Unresolved domains, it helps to point these out first, and acknowledge them as parent strengths. Listen and praise the parent's descriptions about how they successfully cope in these areas, in a way that provides recognition and encouragement for the parent.

For medium scores (around 3), you may ask the parent whether they may value supports in these areas, and discuss these with them.

Higher scores (around 4-5) in the Unresolved domains indicate areas of concern or difficulty for the parent. A high score on any single item on any of the unresolved domains can also indicate a specific concern for the parent. Allow parents to further describe their own concerns and difficulties in relation to these domains or individual items. Compassionately

discuss their situation with them and suggest services and supports that may be helpful for them in these areas.

Our measure contains seven Unresolved domain scales: Emotionally Overwhelmed, Angry Feelings, Depressed Feelings, Confused Feelings, Neutralizing Unconcerned, Neutralizing Resistant, and Negative Distortions.

**Emotionally Overwhelmed**

It is easy to become overwhelmed when a child is first diagnosed with a disability such as autism, and even after a child has had the diagnosis for a while, parents can still experience reoccurring difficult emotions. Parents do not expect a child to be born with special needs, and there is a learning curve to traverse that is beyond typical parenting. A child's changing needs as they develop and grow older can also trigger difficult emotions, and a parent can again become overwhelmed.

If the parent has a high score for Emotionally Overwhelmed, take the time to encourage them to talk about their emotions. Listen to the parent's narrative and reassure the parent that feeling overwhelmed is natural for parents, especially parents of a child with special needs. Let them know that it is natural for these feelings to come and go over time. Point out that the team is there to support them as needed, as well as help their child. Offer the parent information about their child's diagnosis and patiently discuss the information with them and answer any questions that you can with clear information. For a parent who is emotionally overwhelmed, you may need to calmly explain the material several times until it is understood. Encourage the parent to contact you or other professionals working with their child with any questions they might have.

Reassure the parent that they are part of a strong team working together to help their child. Some resources that you can offer the parent are

calming techniques. For example, meditation, breathing techniques, and relaxation exercises are activities that can be helpful in reducing stress when feeling overwhelmed. Using a calendar to make daily and weekly schedules, which include scheduling time for activities the parent enjoys, can make life a bit more predictable and reduce stress for the parent.

Parent support groups can help a parent work through difficult emotions, offering them a safe place to talk about their child and the difficulties they are facing. Experienced parents can offer support and share about their own similar parenting experiences raising a child with special needs. Support from parents who have had the similar experiences of feeling overwhelmed can help the parent recognize that they are not alone and that the emotions they are experiencing can reduce and change over time.

Suggest possible coping strategies for the parent to practice for when they feel overwhelmed or feel they are being judged by others. Breathing exercises are a non-obtrusive way to help with focus and control in a public situation. The parent can practice these breathing exercises at home so they have experience and confidence in using them. You can model and role play assertive techniques with the parent to help them respond confidently when they are feeling judged by others. Other parents in a support group can share their ways for coping with others' judgments. You may suggest the parent keep a list of contacts for persons they can call when feeling overwhelmed.

### **Angry Feelings**

Anger is an understandable response when grieving, and parents may need to hear that anger can be a natural response for many people. Remaining angry, however, can result in extreme distress for the parent. Listen to the parent's narrative and empathize with them about their emotions. Assure the parents that you are working with them as part of a highly qualified

team to help them and their child. If applicable, remind the parent that no one is responsible for the child's disability, but many people are there to help their child.

Parents who remain highly angry may benefit from professional counseling. If there are compelling indicators of strong parent anger, however, you will need to make sure the child or others are not in danger as a recipient of the parent's anger. If you see possible signs of violent behavior or serious neglect, you have a mandated duty to report, which includes informing your supervisors and making a report to child welfare services. Follow up to make sure the child and family are safe. Connect the family with mental health services to get the type of counseling that is needed.

### **Depressed Feelings**

Assure parents that it is natural to feel varying levels of sadness when a child is diagnosed with a disability. This scale reflects a parent's sad feelings relating specifically to their child's condition, and it is not designed in any way to diagnose overall depression. Take care to avoid using the single-word term of depression when talking with the parent, but rather speak in terms of depressed feelings or sadness the parent may feel.

While a higher score does not necessarily mean depression in a clinical sense, it can be an indicator that the parent needs stronger levels of support. Interventions such as professional counseling or cognitive behavioral therapy can help the parent cope with their sadness and grief. Suggesting grief counseling for groups may also be beneficial. A parent support group can help the parent to not feel so isolated and alone. Offer parent training classes that might be available, so they can become empowered and hopeful in actively helping their child. Learning new skills and working with their child can increase the parents' confidence and help reduce the depressed feelings.

### **Confused Feelings**

It is natural for a parent to feel confused when a child receives a diagnosis of autism or any disability. A child's new diagnosis comes with a lot of information about the diagnosis, which parents are not always able to understand quickly. There is a learning curve when one's child is diagnosed with autism or any disability. A lot of professionals come into the family's life with various jobs and titles to help the child, and a parent is not always ready to take it all in at once.

For a parent who scores high in Confused Feelings, listen to the parent and encourage them to express opinions and ask questions. Reassure them that as a team you are all working together to help their child. Explain about each service or intervention that is being implemented. Use clear, concise language that the parent can understand. Some information may need to be repeated until the parent has a working knowledge of their child's condition. Ask the parents if they would like to attend any seminars or trainings relating to their child's diagnosis.

Help the parent get organized by having them post schedules of the various therapies, and who will be working with the child, and at what times. Organize any needed materials for these therapies and keep them in one place for therapists' easy access. Remind the therapy team that consistency with the training schedule and having a predictable routine benefits the family. It also helps reduce parents' confusion when they are included in training sessions to learn how to support their child. A child will make better progress when a parent is confident in helping the child learn new skills.

### **Neutralizing Unconcerned**

It can be difficult to motivate a neutralizing unconcerned parent. This domain correlated positively with positive emotions and negatively with distressed emotions in the PRADS research. Thus, the child's diagnosis can

have less of an emotional impact on a parent who scores highly in the Neutralizing Unconcerned domain, limiting their involvement in a child's programs. Emphasize the value of parent involvement with the child, and give the parent information about the importance of the parents' role with their child, their child's success, and future outcomes. Offer the parents opportunities for some skills training for easily do-able parenting skills to support their child.

If one parent is neutralizing unconcerned, the other parent may have taken on the burden of parenting the child and coordinating the child's supports and services. If applicable, help the more active parent with additional supports, such as respite care, behavioral training, and contact with other parents in parent support groups. Offer the parents additional information about their child's diagnosis.

Encourage the less active parent to consider ways to increase their parenting involvement. Engage the parent in a discussion about their child and listen to the narrative. Motivational interviewing methods include asking open-ended questions, listening and reflecting upon the parent's own wishes and ideas, helping the parent consider their options, pointing out signs of parent strengths, reinforcing parent comments about possible future activities, and collaborating together on plans for actively caring for the child. To help support the parent's active involvement, be sure to recognize and praise the parent's increasing helpful behaviors and share joy in their child's successes.

### **Neutralizing Resistant**

The Neutralizing Resistant domain correlates negatively with positive emotions and positively with distressed emotions. A parent scoring high in the Neutralizing Resistant domain may not agree with their child's diagnosis, or may not agree that their child has any problems or special needs at all. Experiencing distressing emotions can impair a parent's ability to

recognize that a child is struggling, and the parent may resist seeking answers.

It is important to try to gently discuss the reasons the child was given the diagnosis. The parent may be averse to discussing anything that has to do with the child's condition or available services. Sharing something like a simple checklist with the signs and symptoms of their child's diagnosis may help when approaching the parent to discuss the child's supports and services.

Calm use of motivational interviewing methods can be helpful, including open-ended questions, respectful and reflective listening, pointing out signs of parent strengths that foster self-efficacy, encouraging the parent to consider ideas for future activities, and collaborating with the parent on these plans.

Offer the parent some training in easily doable parenting skills, and encourage them to take the opportunity to learn how to work with their child to actively use this new knowledge. Provide them with information that shows the positive gains a child makes when a parent is involved with teaching their child new skills. Offer them various types of training so that they have a range of parenting skills to use when working with their child. Learning and using new skills successfully with their child can increase their parenting confidence. The parent may eventually become more open to additional parent training and parent groups after they have acknowledged their child's diagnosis.

As with the Neutralizing Unconcerned parent, one parent may be carrying more of the responsibility of supporting the child. It might be useful for both parents to take the PRADS-2 measure to pinpoint services which could benefit each of them individually, as well as the family unit. Additional supports may be needed for the more involved parent. Offer respite care, if any is available, and encourage the parent to use that time for self-care. A parent support group can be an added benefit for a parent who is shouldering

most of the responsibilities of their child's programs and therapies. Encourage the more active parent to foster the involvement of the other parent when possible, as the neutralizing resistant parent gains more skills and confidence in helping their child.

### **Negative Distortions**

The Negative Distortions domain correlates highly with distressed feelings and correlates negatively with parenting confidence. It can be difficult for the parent to have a realistic view of their child if they tend to view everything about the child's diagnosis as negative. The parent may feel guilty about their child's condition, so it can be helpful to remind the parent that no one is to blame for their child's autism.

Engage the parent in a conversation and listen to the parent narrative. Calmly speak to their extremely negative beliefs. Reassure the parent that they are part of a highly qualified team working to help their child make progress, and the parent is not alone in trying to help their child. Acknowledge the parents' difficult emotions and assure them that having a child with a disability can be challenging for the whole family. Point out any positives you know of regarding the child and acknowledge the parents' role in their child's success.

You may offer other supports such as counseling with a professional therapist trained in cognitive behavioral therapy to help them develop more realistic and constructive thoughts about themselves and their child's condition.

### **Positive Distortions**

While earlier researchers labeled parents who seemed to have positive distortions as being unresolved, the Positive Distortions scores correlated significantly and positively with Resolution and not significantly with Nonresolution, and thus this domain scale is a special case.



The parents' mean score on this scale was 2.18, close to "*Slightly like me*", and their scores ranged from 1.00 to 4.50. Our correlations showed that the parents scoring higher in this range had noticed earlier that their child might have a problem, and they were more satisfied with their child's behavioral program. They reported feeling more closeness with their child, and greater confidence in managing behaviors and teaching skills to their child. They also reported feeling less initial and current distressed emotions, and greater initial and current positive emotions.

If a parent scores high in Positive Distortions, it is appropriate to respect the parents' hopefulness about their child's future, without judgment. Acknowledge the child's progress and show realistic optimism about the child's actual

gains. Encourage the parents to continue working with their child.

If a parent scores low in this area, there is not a problem with distorted optimism. Express realistic optimism and hope about the child's progress, and praise the parent for any support they have given their child. You may offer services related to this topic only if the parent expresses concern about it.

### **Summary of Tailored Supports**

We end this chapter with a concise summary of the tailored supports that we have discussed in relation to each of the scale scores. This summary can be a helpful reference for ideas when filling out the Services Worksheet for an individual parent.

## **SUMMARY OF TAILORED SUPPORTS**

Here we are providing a concise summary of the tailored supports that we have discussed in relation to each of the scale scores. This summary can be a helpful reference for ideas when filling out the Services Worksheet for an individual parent.

### **RESOLVED DOMAINS:**

For **high** scores (around 4-5): Praise, reflect, and congratulate the parent on these strengths.

For **medium** scores (around 3): Ask the parent whether they may value services in this area.

For **low** scores (around 1-2): Suggest resources and services tailored to these difficulties.

#### **1. Positive Feelings**

For **high** scores: Congratulate, listen, share enjoyment.

For **low** scores: Empathize with the parent; recognize and praise positive parent actions; point out parent actions to be proud of; point out things you yourself like about the child; point out positive child progress; suggest journaling about any positive experiences with child; discuss fun activities parent and child can share together; suggest enjoyable family and community activities.

#### **2. Working through Emotions**

For **high** scores: Congratulate, listen to how they have acknowledged and coped with emotions.

For **low** scores: Listen and encourage the parent to acknowledge and express their varied emotions with you; reassure feelings of grief are natural; may suggest journaling to sort out emotions; parent support groups where parents can express emotions with other more experienced parents; may suggest individual or group grief counseling.

#### **3. Active Research**

For **high** scores: Praise and offer further current, specific, and advanced information and training.

For **low** scores: Provide information on autism that is easy to understand and relevant; graduate in time to more complex information; encourage parent questions; get parent's preferences for types of information they would like; provide resources where parent can look for additional information of interest to them.

#### **4. Participation and Helping**

For **high** scores: Praise and offer further training and inclusion in their child's treatments.

For **low** scores: Invite to participate in easy tasks first; praise and gradually raise involvement; individual or group parent training; behavioral skills training; progress to more advanced skills in evidence-based treatment; encourage the parent's suggestions and participation with the therapy team; point out ways their helping contributes to their child's success.

## 5. Self-Help Routines

For **high** scores: Praise and affirm that self-care activities are important for caregivers.

For **low** scores: Affirm importance of self-care activities for caregivers; help schedule respite times; create a network of extended family or friends who can help out; provide cognitive behavioral supports, relaxation, mindfulness exercises, positive self-statements; help identify and schedule times for activities that the parent used to enjoy.

## 6. Broad Perspectives

For **high** scores: Respect the parent's positive views of their child in relation to their family, culture, beliefs, and future.

For **low** scores: Suggest positive ways the child can be included in extended family, cultural, and community activities; journaling about parent observations and understanding of their child; planning for the child's transitions into the future.

## 7. Focused Thought

For **high** scores: Praise the parent's daily planning, their focus on learning about the diagnosis and helping their child, and acknowledging their own successes in helping the child.

For **low** scores: Help the parent devise ways to schedule and plan for possibilities of each day, to focus on learning about the diagnosis and supporting their child, and to recognize and acknowledge their successes in parenting.

## UNRESOLVED DOMAINS:

For **high** scores (around 4-5): Suggest resources and services tailored to these difficulties.

For **medium** scores (around 3): Ask the parent whether they may value services in this area.

For **low** scores (around 1-2): Praise, reflect, and congratulate the parent on these strengths.

## 8. Emotionally Overwhelmed

For **high** scores: Listen and empathize with the parent's varying emotions; assure overwhelmed feelings are natural in parenting a child with special needs; parent support group for sharing emotions and coping strategies; practice assertive responses for when worried about others judging them; practice calming techniques; use calendar of schedules to make life more predictable; list contacts for persons they can call when overwhelmed.

For **low** scores: Acknowledge the parent's ability to manage stressors as an important strength.

## 9. Angry Feelings

For **high** scores: Listen and empathize; assure they have a highly qualified team to help them and their child; assure them that no one is responsible for causing the disability; suggest professional counseling for strong anger; any signs of possible violence or severe neglect present a mandated duty to report to child welfare services; follow up to ensure safety and family counseling.

For **low** scores: Acknowledge the parent's low degree of angry feelings as a valuable strength.

**10. Depressed Feelings**

For **high** scores: Point out that this scale only measures sad feelings about the child's condition, and does not diagnose clinical depression; suggest parent support group to help reduce feelings of isolation and aloneness; provide parenting skills training to increase empowerment, confidence, and hopefulness; refer for professional grief counseling for intense sadness.

For **low** scores: Acknowledge a parent's low level of depressed feelings as a valuable strength.

**11. Confused Feelings**

For **high** scores: Assure confused feelings are natural; respectfully listen and encourage the parent to state opinions and ask questions; explain rationale for each treatment; use clear language familiar to the parent; offer parent training; help parent organize by posting schedules; keeping therapy materials in one place; invite to participate in seminars and training sessions.

For **low** scores: Acknowledge the parent's organization and clarity as important strengths.

**12. Neutralizing Unconcerned**

For **high** scores: For an unconcerned parent, explain the value of parent involvement for the child's success; offer initially simple parent skills training, and show the child's positive gains; if another parent has taken on the burden of caregiving, offer the more active parent additional supports; encourage the less concerned parent to increase active involvement for the child.

For **low** scores: Acknowledge and praise the parent's strong commitment to the child.

**13. Neutralizing Resistant**

For **high** scores: For an anxious parent who resists the diagnosis, gently share a checklist of signs and symptoms; offer initially simple parent skills training to reduce anxiety and raise confidence; show positive gains the child makes with parent help; offer a more active parent additional supports; guide parents to coordinate and celebrate their parenting activity.

For **low** scores: Acknowledge and praise the parent for actively accepting their parenting role.

**14. Negative Distortions**

For **high** scores: Calmly listen and gently discuss negatively distorted beliefs; may point out that no one is to blame for causing the child's disability, that there are positive qualities to appreciate about the child, that there is a team to help so parent is not alone; may suggest cognitive behavioral counseling to support more realistic and constructive thoughts about themselves and their child.

For **low** scores: Acknowledge and praise the parent for their constructive viewpoints.

**INDEPENDENT DOMAIN:****15. Positive Distortions**

For **any** score (1-5): Acknowledge and respect the parent's views in this domain, and express realistic hope for the child. If the parent expresses specific concerns relating to this area, however, you may discuss services that may be of help to the parent.

## Chapter 10

### USING THE SERVICES WORKSHEET

The Services Worksheet contains spaces on the left to write the parent's scale scores. It contains spaces on the right to list possible services relating to the parent's scale scores. This Services Worksheet is provided to help the service coordinator prepare a list of possible services and vendors, to share and discuss with the parents in a follow-up interview, to help in deciding the types of services that might be beneficial and valued by the family.

First, information from the Scoring Sheet is transferred into the Services Worksheet. While doing this, it helps to place the completed Scoring Sheet next to the blank Services Worksheet. The Scoring Sheet shows the parent's ratings for each item in a scale, as well as the parent's scale scores.

#### Resolved Scores and Services

On the first page of the Services Worksheet, write in the parent's Total Resolved Score at the top, and write in the parent's Resolved scale scores in the first column of the table.

For each Resolved domain, on the Services Worksheet, if the Resolved scale score or any of its item ratings are low (around 1-2), you may make a check by Possible Services. Otherwise, you may make a check by Fine.

In the box next to each domain, you can list notes and possible services that may be helpful for the parent in areas with relatively low Resolved scale scores or item ratings (around 1-2).

For scales or items with medium scores (around 3 "Somewhat like me"), you may ask the parent whether they may value services in this area.

For Resolved scales with higher scores (around 4-5), be sure to point these out to the parent as areas of strength for them.

#### Unresolved Scores and Services

On the third page of the Services Worksheet, write in the parent's Total Unresolved Score at the top, and write in the parent's Unresolved scale scores in the first column of the table.

For each Unresolved domain, on the Services Worksheet, if the Unresolved scale score or any of its item ratings are high (around 4-5), you may make a check by Possible Services. Otherwise, you may make a check by Fine.

In the box next to each domain, you can list notes and possible services that may be helpful for the parent in areas with relatively high Unresolved scale scores or item ratings (around 4-5).

For scales or items with medium scores (around 3 "Somewhat like me"), you may ask the parent whether they may value services in this area.

For Unresolved scales with lower scores (around 1-2), be sure to point these out to the parent as areas of strength for them.

#### Listing the Tailored Services

You can refer to Chapters 9 and 10, including the concise Summary of Tailored Supports at the end of Chapter 10, to consider specific service ideas relating to each area. These areas and possible services can then be written into the second column of the Services Worksheet, and then shared and discussed with the parent.

Services should be in the community whenever possible to help the family connect with those services closest to them. Any special aspects that the parents should know about each service, such as contact information, additional fees, or childcare, if available, can also be included with the services worksheet. When filling out the planning form, be mindful that these are notes that the parent can see when discussing services with them.

### **Positive Distortions Domain and Notes**

On the last page of the Services Worksheet, you will write in the parent's Positive Distortions score. You may acknowledge and respect the parent's views in this domain (with scores from 1-5), and express realistic hope for the child. However, if the parent expresses specific concerns relating to this area, then you may suggest services that may be of help to the parent.

There is also a space on this page for you to write more notes elaborating on available services.

### **Further Considerations**

An additional section at the end of the survey asks parents if there are any further comments they would like to add. This section can be very relevant when considering supports for families, along with information the parent speaks with you about in any discussions or interviews. Personal information the parent provides, such as additional persons in the household, remarks about their family and circumstances, other needs such as transportation and health care, and other aspects such as school issues, can all be considered when planning supports. These parent

comments are part of the PRADS-2 process, and should be kept as confidential as the information from the scores.

The PRADS-2 is not a clinical diagnostic tool. However, in reviewing parent scores and considering any additional remarks, you may need to ask the parent if they feel a referral to a mental health professional may be of benefit to them. Parent mental health is important when raising and supporting a child with special needs.

Above all, maintain respect for the family, and always discuss the services pages with the parent in a positive and considerate manner. Instead of professional jargon, use language the parent can understand. If an interpreter is needed to work with the family, make sure that this individual also follows the ethical standards required. It can be overwhelming to raise a child with special needs, and it takes time to absorb and understand new information. Give the parent time to discuss and review the information on the services worksheet so that they can make thoughtful informed decisions.

### **Collaborating with the Parent**

When meeting with the parent in the follow-up interview, you may show the parent the profile graph and your draft Services Worksheet, and discuss these with the parent. Then, in collaboration with the parent, you may fill out a new blank Services Worksheet, listing those services that you and the parent agree would be desirable. Both you and the parent can initial the final services plan. You can then provide the parent with further information on the chosen services, and follow up in providing the parent with the needed contact information, paperwork, and referrals for these services.

**PRADS-2 SERVICES WORKSHEET**

Parent ID \_\_\_\_\_

This worksheet helps to compile suggested services to discuss with the parent. In these **Resolved** domains, services would especially benefit a parent who scores **low** (around 1-2) in a scale, or in a specific item in the scale. For scales with medium scores (around 3), ask the parent whether they may value services in this area. For Resolved scales with higher scores (around 4-5), be sure to point these out to the parent as areas of strength.

**Total Resolved Score:** \_\_\_\_\_

**Resolved Domains**

**Notes and Possible Services**

<p><b>1. Positive Feelings</b></p> <p>Score: _____</p> <p>____ Fine (4-5) ____ Possible Services</p>	
<p><b>2. Working through Emotions</b></p> <p>Score: _____</p> <p>____ Fine (4-5) ____ Possible Services</p>	
<p><b>3. Active Research</b></p> <p>Score: _____</p> <p>____ Fine (4-5) ____ Possible Services</p>	

**PRADS-2 SERVICES WORKSHEET**

**Resolved Domains**

**Notes and Possible Services**

<p><b>4. Participation and Helping</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>5. Self-Help Routines</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>6. Broad Perspectives</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>7. Focused Thought</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	



**PRADS-2 SERVICES WORKSHEET**

This worksheet helps to compile suggested services to discuss with the parent. In these **Unresolved** domains, services would especially benefit a parent who scores **high** (around 4-5) in a scale, or in a specific item in the scale. For scales with medium scores (around 3), ask the parent whether they may value services in this area. For Unresolved scales with lower scores (around 1-2), be sure to point these out to the parent as areas of strength.

**Total Unresolved Score:** \_\_\_\_\_

**Unresolved Domains**

**Notes and Possible Services**

<p><b>8. Emotionally Overwhelmed</b></p> <p>Score: _____</p> <p>___ Fine (1-2)</p> <p>___ Possible Services</p>	
<p><b>9. Angry Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2)</p> <p>___ Possible Services</p>	
<p><b>10. Depressed Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2)</p> <p>___ Possible Services</p>	

**PRADS-2 SERVICES WORKSHEET**

**Unresolved Domains**

**Notes and Possible Services**

<p><b>11. Confused Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>12. Neutralizing Unconcerned</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>13. Neutralizing Resistant</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>14. Negative Distortions</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	

**PRADS-2 SERVICES WORKSHEET**

The **Positive Distortions** scale is separate from the other scales. This scale correlates positively with Resolution rather than Nonresolution. It represents the parent's hope for their child's future. You may acknowledge and respect the parent's views in this domain (from 1-5), and express realistic hope for the child. However, if the parent expresses specific concerns relating to this area, then you may discuss services that may be of help to the parent.

**Positive Distortions Domain**

**Notes and Possible Services**

<p><b>15. Positive Distortions</b></p> <p>Score: _____</p> <p>____ Fine (1-5)</p> <p>____ Possible Services</p>	
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**Additional Notes and Available Services:**

\_\_\_\_\_ Parent's Initials

\_\_\_\_\_ Service Coordinator's Initials

\_\_\_\_\_ Date

## Chapter 11

**THE FOLLOW-UP INTERVIEW WITH THE PARENT**

The PRADS-2 provides the opportunity to build meaningful and lasting rapport with parents. Positivity, empathy, compassion, and collaboration are beneficial skills to have when consulting with families. To demystify these qualities, researchers have identified specific behaviors that contribute to each of these essential relationship skills.

**Therapist Relationship Skills**

Taylor, LeBlanc, and Nosik (2018) have reviewed studies that found positive correlations between therapists' relationship skills and beneficial treatment outcomes in various medical and mental health care services. They conducted a survey asking caregivers of children with autism to rate specific relationship skills of their children's behavior analysts.

Based on their literature review and the caregivers' responses to their survey, they listed specific behaviors that can facilitate **positive interactions**. These behaviors include to: smile and acknowledge the parent with appropriate greetings, make positive comments about the parent's and child's behavior, give realistic and hopeful comments about the child's progress, show general enthusiasm about the direction of the child's progress, ask the parent how he or she is doing, clarify roles, and ask the parent if she or he is happy with how things are going.

They also listed specific behaviors that show **empathy**. These behaviors include to: make eye contact, use a reassuring tone of voice, nod to show active listening, use vocalizations to show ongoing interest, ask open-ended questions, pause to let the parent answer, paraphrase back what the parent states, acknowledge the parent's feelings, identify and respond to the parent's

nonverbal cues, and verify the parent's emotional responses as reasonable.

They then listed behaviors that show **compassion**. These behaviors include to: provide pauses and opportunities for the parent to say how he or she is feeling, confirm the parent's emotional response in a nonjudgmental way, give acknowledgement and supportive comments, discuss how as a team they may address the parent's concerns, give reassurance that things will get better, show understanding of the parent's feelings, offer actions to take to alleviate the parent's distress, and celebrate the parent's and child's achievements.

They further listed behaviors that demonstrate **collaboration**. These behaviors include to: seek the parent's ideas for services, give explanations for suggested services, use reasonably understandable terms, ask the parent if suggested services are acceptable, ask the parent what obstacles may interfere with a service, acknowledge the parent's statements of concerns or obstacles and paraphrase the concerns, compromise and model flexibility, acknowledge one's own mistakes and apologize when appropriate, ask about parent satisfaction with services, and identify and adjust service goals based on the family's culture, beliefs, or lifestyle.

These suggested behaviors can help guide service providers in building positive relationships while discussing and planning services for families.

**The Follow-Up Interview Process**

The follow-up interview is an essential part of the PRADS-2 process. It gives the service provider an opportunity to increase rapport with

the family, to develop positive relationships for further communications, and to put needed family supports in place in a timely manner. The follow-up interview may occur in person or in an online meeting, depending on the conditions that are safest at the time.

The follow-up interview process includes seven essential phases. These phases are: preparing for the meeting, greeting and listening to the parent, sharing the scores and profile graph with the parent, discussing and celebrating areas of parent strengths, discussing areas of parent difficulties, collaborating with the parent to plan tailored supports in the parent's areas of difficulties, and concluding the interview on a positive note.

### **1. Preparing for the Interview**

To prepare for meeting with the parent after the parent has filled out the survey, you will fill out the scoring form, the profile graph, and the services worksheet for this parent. Be sure to recheck your scoring and graphing for accuracy.

It will help to review the items in each of the domains before discussing the profile with the parent. Familiarity with the items in each of the domains will help with clarity when working with the family.

It is important to consider and learn about the family's culture, so you can consider services that may complement their preferred customs. You should use language that is clearly understandable to the family, and to consider whether it may help to include an interpreter who is skilled in the family's preferred language.

Other information for planning parent and family services includes considering the ecology and demographics of the family, and the available community resources, schools, and places and activities in the community where the family

members might be comfortable participating. Any additional information obtained from interviews, observations, and comments which the parent may have written at the end of the survey should also be considered.

A comprehensive list of available services in the community, including location, transportation, and costs, is an especially valuable resource.

You may use the Summary of Tailored Supports for ideas of supports relating to the parent's specific scale scores, and write your ideas for support services into the services worksheet notes sections. You can then fill out another services worksheet with the scores, but with blank notes sections, to discuss and fill in together with the parent.

You will then list specific information about the available support services which may be of help and of interest to the parent and family. You may also bring copies of any available brochures describing these services.

Now you will be well prepared to have a beneficial meeting with the parent.

### **2. Greeting and Listening to the Parent**

When meeting with the parent, first warmly greet the parent. Point out that in this meeting you hope to plan ways to support the parent and family. Ask how the parent and family are doing, and listen and reflect on the parent's answers. Thank the parent for filling out the measure.

### **3. Sharing the Scores and Profile Graph**

You may then show the completed scoring form and profile graph to the parent. You can point out that these reflect the parent's current areas of parenting strengths and difficulties.

#### **4. Discussing Areas of Parent Strengths**

In showing the profile graph, you will first point out the parent's strengths, as seen in any high Resolved scores (around 4-5). You will then point out further parent strengths, as seen in any low Unresolved scores (around 1-2). You may celebrate these areas of strengths, and invite the parent to comment further about them.

You can then show the parent the services worksheet with the scores and blank notes sections. Write specific positive comments about the parent's strengths into the services worksheet notes sections.

#### **5. Discussing Areas of Parent Difficulties**

You can next gently point out possible areas of difficulty in the profile graph, as seen in any low Resolved scores (around 1-2). You can then point out further areas of possible difficulty, as seen in any high Unresolved scores (around 4-5). Show compassion and invite the parent's further comments about these areas.

You can also ask about any other concerns that the parent wishes to discuss. For any scales with medium scores (around 3), you can ask if the parent would value assistance in these areas as well.

Describe and collaborate about possible supports that may assist the parent or family in each of the areas of difficulty, and invite the parent's questions and comments about them.

#### **6. Planning Supports and Services**

Your supportive comments provide immediate and ongoing valuable supports. For the other relevant available services, describe each of these and invite the parent to ask questions and express their views about them. You may also ask the parent if they know of any other specific resources that they may be interested in.

For services of interest to the parent, provide specific information, and answer any parent questions about them. Write each of these possible supports into the services worksheet notes sections. Obtain the parent's consent for any possible referrals or sharing of confidential information with specific services agencies.

#### **7. Concluding on a Positive Note**

You may offer the parent copies of their scoring form, profile graph, services worksheet, and service information. Discuss and agree on any planned actions to do prior to the next meeting. Arrange for the next meeting with the parent and family. Thank the parent for their valuable involvement in parenting their child. Follow up with contacting and making any agreed-upon referrals to the service agencies of interest to the parent.

#### **Further Reflections**

While each of these steps is essential to include in the follow-up interview, the exact sequence does not have to be rigidly set. You may use some flexibility with the sequencing of the elements you cover with the parent, by going with the flow in responding to any comments and questions the parent brings up in the moment.

It is valuable, however, to aim for a strength-based approach, by pointing out and applauding the parent's strengths, prior to pointing out and discussing the parent's possible areas of difficulty. Identifying the more highly resolved areas first shows parents that they have positive parenting strengths to acknowledge and feel confident about. This approach helps the parent recognize their parenting strengths, which can bolster their confidence when next discussing their areas of difficulty.

The parent's scores for each scale reveal areas of strength and areas of difficulty. In

addition, scores for single items within each scale can pinpoint very specific areas of positive strengths or difficulties, which can also be discussed with the parent. For instance, if a parent has responded with high ratings to most of the items in a Resolved scale, except for a particularly low rating on one item, that item with a lower rating could pinpoint a specific area of difficulty that services may help with, even if the overall scale score is high. Also, if a parent has given low ratings to most items in an Unresolved scale, except for a high rating on one specific item, identifying services relating to that item may be particularly helpful for the parent.

Designing services is a creative process involving identifying options for families from a variety of resources. Consider and respect the family's culture, so that supports you suggest may be consistent with the family's values and customs. If a parent is resistant to certain types of supports, respect the parent's opinions and discuss other options. There will be more opportunities for addressing unmet needs after the parent has had time to think about the information in the profile and services that they may find helpful.

Community-based services are important for a family with a child who has a disability. Services should ideally be close to home and in the community if available. Traveling long distances with the child can be complicated. Children with special needs should be included in their own communities whenever possible. Familiarity with the community helps safeguard a child. Services through other venues may be an option if community services are not available. For example, resources are available online for families who like to use the internet.

Raising a child with a disability can be highly stressful and confusing. Anyone administering the measures should be prepared to help a parent deal with difficult emotions that may arise when reflecting on parenting their child with special needs. Recognizing and validating parent responses to a child's diagnosis helps build

rapport with the family. Offering empathy, respect, and support to families can help the parents know that they are an important part of their child's team.

Parenting a child with special needs takes a tremendous amount of sustained effort, including the increased vigilance that is required to keep a child safe, to teach new skills to the child, to advocate for appropriate services for home and school, to reorganize the family structure, and to gain needed supports for the family and the child.

These tasks require additional skills that most parents are unprepared for prior to their child receiving a diagnosis. This shock to the parenting system takes time to adjust. A parent whose child has received a more recent diagnosis can experience greater levels of stress and confusion than a parent who has had time to learn ways to respond and support their child. Parents can adapt to their child's diagnosis over time, but any parent may still periodically experience varying difficult emotions.

You may point out to the parent that the profile graph is only a current snapshot which is useful for creating a family service plan. Explain that as a child grows and progresses, their requirements can change and services may increase in complexity. Parents and family members will need to learn and use new skills on an ongoing basis. Thus, it is understandable that parenting a child with a disability can continue to feel effortful as the child grows and develops over time. Assure parents that they may retake this measure in future times, to learn about newer areas of concerns and strengths, and to allow for updating supports to fit the family's current situation.

Within the child's family, there may be several adults who have interest and potential to provide helpful caregiving for the child. These may include parents, stepparents, partners, adult siblings, and extended family members, such as grandparents, aunts, and uncles. You may greet

and invite other adults in the child's family to fill out the measure, to learn about their viewpoints, to consider supports for each of them, and to plan ways the adult caregivers can coordinate their support for the child and for each other.

The follow-up interview is an integral part of the PRADS-2 process. It provides the opportunity to understand and develop positive rapport with the family, and to identify and begin needed family supports in a timely manner.

We are ending this chapter with a concise summary of the sequence of essential steps for the follow-up interview with the parent.



## SUMMARY OF STEPS FOR THE FOLLOW-UP INTERVIEW

### **Preparing:**

- Fill out the scoring form, profile graph, and services worksheet for the parent
- Use the Summary of Tailored Supports for ideas of supports relating to the parent's specific scale scores
- Write in your ideas for support services in the services worksheet notes section
- Fill out another services worksheet with the scores, but with blank notes sections, to discuss and fill in together with the parent
- Collect specific information about the available support services

### **Greeting:**

- Greet the parent
- Ask how the parent and family are doing - listen and reflect
- Thank the parent for filling out the measure

### **Sharing:**

- Show the completed scoring form and the profile graph
- Point out that these can show current areas of parent strengths and difficulties

### **Strengths:**

- Point out areas of strengths - in high Resolved scores and items (around 4-5)
- Point out areas of strengths - in low Unresolved scores and items (around 1-2)
- Celebrate these areas of strengths and invite the parent's comments on these
- Show the services worksheet with scores, but with blank notes sections
- Write specific positive comments into the services worksheet notes sections

### **Difficulties:**

- Point out areas of difficulty - in low Resolved scores and items (around 1-2)
- Point out areas of difficulty - in high Unresolved scores and items (around 4-5)
- Ask about any other parent concerns, and about any medium scores (around 3)
- Show compassion and invite the parent's further comments about these areas
- Discuss and collaborate about possible supports for the family in these areas

### **Services:**

- Your supportive comments provide valuable insight and encouragement
- Available services - describe these and invite the parent's questions and opinions
- For services of interest to the parent - provide specific information and referrals
- Write each of these possible supports into the services worksheet notes sections

### **Concluding:**

- Offer the parent copies of their scoring form, graph, services worksheet, and service information
- Agree on any planned actions and referrals to do prior to the next meeting
- Arrange for the next meeting with the parent and family
- Thank the parent for their valuable involvement in parenting their child!

**Chapter 12****ILLUSTRATION FOR AN EXAMPLE PARENT**

In this chapter we are presenting an example with a completed scoring sheet, completed profile graph, interpretation, completed services worksheet, and suggested services for an example parent. Parent #070 is an actual parent who participated in our original research and is a mother of a child with autism.

**Table 16. EXAMPLE SCORING SHEET FOR THE PRADS-2 SCALES**

Parent ID: 070

For a scale score, we enter and add the parent's ratings on each of the items in the scale, and then divide by the number of answered items in the scale, rounding to two digits past the decimal point. This gives the parent's average rating on the scale items. It also expresses the scale score on the same 1-5 scale as the original rating scale, thus facilitating interpretation.

**RESOLVED Feeling-Oriented Scales:**

**1. Positive Feelings Scale:**

- 3 Item 1. I feel a strong emotional connection with my child.
- 4 Item 30. I feel more positive now about my child's diagnosis of autism.
- 3 Item 45. I am proud of myself for how well I am helping my child.
- 4 Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{14}{4} = \boxed{3.50}$$

**2. Working through Emotions Scale:**

- 4 Item 4. I worked through a lot of emotions about my child's diagnosis.
- 4 Item 20. Being able to express myself and talk to others about my emotions helps me to cope with my child's autism.
- 3 Item 33. I feel that by addressing my emotions after my child's diagnosis, I am better able to support my child.
- 4 Item 46. I felt a need to grieve after my child's diagnosis.

$$\text{Working through Emotions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{15}{4} = \boxed{3.75}$$

**RESOLVED Action-Oriented Scales:**

**3. Active Research Scale:**

- 5 Item 3. I sought answers immediately when I realized that my child was having problems.  
5 Item 18. When my child was diagnosed with autism, I researched everything I could.  
4 Item 37. I try to stay current with new interventions so that I can actively help my child.  
4 Item 57. I take charge of getting my child appropriate services.

$$\text{Active Research Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{18}{4} = \boxed{4.50}$$

**4. Participation and Helping Scale:**

- 4 Item 6. I actively participate in interventions and programs for my child.  
4 Item 24. I continue to do what I have to do to help my child every day.  
5 Item 35. I work with all the professionals in my child's life to understand my child's changing needs.  
4 Item 48. It is important that I actively participate in helping my child make progress.

$$\text{Participation and Helping Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{17}{4} = \boxed{4.25}$$

**5. Self-Help Routines Scale:**

- 2 • Item 10. I schedule special time for myself to relax, rejuvenate, and restore my well-being.  
4 Item 22. I have created routines that help me to meet my child's needs.  
3 Item 38. I have created self-help routines to help me get through my day.  
2 • Item 59. I have supportive phrases I tell myself that help me get through each day.

$$\text{Self-Help Routines Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{11}{4} = \boxed{2.75}$$

**RESOLVED Thinking-Oriented Scales:**

**6. Broad Perspectives Scale:**

- 4 Item 14. I think my child makes a positive contribution to our family.  
4 Item 28. Observing what my child does helps me to understand my child better.  
4 Item 40. Thinking positively about my child's future helps me to help my child.  
3 Item 55. My personal beliefs have helped me to come to terms with my child's diagnosis.

$$\text{Broad Perspectives Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{15}{4} = \boxed{3.75}$$

**7. Focused Thought Scale:**

- 4 Item 12. I believe that the more I plan for the possibilities of each day, the more prepared I am to help my child.  
4 Item 29. I stay focused on learning everything I can about autism to help me support my child.  
5 Item 43. It is important for me to have information about autism.  
5 Item 52. I think it is important for me to acknowledge my success in helping my child.

$$\text{Focused Thought Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{18}{4} = \boxed{4.50}$$

- Place a dot by any of the above Resolved items which the parent rated low (1 or 2).

**RESOLVED TOTAL SCORE:**

For the Resolved Total Score, we add the parent's scores on each of these seven Resolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\begin{aligned} \text{Resolved Total Score} &= \frac{(\text{PFS} + \text{WES} + \text{ARS} + \text{PHS} + \text{SRS} + \text{BPS} + \text{FTS})}{7} \\ &= \frac{(3.50 + 3.75 + 4.50 + 4.25 + 2.75 + 3.75 + 4.50)}{7} = \frac{27.00}{7} = \boxed{3.86} \end{aligned}$$

**UNRESOLVED Overwhelmed, Angry, Depressed, and Confused Scales:**

**8. Emotionally Overwhelmed Scale:**

- 2   Item 9. Every day I experience the same overwhelming emotions I had when my child received a diagnosis.
- 5  • Item 19. I worry about other people judging me as a parent of a child with autism.
- 4  • Item 41. I feel that I am in a continual state of crisis.
- 4  • Item 47. I am overwhelmed when caring for my child.

$$\text{Emotionally Overwhelmed Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{15}{4} = \boxed{3.75}$$

**9. Angry Feelings Scale:**

- 1   Item 5. It is important to me that someone be held responsible for my child having autism.
- 1   Item 27. I am angry with the professionals who diagnosed my child with autism.
- 2   Item 42. I want others to be as angry as I am about my child's situation.
- 1   Item 58. I am constantly angry that my child has autism.

$$\text{Angry Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{5}{4} = \boxed{1.25}$$

**10. Depressed Feelings Scale:**

- 4  • Item 11. I am stuck in sadness about my child having autism.
- 2   Item 21. I do not have much hope for my child's future.
- 5  • Item 36. I feel isolated and alone since my child's diagnosis.
- 1   Item 49. I feel powerless to help my child.

$$\text{Depressed Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{12}{4} = \boxed{3.00}$$

**11. Confused Feelings Scale:**

- 5  • Item 8. Sometimes I think everything will be okay and then it just becomes too much to handle.
- 2   Item 23. I get so confused and at a loss when I try to talk about my child's autism.
- 2   Item 34. I am so confused about autism that I don't know what to do to help my child.
- 4  • Item 54. I just cannot get myself organized and focused enough to help my child.

$$\text{Confused Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{13}{4} = \boxed{3.25}$$

**UNRESOLVED Unconcerned, Resistant, and Negative Distortions Scales:**

**12. Neutralizing Unconcerned Scale:**

- 2   Item 13. I have never felt strong emotions about my child's diagnosis of autism.  
  1   Item 26. My child's diagnosis of autism never bothered me.  
  1   Item 44. I feel I don't need to do anything more to help my child.  
  1   Item 56. I believe my child's diagnosis of autism has had no effect on our family.

$$\text{Neutralizing Unconcerned Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{5}{4} = \boxed{1.25}$$

**13. Neutralizing Resistant Scale:**

- 1   Item 2. I really believe that my child's diagnosis of autism is incorrect.  
  1   Item 17. Someone else noticed my child was having problems before I did and told me.  
  1   Item 32. I waited to get my child diagnosed because I did not think there was a problem.  
  1   Item 53. I avoid thinking about my child's autism.

$$\text{Neutralizing Resistant Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{4}{4} = \boxed{1.00}$$

**14. Negative Distortions Scale:**

- 2   Item 15. Since receiving the diagnosis, I feel that I am the only one who can help my child.  
  1   Item 25. I blame myself for causing my child's autism.  
  3   Item 39. I feel that my child's autism has been harder for me as the parent than for my child.  
  1   Item 51. I feel that everything about my child's autism is negative.

$$\text{Negative Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{7}{4} = \boxed{1.75}$$

- Place a dot by any of the above Unresolved items which the parent rated highly (4 or 5).

**UNRESOLVED TOTAL SCORE:**

For the Unresolved Total Score, we add the parent's scores on each of these seven Unresolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\begin{aligned} \text{Unresolved Total Score} &= \frac{(\text{EOS} + \text{AFS} + \text{DFS} + \text{CFS} + \text{NUS} + \text{NRS} + \text{NDS})}{7} \\ &= \frac{(3.75 + 1.25 + 3.00 + 3.25 + 1.25 + 1.00 + 1.75)}{7} = \frac{15.25}{7} = \boxed{2.18} \end{aligned}$$

### 15. Positive Distortions Scale:

The Positive Distortions Scale is calculated separately from the Resolved and Unresolved scales.

- 1 Item 7. My child's having autism has been a wonderful blessing for our family.
- 1 Item 16. Without my child having a diagnosis of autism, my life would not have a purpose.
- 4 Item 31. My child was given autism to help me with my own personal growth.
- 5 Item 50. I believe my child's brilliance will make a huge difference in the world someday.

$$\text{Positive Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{11}{4} = \boxed{2.75}$$

### Missing Responses:

If there are some missing responses, you may remind the parent that there are no right or wrong answers to the questions, and you may encourage them to fill in their best estimate for how much each item applies to their experiences. Be careful not to suggest specific answers to the parent, however. Also, be careful to respect the parent's choice to not answer all the items if the parent prefers this.

If there are still some missing responses, you may use prorating to calculate the parent's scale score, by adding the parent's ratings on the answered items, and then dividing by the number of answered items in that scale.

For example, if a parent did not answer Item 45 on the Positive Feelings scale, you may calculate a Positive Feelings scale score by adding the responses on the other three items and then dividing by three instead of four. This gives the parent's average rating on the items that they did answer.

### Positive Feelings Scale - Example with a missing response:

- 4 Item 1. I feel a strong emotional connection with my child.
- 3 Item 30. I feel more positive now about my child's diagnosis of autism.
- ~~m~~ Item 45. I am proud of myself for how well I am helping my child.
- 5 Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4 - 1} = \frac{12}{3} = \boxed{4.00}$$



Parent ID: 070

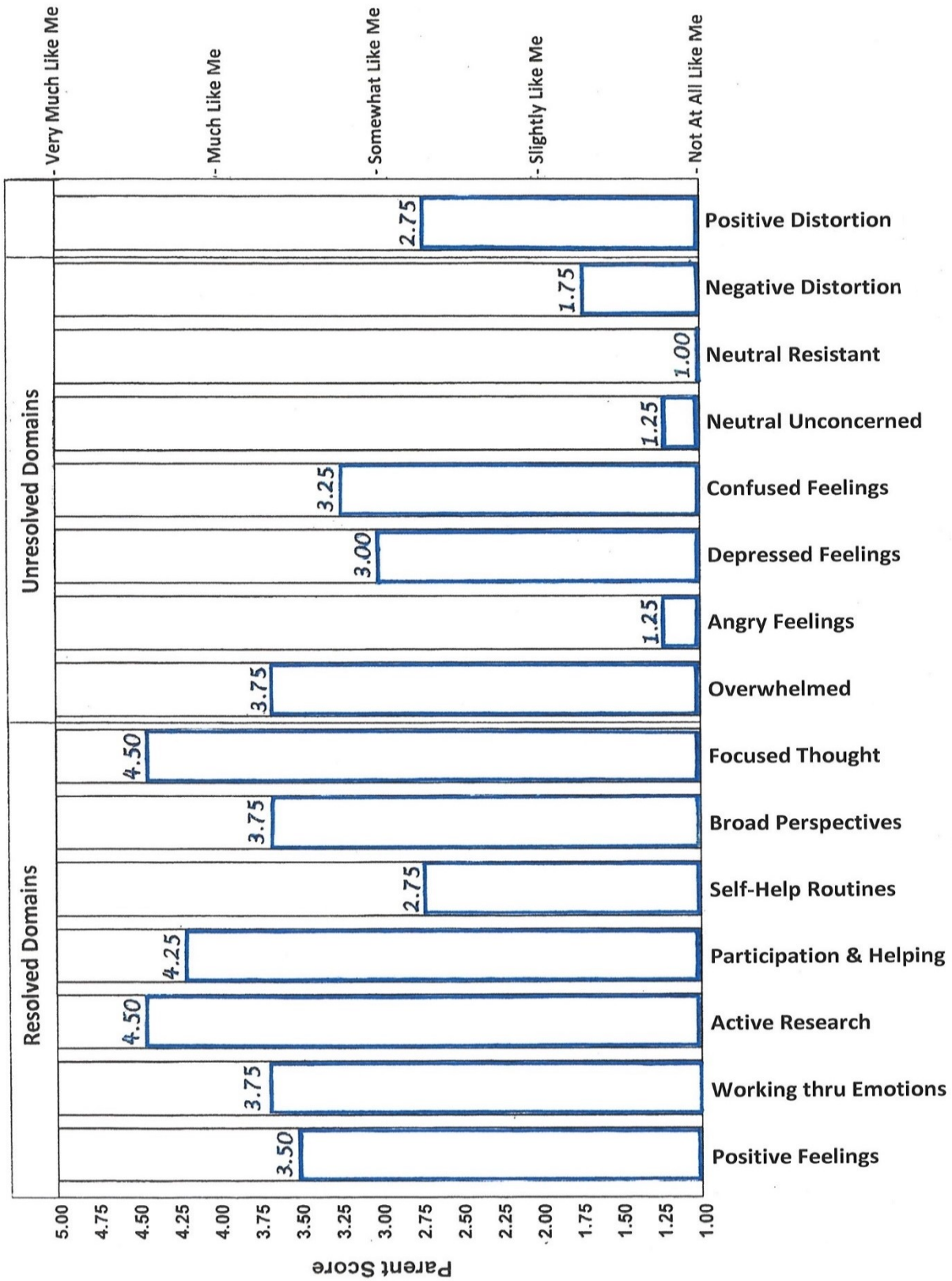


Figure 3. Profile graph form showing the profile of scores for the example Parent #070.

## INTERPRETING SCORES FOR THIS EXAMPLE PARENT

We are providing our interpretation of the scores for our example Parent #070, who participated in our original research and is a mother of a child with autism.

The parent's item ratings and the scale scores are all expressed on a 1 to 5 scale, from 1 "Not at all like me", 2 "Slightly like me", 3 "Somewhat like me", 4 "Much like me", up to 5 "Very much like me", to facilitate interpretation of what the parent is experiencing.

### Resolved and Unresolved Total Scores

Parent #070 has a Resolved Total score of 3.86 (near to "Much like me"). She has a lower Unresolved Total score of 2.18 (near to "Slightly like me").

### Scale Scores

Figure 3 shows this parent's profile of scale scores, graphed on the scale from 1 to 5. It shows that on the Resolved scales, her scores are especially strong in Active Research, Focused Thought, and Participation and Helping; while being quite strong in Working through Emotions and Broad Perspectives; moderate in Positive Emotions; and somewhat lower in Self-Help Routines. It shows that on the Unresolved scales, she rates herself as feeling quite Overwhelmed, somewhat Confused, and somewhat Depressed; while scoring nicely low on the other Unresolved scales of Angry, Unconcerned, Resistant, and Negative Distortions. She shows a moderate score on Positive Distortions.

### Item Scores

Table 16 above shows the scoring sheet with the parent's ratings on each of the actual items, which may then be looked at for more specificity. It can help to pinpoint the items with especially high or low ratings. For example, on

the Resolved items, this parent gave her highest ratings of 5 "Very much like me" on five items, with two items in Active Research ("I sought answers immediately when I realized that my child was having problems" and "When my child was diagnosed with autism I researched everything I could"), two items in Focused Thought ("It is important for me to have information about autism" and "I think it is important for me to acknowledge my success in helping my child"), and one item in Participation and Helping ("I work with all the professionals in my child's life to understand my child's changing needs").

For all the Resolved items, this parent gave item ratings in the upper part of the rating scale between 3 and 5, except for two items. She gave lower ratings of 2 "Slightly like me" to two items, which were in the Self-Help Routines domain ("I schedule special times to relax, rejuvenate, and restore my well-being" and "I have supportive phrases I tell myself that help me get through each day").

On the Unresolved items, this parent gave high ratings of 5 "Very much like me" to three items, and ratings of 4 "Much like me" to four items. Unresolved items with high ratings can be viewed to pinpoint specific areas that seem especially problematic for the parent. For example, in the Emotionally Overwhelmed scale, this parent gave a 5 to "I worry about other people judging me as a parent of a child with autism", and she gave ratings of 4 to "I feel that I am in a continual state of crisis" and "I am overwhelmed when caring for my child". In the Confused Feelings scale, she gave a 5 to "Sometimes I think everything will be okay and then it just becomes too much to handle" and a 4 to "I just cannot get myself organized and focused enough to help my child", while giving low ratings to the other two items on confusion in discussing autism and confusion in knowing what to do. In the

Depressed Feelings scale, she gave a 5 to “I feel isolated and alone since my child’s diagnosis” and gave a 4 to “I am stuck in sadness about my child having autism”, while giving low ratings to the other two items about feeling hopeless and powerless. These responses indicate that this parent is feeling alone and sad about her child’s autism, but she is not feeling hopeless or powerless.

In the separate Positive Distortions scale she gave a 5 to “I believe my child’s brilliance will make a huge difference in the world someday”, indicating hope for her child’s future.

### **Services Worksheet**

This parent’s item responses and scale scores can next be used to fill out the Services Worksheet, identifying her strengths and also identifying possible services that may be of help to her.

EXAMPLE PRADS-2 SERVICES WORKSHEET Parent ID 070

This worksheet helps to compile suggested services to discuss with the parent. In these **Resolved** domains, services would especially benefit a parent who scores **low** (around 1-2) in a scale, or in a specific item in the scale. For scales with medium scores (around 3), ask the parent whether they may value services in this area. For Resolved scales with higher scores (around 4-5), be sure to point these out to the parent as areas of strength.

Total Resolved Score: 3.86

**Resolved Domains**

**Notes and Possible Services**

<p><b>1. Positive Feelings</b></p> <p>Score: <u>3.50</u></p> <p><input checked="" type="checkbox"/> Fine (4-5) <input type="checkbox"/> Possible Services</p>	<p>- <i>Fine</i></p> <p>- <i>Listen and share in her positive feelings about herself and her child</i></p>
<p><b>2. Working through Emotions</b></p> <p>Score: <u>3.75</u></p> <p><input checked="" type="checkbox"/> Fine (4-5) <input type="checkbox"/> Possible Services</p>	<p>- <i>Strength</i></p> <p>- <i>Listen, respect, and reflect on how she has been acknowledging, sharing, and coping with her emotions</i></p>
<p><b>3. Active Research</b></p> <p>Score: <u>4.50</u></p> <p><input checked="" type="checkbox"/> Fine (4-5) <input type="checkbox"/> Possible Services</p>	<p>- <i>Strength</i></p> <p>- <i>Praise her active and continuing research on autism and treatment</i></p> <p>- <i>She may value further current, specific, and advanced information</i></p>

EXAMPLE PRADS-2 SERVICES WORKSHEET

Resolved Domains	Notes and Possible Services
<p><b>4. Participation and Helping</b></p> <p>Score: <u>4.25</u></p> <p><input checked="" type="checkbox"/> Fine (4-5) <input type="checkbox"/> Possible Services</p>	<p><i>- Strength</i></p> <ul style="list-style-type: none"><li><i>- May value further parent training classes</i></li><li><i>- May value more behavioral skills training</i></li><li><i>- Express appreciation for her valuable participation in her child's programs</i></li></ul>
<p><b>5. Self-Help Routines</b></p> <p>Score: <u>2.75</u></p> <p><input type="checkbox"/> Fine (4-5) <input checked="" type="checkbox"/> Possible Services</p>	<ul style="list-style-type: none"><li><i>- Help schedule respite times</i></li><li><i>- Arrange support system with extended family and friends</i></li><li><i>- Cognitive behavioral supports, relaxation, mindfulness, self-compassion</i></li><li><i>- Encourage engaging in her own enjoyable activities</i></li></ul>
<p><b>6. Broad Perspectives</b></p> <p>Score: <u>3.75</u></p> <p><input checked="" type="checkbox"/> Fine (4-5) <input type="checkbox"/> Possible Services</p>	<p><i>- Strength</i></p> <ul style="list-style-type: none"><li><i>- Express respect for her positive views of her child in relation to the family and the future</i></li></ul>
<p><b>7. Focused Thought</b></p> <p>Score: <u>4.50</u></p> <p><input checked="" type="checkbox"/> Fine (4-5) <input type="checkbox"/> Possible Services</p>	<p><i>- Strength</i></p> <ul style="list-style-type: none"><li><i>- Praise her daily planning, her focus on learning about autism and helping her child, and noting her own successes</i></li></ul>

**EXAMPLE PRADS-2 SERVICES WORKSHEET**

This worksheet helps to compile suggested services to discuss with the parent. In these **Unresolved** domains, services would especially benefit a parent who scores **high** (around 4-5) in a domain, or in a specific item in a domain. For domains with medium scores (around 3), ask the parent whether they may value services in this area. For Unresolved domains with lower scores (around 1-2), be sure to point these out to the parent as areas of strength.

Total Unresolved Score: 2.18

**Unresolved Domains**

**Notes and Possible Services**

<p><b>8. Emotionally Overwhelmed</b></p> <p>Score: <u>3.75</u></p> <p><input type="checkbox"/> Fine (1-2)</p> <p><input checked="" type="checkbox"/> Possible Services</p>	<p><i>- Feeling in crisis and overwhelmed - assure natural feelings, offer coping strategies</i></p> <p><i>- Worrying about others judging her - parent support group, assertive responses</i></p> <p><i>- Listen and allow parent to express emotions</i></p> <p><i>- Set up backup support list and routines for coping when feeling overwhelmed</i></p>
<p><b>9. Angry Feelings</b></p> <p>Score: <u>1.25</u></p> <p><input checked="" type="checkbox"/> Fine (1-2)</p> <p><input type="checkbox"/> Possible Services</p>	<p><i>- Fine</i></p> <p><i>- Praise her for her positive view of others in relation to her child</i></p>
<p><b>10. Depressed Feelings</b></p> <p>Score: <u>3.00</u></p> <p><input type="checkbox"/> Fine (1-2)</p> <p><input checked="" type="checkbox"/> Possible Services</p>	<p><i>- Items show she is feeling sad and alone, but is not feeling helpless or powerless</i></p> <p><i>- Note natural sadness for her child's situation, not same as overall depression</i></p> <p><i>- Parent support group for feeling less alone and for sharing coping strategies</i></p> <p><i>- Can express grief with me, parent group, or professional counselor</i></p>

EXAMPLE PRADS-2 SERVICES WORKSHEET

Unresolved Domains

Notes and Possible Services

<p><b>11. Confused Feelings</b></p> <p>Score: <u>3.25</u></p> <p><input type="checkbox"/> Fine (1-2)</p> <p><input checked="" type="checkbox"/> Possible Services</p>	<p><i>- Assure feeling confused is natural for a parent juggling many tasks at once</i></p> <p><i>- Offer clear information, encourage questions, parent training</i></p> <p><i>- Help create and post reliable schedules for events and activities</i></p> <p><i>- Help create a backup support list of family and friends</i></p>
<p><b>12. Neutralizing Unconcerned</b></p> <p>Score: <u>1.25</u></p> <p><input checked="" type="checkbox"/> Fine (1-2)</p> <p><input type="checkbox"/> Possible Services</p>	<p><i>- Fine</i></p> <p><i>- Praise her for her care and commitment</i></p>
<p><b>13. Neutralizing Resistant</b></p> <p>Score: <u>1.00</u></p> <p><input checked="" type="checkbox"/> Fine (1-2)</p> <p><input type="checkbox"/> Possible Services</p>	<p><i>- Fine</i></p> <p><i>- Praise her for affirming her parenting role</i></p>
<p><b>14. Negative Distortions</b></p> <p>Score: <u>1.75</u></p> <p><input checked="" type="checkbox"/> Fine (1-2)</p> <p><input type="checkbox"/> Possible Services</p>	<p><i>- Fine</i></p> <p><i>- Praise her for her constructive viewpoints</i></p>

**EXAMPLE PRADS-2 SERVICES WORKSHEET**

The **Positive Distortions** domain is separate from the other domains. This domain correlates positively with Resolution rather than Nonresolution. It represents the parent's hope for their child's future. You may acknowledge and respect the parent's views in this domain (from 1-5), and express realistic hope for the child. However, if the parent expresses specific concerns relating to this area, then you may discuss services that may be of help to the parent.

**Positive Distortions Domain**

**Notes and Possible Services**

<p><b>15. Positive Distortions</b></p> <p>Score: <u>2.75</u></p> <p><input checked="" type="checkbox"/> Fine (1-5) <input type="checkbox"/> Possible Services</p>	<p><i>-Fine</i> <i>- Show respect for her views in this domain, and for her hopefulness for her child's future</i></p>
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**Additional Notes and Available Services:**

*\* See the next written section which elaborates upon the possible services for this Example Parent.*

\_\_\_\_\_ Parent's Initials

\_\_\_\_\_ Service Coordinator's Initials

\_\_\_\_\_ Date



## IDENTIFYING SERVICES FOR THIS EXAMPLE PARENT

The individual parent's scores can indicate specific types of services that could be especially helpful for that parent, based upon the parent's specific strengths and difficulties. These indicated services will vary depending upon the individual parent's scores.

For example, Parent #070 shows strengths in active research, participation and helping, and focused thought. This parent is especially likely to value learning about additional ongoing sources of **current information** about autism, as well as **specific information** about her child's condition, therapy, and progress. Because she values an active approach, she may appreciate **parent training classes** that use **behavioral skills training** to help her actively practice and further develop her skills in teaching and parenting her child. Therapists who are working with her child could provide her with specific information about her child's current skills programs and **invite her participation** in planning and carrying out the programs. This parent is also especially likely to value **positive feedback** that can help her pinpoint and acknowledge her successes in parenting her child.

This parent scores in the upper part of the scale on all the resolved domains, except for scoring lower on her use of self-help routines. As a caregiver, she may benefit from regularly scheduled **respite times**, when she can have some rest, know her child is being well cared for, and engage in her own activities. She may also be coached in **assertively requesting help** from other adult family members or trusted friends when she is feeling overwhelmed with parenting duties. She may find **relaxation training, mindfulness exercises**, or other **cognitive-behavioral supports** helpful in enhancing her personal feelings of well-being and ability to cope with the challenges of caregiving. She can also be encouraged to schedule times to engage in

physical, social, or creative endeavors that are especially **enjoyable activities** for her.

On the unresolved scales, this parent rates herself as feeling quite overwhelmed, somewhat confused, and somewhat depressed, while scoring low on the four other unresolved scales. She gives high ratings to the item on worrying about other people judging her as a parent of a child with autism, and to the item on feeling isolated and alone since her child's diagnosis. These are common concerns that parents have expressed after receiving their child's diagnosis. A local **parent support group** could be especially valuable for this parent. It can allow her to realize that she is not alone and isolated. The group members can discuss their difficulties and share their strategies for dealing with them. These strategies can include how they cope when feeling that others may be judging them. As a member of the group, this parent can receive social support from others, and she may in turn come to use her areas of strengths to provide social support to others in the group.

This parent gives a high rating to the item on sometimes thinking everything will be okay and then having it become too much to handle, and moderately high ratings to the items on feeling in a continual state of crisis, on feeling overwhelmed when caring for her child, and on not feeling organized and focused enough to help her child. These are common and understandable experiences of parents who need to be juggling all the tasks of providing highly effortful continuing care for their child with a serious diagnosis. This parent may value suggestions for creating and posting **reliable schedules** for her family's daily activities. Even with reliable schedules, unexpected events will come up. She may appreciate brainstorming with her service provider and family about how to prepare for and cope with overwhelming or confusing situations that require handling multiple tasks at once. For example, she

could assertively ask adult relatives or trusted friends whether and when they might be available to assist if needed, and then keep a secure **backup support list** of their names, available times, and contact information. For **predictable scheduling**, she could request that therapists working with her child notify her well in advance if they need to cancel or change a session time. She could be coached in practicing **calming techniques**, such as deep breathing, focused thoughts, or supportive phrases, so that she can use her favorite calming techniques when coping with overwhelming situations as they occur.

On the depressed feelings items, this parent indicates that she is feeling alone and sad about her child's autism, but that she is not feeling hopeless or powerless. It is very understandable and natural for parents to feel sad about their child's serious diagnosis and challenges. It is important to reassure this parent that the depressed feelings scale only measures some feelings of parents about their child's condition, and it is not designed in any way to lead to diagnosing a parent as having depression. Furthermore, this parent's other item ratings give no indication that she might be depressed. It can be comforting for the parent to **acknowledge and express** her feelings of grief to others, who can listen respectfully and give social support, so that she can work through her emotions while feeling that she is not alone. Individuals who may provide support for her could include trusted friends or relatives, other parents in a **parent support group**, or a **professional counselor**.

In the separate positive distortions scale, this parent earned a moderate score, and she gave a high rating to the item on believing her child's brilliance will make a huge difference in the world someday, indicating her hope for her child's future. Since the positive distortions scale correlates positively with total resolution, it is most supportive to **show respect** for parents' hopefulness for their child's future.

### Further Parent Information

In identifying services that may be beneficial for an individual parent, it can also be helpful to consider other information gathered about the parent and child as well. For example, in filling out a demographic section that preceded the survey, this parent responded that her child was receiving six hours of behavioral services per week, and on a 1-5 satisfaction scale, she gave this a rating of 4 "*Mostly satisfied*". The parent also responded that her child was not receiving adequate support services at school, and on the 1-5 scale, she gave school services a rating of 1 "*Not at all satisfied*". This parent may appreciate having **parent advocacy** to aid in meeting with school staff, arranging for assessment, developing and agreeing upon an **individual education plan**, and implementing any needed **school support services** for her child.

It is also helpful for the service provider to consider the **family ecology** in identifying needed services. For example, in filling out the demographic section preceding the survey, this parent responded that she is living with a partner. It may be helpful to invite her adult partner to fill out the survey to learn about the partner's viewpoints, and to consider ways that the two caregivers could **coordinate their support** for their child.

The parent also responded that she has two children, which include her daughter with autism and a sibling. This sibling may appreciate being offered specific **sibling training and supports**.

At the end of the survey, the parent wrote that she would like to have more research-based information about girls with autism and puberty. She may appreciate help in exploring the best **internet resources** on these topics, as well as exploring relevant **community resources** for girls near her daughter's age.

## Chapter 13

### SUMMARY AND CONCLUSIONS

We developed the PRADS-2 measure from a database where 137 parents responded to 214 items relating to their responses to raising a child with autism. We used multivariate statistics to develop the scales, and to determine that the PRADS-2 shows evidence of scale reliability, response validity, content validity, convergent validity, concurrent validity, discriminant validity, face validity, and representational validity.

The PRADS-2 measure is designed to provide a profile of 15 facets of the parent's responses to their child's diagnosis, which can be used to identify possible supports and services of benefit to the family. The PRADS-2 is a comprehensive measure which is sensitive to the many aspects of the parent's experiences, and which are reflected in the graphed profile of the parent's scores on each of the 15 domain scales.

As a measure of parent resolution, the PRADS-2 is a useful tool for researchers interested in parent responses to raising a child with autism, and for service providers working with families of a child with autism. The PRADS-2 meets the psychometric and ethical standards for tests as outlined in the *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 2014).

In addition to the Parent Reaction to Autism Diagnosis Scale (PRADS-2), we are also including the Parent Reaction to Diagnosis Scale (PRDS-2), a more general measure that can be used with parents of a child with any diagnosis. It has the same wording as the PRADS-2, except that the words relating to autism are replaced with more general terms.

Our goal in creating this manual is for the professional to consider how our measures may

be used accurately, ethically, and effectively for the benefit of parents and families.

#### The Need to Evaluate Parent Resolution

Why evaluate for parent resolution? When a child is diagnosed with a disability or medical issue, the whole family is affected. Parent responses to the diagnosis also impact the family system. A restructuring of the family dynamic is needed to successfully provide the child with a foundation to help expand the child's potential. This adjustment includes various aspects of resolution, resulting in modifications to the family dynamic in order to support the child and other family members.

The PRADS-2 measure contributes to an understanding of the individual parent. It provides a quick and systematic assessment of important aspects of a parent's experience. It allows for rapid development of empathy and compassion, allows for supportive feedback to the parent, and allows for selecting optimal services that will fit with the family's strengths and concerns.

Resolution is a fluid process, where a parent can have positive experiences in raising their child, and still experience one or more phases of distress at any time, and possibly many times throughout their lifetime. As a child grows older and their needs change and grow more complex, supports may need to be adjusted, and a parent can again experience a degree of distress. When a child's needs change, the parent can become overwhelmed with emotions, experience confusion, or feel defeated about learning new information needed to help their child, thus requiring further support in making adjustments that will benefit their child and family.

Use of the PRADS-2 measure creates a faceted view of parent resolution to aid in the understanding of the parent's response to their child's diagnosis. This information is transferred onto a profile graph and services page, aiding professionals and service providers in helping parents identify possible beneficial supports. The measure can be used at initial intake, and it can be re-administered as parents' responses change and the family supports need modifying.

### **Applications of the PRADS-2**

For researchers, the PRADS-2 can provide valuable information in a study with a group of participants, and also in single-subject research. It is easily scored and can provide aggregate data for the group. When using interviews as part of a study, the PRADS-2 can help researchers with pinpointing areas of strength and areas of difficulty for the participants, which can aid in subsequent observations or interview processes. The researcher has objective information to aid in further exploring parent responses to raising their child.

Researchers may evaluate the benefits of using, versus not using, the PRADS-2 with parents. They may also correlate the PRADS-2 scores with other variables of interest. And they may compare the PRADS-2 scores before and after specific interventions they wish to evaluate. Thus, the PRADS-2 can be used as an independent variable, correlated variable, or dependent variable, depending on the research design.

Professionals who work with families can use the PRADS-2 to identify areas of strength and areas of difficulty, and to help the family connect with possible beneficial services. The administration and scoring of the PRADS-2 should be done by a professional who has understanding in using assessments, is familiar with scoring procedures, and has knowledge of client's rights and the ethical standards for assessments.

The PRADS-2 should only be administered by someone who has read the manual thoroughly, so that the person using the PRADS-2 has a clear understanding of how to administer and score the measure, and how to use the resulting profile to work with the parent to identify suitable supports and services.

Proper use of the PRADS-2 can also include connecting families with mental health professionals when the parent also feels it is warranted, so anyone making these types of referrals should be qualified to discuss them with the parent. Persons who administer and score the PRADS-2 should have a practical knowledge of the services available in the community, as well as any other types of supports which might benefit the parent and family.

### **Conclusions**

Resolution involves a reorganization of mental, emotional, and behavioral patterns, along with developing stronger knowledge, confidence, and skills. For a parent of a child with a disability, resolution involves becoming more knowledgeable, confident, and skilled in coping with the complex and changing requirements of raising their child.

Throughout our manual, we have given users the information on how to ethically administer and score the PRADS-2, and how the information gained can be used to tailor supports for parents and families.

Our research for the PRADS-2 has shown it to be a psychometrically sound measure. It is our goal to assist researchers in measuring facets of resolution while exploring parent responses in raising a child with special needs. It is also our goal to assist professionals in helping families identify supports and services of benefit to the individual parents as they raise their child with special needs.

We hope these measures can be beneficial in your research or service work. If you have further questions or comments about these measures, we invite you to contact us.

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APA Reference Format for our manual:

- Brewer, K. A., & Gruber, M. B. (2022). *Professional manual for the Parent Reaction to Autism Diagnosis Scales (PRADS-2) with guidance for tailoring parent supports*. Arcata, CA: The Press at Cal Poly Humboldt. Available at <https://digitalcommons.humboldt.edu/textbooks/7/>

**APPENDIX A**

**Professional User Packet  
for the  
Parent Reaction to Autism Diagnosis Scales  
(PRADS-2)  
with  
Guidance for Tailoring Parent Supports**

**Kathleen A. Brewer, M.A.  
Mary B. Gruber, Ph.D., BCBA-D**

**The Press at Cal Poly Humboldt**



**Appendix A**  
**Parent Reaction to Autism Diagnosis Scales (PRADS-2)**  
**Professional User Packet**

This packet for the PRADS-2 measure provides the following materials:

Parent Intake Form

Parent Rights and Informed Consent

PRADS-2 Measure

PRADS-2 Scoring for Researchers

PRADS-2 Scoring Sheet for Individual Parent

Profile Graph Form

Summary of Tailored Supports

Services Worksheet

Summary of Steps for the Follow-Up Interview

This packet is to be used in accordance with our manual:

Brewer, K. A., & Gruber, M. B. (2022). *Professional manual for the Parent Reaction to Autism Diagnosis Scales (PRADS-2) with guidance for tailoring parent supports*. Arcata, CA: The Press at Cal Poly Humboldt. Available at <https://digitalcommons.humboldt.edu/textbooks/7/>

Parent ID Number \_\_\_\_\_

Date \_\_\_\_\_

**PRADS-2**  
**Parent Intake Form**

Parent name \_\_\_\_\_

Child's name \_\_\_\_\_

Child's date of birth \_\_\_\_\_

Age child was diagnosed \_\_\_\_\_

Child's diagnosis \_\_\_\_\_

Notes:

Parent ID Number \_\_\_\_\_

Date \_\_\_\_\_

## PRADS-2

### Parent Rights and Informed Consent

The purpose of this survey is to learn about your reactions to your child's diagnosis. It will aid in identifying supports and services that may be helpful to you and other parents as they raise their child with autism.

All of the items in this survey are statements made by parents about their own experiences in raising their child with autism. You are asked to rate how much each statement relates to your own experiences as a parent raising your child.

This survey measures aspects of parent experiences that can indicate parenting strengths and possible difficulties when raising a child with a disability. It gives information that can assist in understanding parents' experiences and needs in raising their children with autism.

All information gathered from this survey is confidential. It will not be shared with anyone else without specific written permission from you. You have the right to determine how and with whom this information can be shared. The completed survey and assessment will be kept confidential, and the information will be held for up to \_\_\_ years.

Raising a child with autism is challenging. If at any time answering these questions becomes too stressful, you have the right to stop answering the items, or you can set the survey aside and may continue filling it out at a later time. Not completing this survey will not affect your family's rights to services. You are free to decline to answer this survey or any question you do not wish to answer for any reason.

This survey typically takes about 20 to 30 minutes. However, it is not timed, and you may take as long as you like. There are no right or wrong answers. Please try to fill out the form completely, as this will give a more comprehensive understanding of what types of services may be helpful to support you as you parent your child.

If you are willing to respond to this survey, you may sign with your consent below.

Parent Signature \_\_\_\_\_

Date \_\_\_\_\_

Parent ID \_\_\_\_\_ Date \_\_\_\_\_

## Parent Reaction to Autism Diagnosis Scales (PRADS-2)

Kathleen A. Brewer, M.A., and Mary B. Gruber, Ph.D., BCBA-D

Below are various statements that some parents of children with autism have said about their experiences raising their child. Please circle the degree to which each statement currently applies to your own experiences as a parent raising your child with autism. The statements are listed in a random order.

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me
	1	2	3	4	5
1. I feel a strong emotional connection to my child with autism.	1	2	3	4	5
2. I really believe that my child's diagnosis is incorrect.	1	2	3	4	5
3. I sought answers immediately when I realized that my child was having problems.	1	2	3	4	5
4. I worked through a lot of emotions about my child's diagnosis.	1	2	3	4	5
5. It is important to me that someone be held responsible for my child's having autism.	1	2	3	4	5
6. I actively participate in interventions and programs for my child.	1	2	3	4	5
7. My child's having autism has been a wonderful blessing for our family.	1	2	3	4	5
8. Sometimes I think everything will be okay and then it just becomes too much to handle.	1	2	3	4	5
9. Every day I experience the same overwhelming emotions I had when my child received a diagnosis.	1	2	3	4	5
10. I schedule special time for myself to relax, rejuvenate, and restore my well-being.	1	2	3	4	5
11. I am stuck in sadness about my child having autism.	1	2	3	4	5
12. I believe that the more I plan for the possibilities of each day, the more prepared I am to help my child.	1	2	3	4	5
13. I have never felt strong emotions about my child's diagnosis of autism.	1	2	3	4	5
14. I think my child makes a positive contribution to our family.	1	2	3	4	5

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me
	1	2	3	4	5
15. Since receiving the diagnosis, I feel that I am the only one who can help my child.	1	2	3	4	5
16. Without my child having a diagnosis of autism, my life would not have a purpose.	1	2	3	4	5
17. Someone else noticed my child was having problems before I did and told me.	1	2	3	4	5
18. When my child was diagnosed with autism, I researched everything I could.	1	2	3	4	5
19. I worry about other people judging me as a parent of a child with autism.	1	2	3	4	5
20. Being able to express myself and talk to others about my emotions helps me to cope with my child's autism.	1	2	3	4	5
21. I do not have much hope for my child's future.	1	2	3	4	5
22. I have created routines that help me to meet my child's needs.	1	2	3	4	5
23. I get so confused and at a loss when I try to talk about my child's autism.	1	2	3	4	5
24. I continue to do what I have to do to help my child each day.	1	2	3	4	5
25. I blame myself for causing my child's autism.	1	2	3	4	5
26. My child's diagnosis of autism has never bothered me.	1	2	3	4	5
27. I am angry with the professionals who diagnosed my child's autism.	1	2	3	4	5
28. Observing what my child does helps me to understand my child better.	1	2	3	4	5
29. I stay focused on learning everything I can about autism to help me support my child.	1	2	3	4	5
30. I feel more positive now about my child's diagnosis of autism.	1	2	3	4	5
31. My child was given autism to help me with my own personal growth.	1	2	3	4	5
32. I waited to get my child diagnosed because I did not think there was a problem.	1	2	3	4	5
33. I feel that by addressing my emotions after my child's diagnosis, I am better able to support my child.	1	2	3	4	5
34. I am so confused about autism that I don't know what to do to help my child.	1	2	3	4	5

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me
	1	2	3	4	5
35. I work with all the professionals in my child's life to understand my child's changing needs.	1	2	3	4	5
36. I feel isolated and alone since my child's diagnosis.	1	2	3	4	5
37. I try to stay current with new interventions so that I can actively help my child.	1	2	3	4	5
38. I have created self-help routines to help me get through my day.	1	2	3	4	5
39. I feel that my child's autism has been harder for me as the parent than for my child.	1	2	3	4	5
40. Thinking positively about my child's future helps me to help my child.	1	2	3	4	5
41. I feel that I am in a continual state of crisis.	1	2	3	4	5
42. I want others to be as angry as I am about my child's situation.	1	2	3	4	5
43. It is important for me to have information about my autism.	1	2	3	4	5
44. I feel I don't need to do anything more to help my child.	1	2	3	4	5
45. I am proud of myself for how well I am helping my child.	1	2	3	4	5
46. I felt a need to grieve after my child's diagnosis.	1	2	3	4	5
47. I am overwhelmed when caring for my child.	1	2	3	4	5
48. It is important that I actively participate in helping my child make progress.	1	2	3	4	5
49. I feel powerless to help my child.	1	2	3	4	5
50. I believe my child's brilliance will make a huge difference in the world someday.	1	2	3	4	5
51. I feel that everything about my child's autism is negative.	1	2	3	4	5
52. I think it is important for me to acknowledge my success in helping my child.	1	2	3	4	5
53. I avoid thinking about my child's autism.	1	2	3	4	5
54. I just cannot get myself organized and focused enough to help my child.	1	2	3	4	5

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me
	1	2	3	4	5
55. My personal beliefs have helped me to come to terms with my child's diagnosis.	1	2	3	4	5
56. I believe my child's diagnosis has had no effect on our family.	1	2	3	4	5
57. I take charge of getting my child appropriate services.	1	2	3	4	5
58. I am constantly angry that my child has autism.	1	2	3	4	5
59. I have supportive phrases I tell myself that help me get through each day.	1	2	3	4	5
60. I have found joy in raising my child.	1	2	3	4	5

Thank you for filling out this survey.

If you have any further comments, you may write them here:

## **INSTRUCTIONS FOR SCORING THE PRADS-2 SCALES**

### **FOR RESEARCHERS**

Kathleen A. Brewer, M.A., and Mary B. Gruber, Ph.D., BCBA-D

California State Polytechnic University Humboldt

For a scale score, we add the respondent's ratings on each of the items in the scale, and then divide by the number of items in the scale, keeping two digits past the decimal point. This gives the parent's average rating on the scale items. It also expresses the scale score on the same 1-5 scale as the original rating scale, thus facilitating interpretation.

The item numbers for each of the Resolved scales are listed below:

Positive Feelings:	Items 1, 30, 45, and 60.
Working through Emotions:	Items 4, 20, 33, and 46.
Active Research:	Items 3, 18, 37, and 57.
Participation and Helping:	Items 6, 24, 35, and 48.
Self-Help Routines:	Items 10, 22, 38, and 59.
Broad Perspectives:	Items 14, 28, 40, and 55.
Focused Thought:	Items 12, 29, 43, and 52.

The item numbers for each of the Unresolved scales are listed below:

Emotionally Overwhelmed:	Items 9, 19, 41, and 47.
Angry Feelings:	Items 5, 27, 42, and 58.
Depressed Feelings:	Items 11, 21, 36, and 49.
Confused Feelings:	Items 8, 23, 34, and 54.
Neutralizing Unconcerned:	Items 13, 26, 44, and 56.
Neutralizing Resistant:	Items 2, 17, 32, and 53.
Negative Distortions:	Items 15, 25, 39, and 51.

The item numbers for the Positive Distortions scale are listed below:

Positive Distortions:	Items 7, 16, 31, and 50.
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For each scale score, we add the respondent's ratings on each of the four items in that scale, and then divide by four, keeping two digits past the decimal point.

For the Resolved Total score, we add the respondent's scores on each of the seven Resolved scale scores, and then divide by seven, rounding to two digits past the decimal point.

For the Unresolved Total score, we add the respondent's scores on each of the seven Unresolved scale scores, and then divide by seven, rounding to two digits past the decimal point.



As a researcher, you can enter the item responses for each parent into your data file. Then you can enter the computing commands in the format used by your statistical program, resulting in the scale scores for each parent being computed and added into your data file.

If not all of the items in a scale were answered, and you are conducting research with a group of parents, the most conservative and stable treatment of missing responses is to substitute the group's item mean for that parent's missing item, prior to calculating the scale and total scores.

If not all of the items in a scale were answered, and you are working with just one parent at the time, the parent's scale score is best calculated via prorating, by adding the parent's ratings on the answered items, and then dividing by the number of answered items.

We hope these measures can be beneficial in your research or service work.

## SCORING SHEET FOR THE PRADS-2 SCALES

### FOR AN INDIVIDUAL PARENT

**Parent ID:** \_\_\_\_\_

For a scale score, we enter and add the parent's ratings on each of the items in the scale, and then divide by the number of answered items in the scale, keeping two digits past the decimal point. This gives the parent's average rating on the scale items. It also expresses the scale score on the same 1-5 scale as the original rating scale, thus facilitating interpretation.

#### **RESOLVED Feeling-Oriented Scales:**

##### **1. Positive Feelings Scale:**

- \_\_\_\_\_ Item 1. I feel a strong emotional connection with my child.  
\_\_\_\_\_ Item 30. I feel more positive now about my child's diagnosis of autism.  
\_\_\_\_\_ Item 45. I am proud of myself for how well I am helping my child.  
\_\_\_\_\_ Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

##### **2. Working through Emotions Scale:**

- \_\_\_\_\_ Item 4. I worked through a lot of emotions about my child's diagnosis.  
\_\_\_\_\_ Item 20. Being able to express myself and talk to others about my emotions helps me to cope with my child's autism.  
\_\_\_\_\_ Item 33. I feel that by addressing my emotions after my child's diagnosis, I am better able to support my child.  
\_\_\_\_\_ Item 46. I felt a need to grieve after my child's diagnosis.

$$\text{Working through Emotions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**RESOLVED Action-Oriented Scales:**

**3. Active Research Scale:**

- \_\_\_\_\_ Item 3. I sought answers immediately when I realized that my child was having problems.  
\_\_\_\_\_ Item 18. When my child was diagnosed with autism, I researched everything I could.  
\_\_\_\_\_ Item 37. I try to stay current with new interventions so that I can actively help my child.  
\_\_\_\_\_ Item 57. I take charge of getting my child appropriate services.

$$\text{Active Research Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**4. Participation and Helping Scale:**

- \_\_\_\_\_ Item 6. I actively participate in interventions and programs for my child.  
\_\_\_\_\_ Item 24. I continue to do what I have to do to help my child every day.  
\_\_\_\_\_ Item 35. I work with all the professionals in my child's life to understand my child's changing needs.  
\_\_\_\_\_ Item 48. It is important that I actively participate in helping my child make progress.

$$\text{Participation and Helping Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**5. Self-Help Routines Scale:**

- \_\_\_\_\_ Item 10. I schedule special time for myself to relax, rejuvenate, and restore my well-being.  
\_\_\_\_\_ Item 22. I have created routines that help me to meet my child's needs.  
\_\_\_\_\_ Item 38. I have created self-help routines to help me get through my day.  
\_\_\_\_\_ Item 59. I have supportive phrases I tell myself that help me get through each day.

$$\text{Self-Help Routines Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**RESOLVED Thinking-Oriented Scales:**

**6. Broad Perspectives Scale:**

- \_\_\_\_\_ Item 14. I think my child makes a positive contribution to our family.  
 \_\_\_\_\_ Item 28. Observing what my child does helps me to understand my child better.  
 \_\_\_\_\_ Item 40. Thinking positively about my child's future helps me to help my child.  
 \_\_\_\_\_ Item 55. My personal beliefs have helped me to come to terms with my child's diagnosis.

$$\text{Broad Perspectives Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**7. Focused Thought Scale:**

- \_\_\_\_\_ Item 12. I believe that the more I plan for the possibilities of each day, the more prepared I am to help my child.  
 \_\_\_\_\_ Item 29. I stay focused on learning everything I can about autism to help me support my child.  
 \_\_\_\_\_ Item 43. It is important for me to have information about autism.  
 \_\_\_\_\_ Item 52. I think it is important for me to acknowledge my success in helping my child.

$$\text{Focused Thought Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

- Place a dot by any of the above Resolved items which the parent rated low (1 or 2).

**RESOLVED TOTAL SCORE:**

For the Resolved Total Score, we add the parent's scores on each of these seven Resolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\begin{aligned} \text{Resolved Total Score} &= \frac{(\text{PFS} + \text{WES} + \text{ARS} + \text{PHS} + \text{SRS} + \text{BPS} + \text{FTS})}{7} \\ &= \frac{(\quad + \quad + \quad + \quad + \quad + \quad)}{7} = \frac{\quad}{7} = \boxed{\quad . \quad} \end{aligned}$$

**UNRESOLVED Overwhelmed, Angry, Depressed, and Confused Scales:**

**8. Emotionally Overwhelmed Scale:**

- \_\_\_\_\_ Item 9. Every day I experience the same overwhelming emotions I had when my child received a diagnosis.
- \_\_\_\_\_ Item 19. I worry about other people judging me as a parent of a child with autism.
- \_\_\_\_\_ Item 41. I feel that I am in a continual state of crisis.
- \_\_\_\_\_ Item 47. I am overwhelmed when caring for my child.

$$\text{Emotionally Overwhelmed Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**9. Angry Feelings Scale:**

- \_\_\_\_\_ Item 5. It is important to me that someone be held responsible for my child having autism.
- \_\_\_\_\_ Item 27. I am angry with the professionals who diagnosed my child with autism.
- \_\_\_\_\_ Item 42. I want others to be as angry as I am about my child's situation.
- \_\_\_\_\_ Item 58. I am constantly angry that my child has autism.

$$\text{Angry Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**10. Depressed Feelings Scale:**

- \_\_\_\_\_ Item 11. I am stuck in sadness about my child having autism.
- \_\_\_\_\_ Item 21. I do not have much hope for my child's future.
- \_\_\_\_\_ Item 36. I feel isolated and alone since my child's diagnosis.
- \_\_\_\_\_ Item 49. I feel powerless to help my child.

$$\text{Depressed Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**11. Confused Feelings Scale:**

- \_\_\_\_\_ Item 8. Sometimes I think everything will be okay and then it just becomes too much to handle.
- \_\_\_\_\_ Item 23. I get so confused and at a loss when I try to talk about my child's autism.
- \_\_\_\_\_ Item 34. I am so confused about autism that I don't know what to do to help my child.
- \_\_\_\_\_ Item 54. I just cannot get myself organized and focused enough to help my child.

$$\text{Confused Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**UNRESOLVED Unconcerned, Resistant, and Negative Distortions Scales:**

**12. Neutralizing Unconcerned Scale:**

- \_\_\_\_\_ Item 13. I have never felt strong emotions about my child's diagnosis of autism.  
 \_\_\_\_\_ Item 26. My child's diagnosis of autism never bothered me.  
 \_\_\_\_\_ Item 44. I feel I don't need to do anything more to help my child.  
 \_\_\_\_\_ Item 56. I believe my child's diagnosis of autism has had no effect on our family.

$$\text{Neutralizing Unconcerned Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**13. Neutralizing Resistant Scale:**

- \_\_\_\_\_ Item 2. I really believe that my child's diagnosis of autism is incorrect.  
 \_\_\_\_\_ Item 17. Someone else noticed my child was having problems before I did and told me.  
 \_\_\_\_\_ Item 32. I waited to get my child diagnosed because I did not think there was a problem.  
 \_\_\_\_\_ Item 53. I avoid thinking about my child's autism.

$$\text{Neutralizing Resistant Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**14. Negative Distortions Scale:**

- \_\_\_\_\_ Item 15. Since receiving the diagnosis, I feel that I am the only one who can help my child.  
 \_\_\_\_\_ Item 25. I blame myself for causing my child's autism.  
 \_\_\_\_\_ Item 39. I feel that my child's autism has been harder for me as the parent than for my child.  
 \_\_\_\_\_ Item 51. I feel that everything about my child's autism is negative.

$$\text{Negative Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

- Place a dot by any of the above Unresolved items which the parent rated highly (4 or 5).

**UNRESOLVED TOTAL SCORE:**

For the Unresolved Total Score, we add the parent's scores on each of these seven Unresolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\begin{aligned} \text{Unresolved Total Score} &= \frac{(\text{EOS} + \text{AFS} + \text{DFS} + \text{CFS} + \text{NUS} + \text{NRS} + \text{NDS})}{7} \\ &= \frac{(\quad + \quad + \quad + \quad + \quad + \quad)}{7} = \frac{\quad}{7} = \boxed{\quad . \quad} \end{aligned}$$

**15. Positive Distortions Scale:**

The Positive Distortions Scale is calculated separately from the Resolved and Unresolved scales.

- Item 7. My child’s having autism has been a wonderful blessing for our family.
- Item 16. Without my child having a diagnosis of autism, my life would not have a purpose.
- Item 31. My child was given autism to help me with my own personal growth.
- Item 50. I believe my child’s brilliance will make a huge difference in the world someday.

$$\text{Positive Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad .}$$

**Missing Responses**

If there are some missing responses, you may remind the parent that there are no right or wrong answers to the questions, and you may encourage them to fill in their best estimate for how much each item applies to their experiences. Be careful not to suggest specific answers to the parent, however. Also, be careful to respect the parent’s choice to not answer all the items if the parent prefers this.

If there are still some missing responses, you may use prorating to calculate the parent’s scale score, by adding the parent’s ratings on the answered items, and then dividing by the number of answered items in that scale.

For example, if a parent did not answer Item 45 on the Positive Feelings scale, you may calculate a Positive Feelings scale score by adding the responses on the other three items and then dividing by three instead of four. This gives the parent’s average rating on the items that they did answer.

**Positive Feelings Scale - Example with a missing response:**

- 4   Item 1. I feel a strong emotional connection with my child.
- 3   Item 30. I feel more positive now about my child’s diagnosis of autism.
- n   Item 45. I am proud of myself for how well I am helping my child.
- 5   Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4 - 1} = \frac{12}{3} = \boxed{4.00}$$

## **GRAPHING THE PARENT'S PROFILE**

### **OF SCORES ON THE PROFILE FORM**

After calculating a parent's scale scores, you can graph the parent's profile on the profile template form, shown in Figure 2. The vertical axis shows the score values from 1 to 5. A blank column is shown above each of the 15 scale labels. Within each scale column, draw a colored line at the height of the parent's score, and write the parent's score value above the line, as shown in the example in Figure 3.



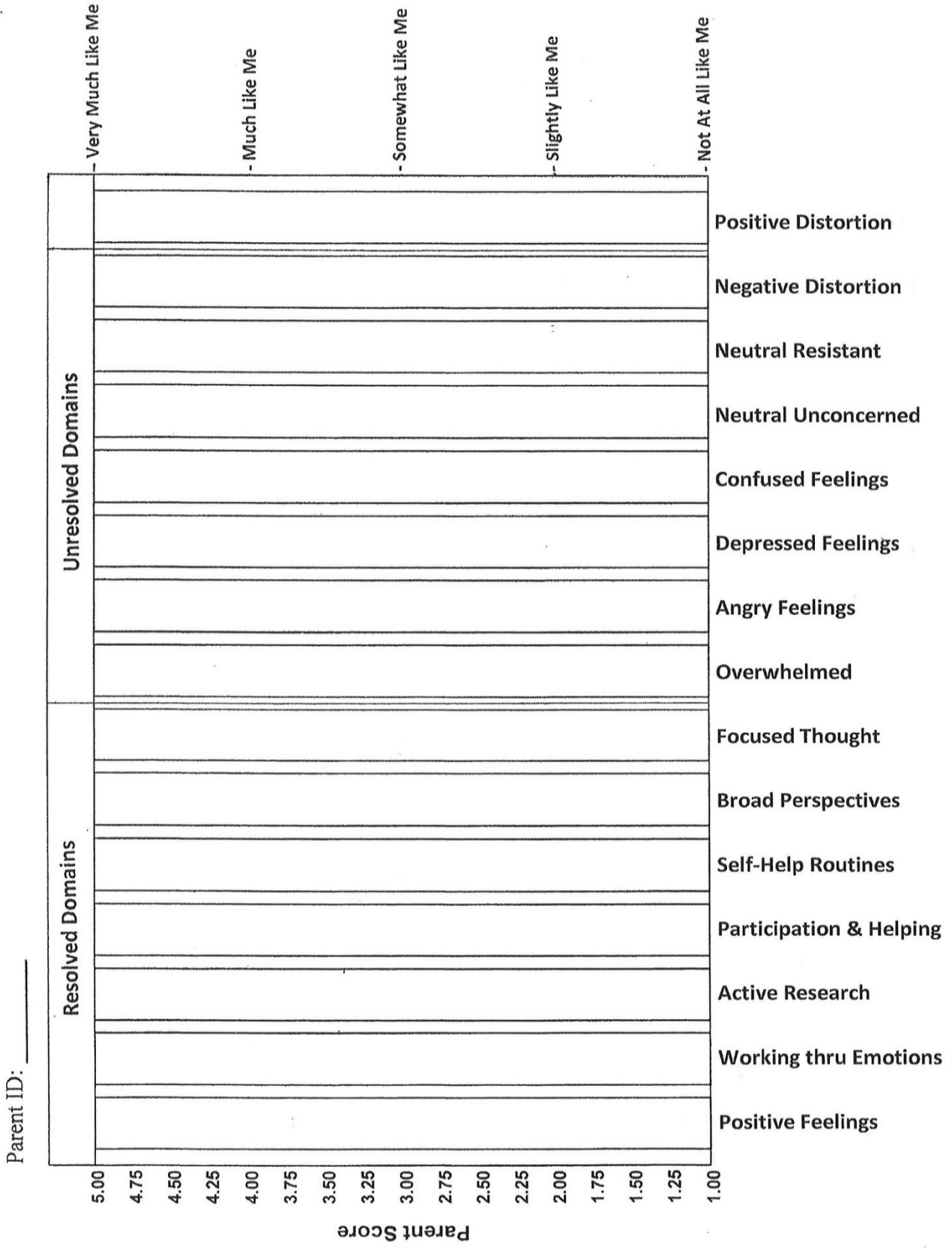


Figure 2. Profile graph form for showing the profile of scores for an individual parent.

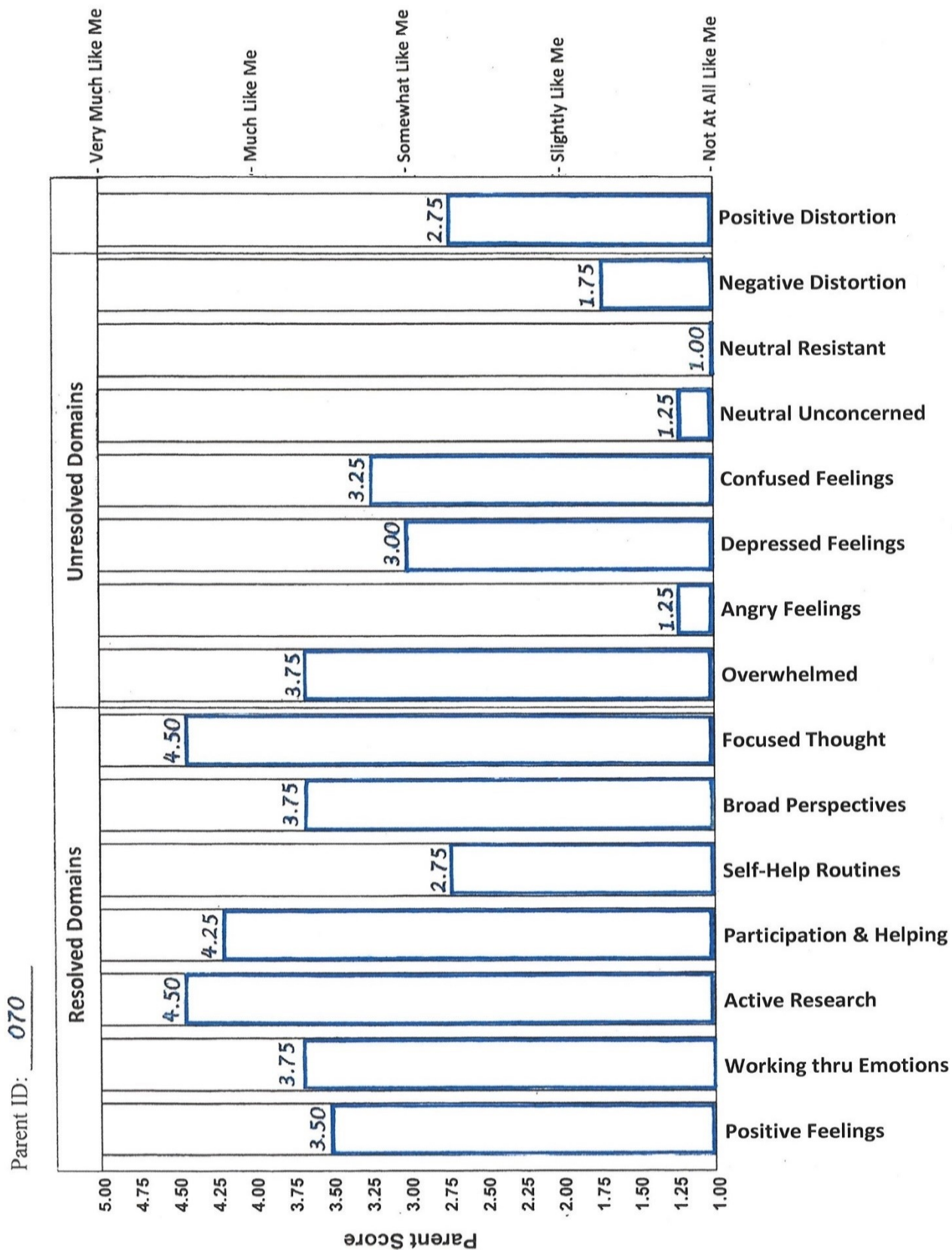


Figure 3. Profile graph form showing the profile of scores for the example Parent #070.

## **SUMMARY OF TAILORED SUPPORTS**

Here we are providing a concise summary of the tailored supports that we have discussed in relation to each of the scale scores. This summary can be a helpful reference for ideas when filling out the Services Worksheet for an individual parent.

### **RESOLVED DOMAINS:**

For **high** scores (around 4-5): Praise, reflect, and congratulate the parent on these strengths.

For **medium** scores (around 3): Ask the parent whether they may value services in this area.

For **low** scores (around 1-2): Suggest resources and services tailored to these difficulties.

#### **1. Positive Feelings**

For **high** scores: Congratulate, listen, share enjoyment.

For **low** scores: Empathize with the parent; recognize and praise positive parent actions; point out parent actions to be proud of; point out things you yourself like about the child; point out positive child progress; suggest journaling about any positive experiences with child; discuss fun activities parent and child can share together; suggest enjoyable family and community activities.

#### **2. Working through Emotions**

For **high** scores: Congratulate, listen to how they have acknowledged and coped with emotions.

For **low** scores: Listen and encourage the parent to acknowledge and express their varied emotions with you; reassure feelings of grief are natural; may suggest journaling to sort out emotions; parent support groups where parents can express emotions with other more experienced parents; may suggest individual or group grief counseling.

#### **3. Active Research**

For **high** scores: Praise and offer further current, specific, and advanced information and training.

For **low** scores: Provide information on autism that is easy to understand and relevant; graduate in time to more complex information; encourage parent questions; get parent's preferences for types of information they would like; provide resources where parent can look for additional information of interest to them.

#### **4. Participation and Helping**

For **high** scores: Praise and offer further training and inclusion in their child's treatments.

For **low** scores: Invite to participate in easy tasks first; praise and gradually raise involvement; individual or group parent training; behavioral skills training; progress to more advanced skills in evidence-based treatment; encourage parent's suggestions and participation with the therapy team; point out ways their helping contributes to their child's success.

## 5. Self-Help Routines

For **high** scores: Praise and affirm that self-care activities are important for caregivers.

For **low** scores: Affirm importance of self-care activities for caregivers; help schedule respite times; create a network of extended family or friends who can help out; provide cognitive behavioral supports, relaxation, mindfulness exercises, positive self-statements; help identify and schedule times for activities that the parent used to enjoy.

## 6. Broad Perspectives

For **high** scores: Respect the parent's positive views of their child in relation to their family, culture, beliefs, and future.

For **low** scores: Suggest positive ways the child can be included in extended family, cultural, and community activities; journaling about parent observations and understanding of their child; planning for the child's transitions into the future.

## 7. Focused Thought

For **high** scores: Praise the parent's daily planning, their focus on learning about autism and helping their child, and acknowledging their own success in helping the child.

For **low** scores: Help parent devise ways to schedule and plan for possibilities of each day, to focus on learning about autism and supporting their child, and to recognize and acknowledge their successes in parenting.

## UNRESOLVED DOMAINS:

For **high** scores (around 4-5): Suggest resources and services tailored to these difficulties.

For **medium** scores (around 3): Ask the parent whether they may value services in this area.

For **low** scores (around 1-2): Praise, reflect, and congratulate the parent on these strengths.

## 8. Emotionally Overwhelmed

For **high** scores: Listen and empathize with the parent's varying emotions; assure overwhelmed feelings are natural in parenting a child with special needs; parent support group for sharing emotions and coping strategies; practice assertive responses for when worried about others judging them; practice calming techniques; use calendar of schedules to make life more predictable; list contacts for persons they can call when overwhelmed.

For **low** scores: Acknowledge the parent's ability to manage stressors as an important strength.

## 9. Angry Feelings

For **high** scores: Listen and empathize; assure they have a highly qualified team to help them and their child; assure them that no one is responsible for causing the disability; suggest professional counseling for strong anger; any signs of possible violence or severe neglect present a mandated duty to report to child welfare services; follow up to ensure safety and family counseling.

For **low** scores: Acknowledge the parent's low degree of angry feelings as a valuable strength.

### 10. **Depressed Feelings**

For **high** scores: Point out that this scale only measures sad feelings about the child's condition, and does not diagnose clinical depression; suggest parent support group to help reduce feelings of isolation and aloneness; provide parenting skills training to increase empowerment, confidence, and hopefulness; refer for professional grief counseling for intense sadness.

For **low** scores: Acknowledge a parent's low level of depressed feelings as a valuable strength.

### 11. **Confused Feelings**

For **high** scores: Assure confused feelings are natural; respectfully listen and encourage the parent to state opinions and ask questions; explain rationale for each treatment; use clear language familiar to the parent; offer seminars and trainings; help parent organize by posting schedules; keeping therapy materials in one place; inviting to participate in training sessions.

For **low** scores: Acknowledge the parent's organization and clarity as important strengths.

### 12. **Neutralizing Unconcerned**

For **high** scores: For an unconcerned parent, explain the importance of parent involvement for the child's success; offer initially simple parent skills training, and show the child's positive gains; if another parent has taken on the burden of caregiving, offer the more active parent additional supports; encourage the less concerned parent to increase active involvement for the child.

For **low** scores: Acknowledge and praise the parent's strong commitment to the child.

### 13. **Neutralizing Resistant**

For **high** scores: For an anxious parent who resists the diagnosis, gently share a checklist of signs and symptoms; offer initially simple parent skills training to reduce anxiety and raise confidence; point out positive gains the child makes with parent help; offer a more active parent additional supports; guide parents to coordinate and celebrate their parenting activity.

For **low** scores: Acknowledge and praise the parent for actively accepting their parenting role.

### 14. **Negative Distortions**

For **high** scores: Calmly listen and gently discuss negatively distorted beliefs; may point out that no one is to blame for causing the child's disability, that there are positive qualities to appreciate about the child, that there is a team to help so parent is not alone; may suggest cognitive behavioral counseling to support more realistic and constructive thoughts about themselves and their child.

For **low** scores: Acknowledge and praise the parent for their constructive viewpoints.

## **INDEPENDENT DOMAIN:**

### 15. **Positive Distortions**

For **any** score (1-5): Acknowledge and respect the parent's views in this domain, and express realistic hope for the child. If the parent expresses specific concerns relating to this area, however, you may discuss services that may be of help to the parent.

**PRADS-2 SERVICES WORKSHEET** Parent ID \_\_\_\_\_

This worksheet helps to compile suggested services to discuss with the parent. In these **Resolved** domains, services would especially benefit a parent who scores **low** (around 1-2) in a scale, or in a specific item in a scale. For scales with medium scores (around 3), ask the parent whether they may value services in this area. For Resolved scales with higher scores (around 4-5), be sure to point these out to the parent as areas of strength.

**Total Resolved Score:** \_\_\_\_\_

**Resolved Domains**

**Notes and Possible Services**

<p><b>1. Positive Feelings</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>2. Working through Emotions</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>3. Active Research</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	

**PRADS-2 SERVICES WORKSHEET**

**Resolved Domains**

**Notes and Possible Services**

<p><b>4. Participation and Helping</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>5. Self-Help Routines</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>6. Broad Perspectives</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>7. Focused Thought</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	

**PRADS-2 SERVICES WORKSHEET**

This worksheet helps to compile suggested services to discuss with the parent. In these **Unresolved** scales, services would especially benefit a parent who scores **high** (around 4-5) in a scale, or in a specific item in a scale. For scales with medium scores (around 3), ask the parent whether they may value services in this area. For Unresolved scales with lower scores (around 1-2), be sure to point these out to the parent as areas of strength.

**Total Unresolved Score:** \_\_\_\_\_

**Unresolved Domains**

**Notes and Possible Services**

<p><b>8. Emotionally Overwhelmed</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>9. Angry Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>10. Depressed Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	



**PRADS-2 SERVICES WORKSHEET**

**Unresolved Domains**

**Notes and Possible Services**

<p><b>11. Confused Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>12. Neutralizing Unconcerned</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>13. Neutralizing Resistant</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>14. Negative Distortions</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	

**PRADS-2 SERVICES WORKSHEET**

The **Positive Distortions** scale is separate from the other scales. This scale correlates positively with Resolution rather than Nonresolution. It represents the parent's hope for their child's future. You may acknowledge and respect the parent's views in this scale (from 1-5), and express realistic hope for the child. However, if the parent expresses specific concerns relating to this area, then you may discuss services that may be of help to the parent.

**Positive Distortions Domain**

**Notes and Possible Services**

<p><b>15. Positive Distortions</b></p> <p>Score: _____</p> <p>____ Fine (1-5)</p> <p>____ Possible Services</p>	
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**Additional Notes and Available Services:**

\_\_\_\_\_ Parent's Initials

\_\_\_\_\_ Service Coordinator's Initials

\_\_\_\_\_ Date

## **SUMMARY OF STEPS FOR THE FOLLOW-UP INTERVIEW**

### **Preparing:**

- Fill out the scoring form, profile graph, and services worksheet for this parent
- Use the Summary of Tailored Supports for ideas of supports relating to the parent's specific scale scores
- Write in your ideas for support services in the services worksheet notes section
- Fill out another services worksheet with the scores, but with blank notes sections, to discuss and fill in together with the parent
- Collect specific information about the available support services

### **Greeting:**

- Greet the parent
- Ask how the parent and family are doing - listen and reflect
- Thank the parent for filling out the measure

### **Sharing:**

- Share the completed scoring form and profile graph
- Point out that these can show current areas of parent strengths and difficulties

### **Strengths:**

- Point out areas of strengths - in high Resolved scores and items (around 4-5)
- Point out areas of strengths - in low Unresolved scores and items (around 1-2)
- Celebrate these areas of strengths and invite the parent's comments on these
- Write specific positive comments into the services worksheet notes sections

### **Difficulties:**

- Point out areas of difficulty - in low Resolved scores and items (around 1-2)
- Point out areas of difficulty - in high Unresolved scores and items (around 4-5)
- Ask about any other parent concerns, and about any medium scores (around 3)
- Show compassion and invite the parent's further comments about these areas
- Discuss and collaborate about possible supports for the family in these areas

### **Services:**

- Your supportive comments provide valuable insight and encouragement
- Available services - describe these and invite the parent's questions and opinions
- For services of interest to the parent - provide specific information and referrals
- Write each of these possible supports into the services worksheet notes sections

### **Concluding:**

- Offer the parent copies of their scoring form, graph, services worksheet, and service information
- Agree on any planned actions and referrals to do prior to the next meeting
- Arrange for the next meeting with the parent and family
- Thank the parent for their valuable involvement in parenting their child!

**APPENDIX B**

**Professional User Packet  
for the  
Parent Reaction to Diagnosis Scales  
(PRDS-2)  
with  
Guidance for Tailoring Parent Supports**

**Kathleen A. Brewer, M.A.  
Mary B. Gruber, Ph.D., BCBA-D**

**The Press at Cal Poly Humboldt**

## **Appendix B**

### **Parent Reaction to Diagnosis Scale (PRDS-2)**

We are presenting here a more general form of our measure for parents of children with any diagnosis. Previous research which had used the Reaction to Diagnosis Interview studied parent resolution toward many types of childhood diagnoses, including cerebral palsy, epilepsy, intellectual disabilities, and other neurological and physical conditions. Therefore, we have additionally adapted the wording of our survey items to be relevant for parents of children with any diagnosis. This measure is called the Parent Reaction to Diagnosis Scale (PRDS-2). It has the same wording as the items in the Parent Reaction to Autism Diagnosis (PRADS-2), except that the word “autism” is replaced with more general terms. The administration, scoring, graphing, and usage guidelines are identical for the PRADS-2 and PRDS-2.

**Appendix B**  
**Parent Reaction to Diagnosis Scales (PRDS-2)**  
**Professional User Packet**

This packet for the PRDS-2 measure provides the following materials:

Parent Intake Form

Parent Rights and Informed Consent

PRDS-2 Measure

PRDS-2 Scoring for Researchers

PRDS-2 Scoring Sheet for Individual Parent

Profile Graph Form

Summary of Tailored Supports

Services Worksheet

Summary of Steps for the Follow-Up Interview

This packet is to be used in accordance with our manual:

Brewer, K. A., & Gruber, M. B. (2022). *Professional manual for the Parent Reaction to Autism Diagnosis Scales (PRADS-2) with guidance for tailoring parent supports*. Arcata, CA: The Press at Cal Poly Humboldt. Available at <https://digitalcommons.humboldt.edu/textbooks/7/>

Parent ID Number \_\_\_\_\_

Date \_\_\_\_\_

**PRDS-2**  
**Parent Intake Form**

Parent name \_\_\_\_\_

Child's name \_\_\_\_\_

Child's date of birth \_\_\_\_\_

Age child was diagnosed \_\_\_\_\_

Child's diagnosis \_\_\_\_\_

Notes:

Parent ID Number \_\_\_\_\_

Date \_\_\_\_\_

## **Parent Reaction to Diagnosis Scales (PRDS-2)**

### **Parent Rights and Informed Consent**

The purpose of this survey is to learn about your reactions to your child's diagnosis. It can aid in identifying supports and services that may be helpful to you and other parents as they raise their child with special needs.

All of the items in this survey are statements made by parents about their own experiences in raising their child with special needs. You are asked to rate how much each statement relates to your own experiences as a parent raising your child.

This survey measures aspects of parent experiences that can indicate parenting strengths and possible difficulties when raising a child with a disability. It gives information that can assist in understanding parents' experiences in raising their child with special needs.

All information gathered from this survey is confidential and will not be shared with anyone else without specific written permission from you. You have the right to determine how and with whom this information can be shared. The completed survey and assessment will be kept confidential, and the information will be held for up to \_\_\_ years.

Raising a child with a disability is challenging. If at any time answering these questions becomes too stressful, you have the right to stop answering the items, or you can set the survey aside and may continue filling it out at a later time. Not completing this survey will not affect your family's rights to services. You are free to decline to answer this survey or any question you do not wish to answer for any reason.

This survey typically takes about 20 to 30 minutes. However, it is not timed, and you may take as long as you like. There are no right or wrong answers. Please try to fill out the form completely, as this will give a more comprehensive understanding of what types of services may be helpful to support you as you parent your child.

If you are willing to respond to this survey, you may sign with your consent below.

Parent Signature \_\_\_\_\_

Date \_\_\_\_\_



Parent ID \_\_\_\_\_ Date \_\_\_\_\_

### Parent Reaction to Diagnosis Scales (PRDS-2)

Kathleen A. Brewer, M.A., and Mary B. Gruber, Ph.D., BCBA-D

Below are various statements that some parents of children with a disability have said about their experiences raising their child. Please circle the degree to which each statement currently applies to your own experiences as a parent raising your child with a disability. The statements are listed in a random order.

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me					
	1	2	3	4	5					
1.						1	2	3	4	5
2.						1	2	3	4	5
3.						1	2	3	4	5
4.						1	2	3	4	5
5.						1	2	3	4	5
6.						1	2	3	4	5
7.						1	2	3	4	5
8.						1	2	3	4	5
9.						1	2	3	4	5
10.						1	2	3	4	5
11.						1	2	3	4	5
12.						1	2	3	4	5
13.						1	2	3	4	5
14.						1	2	3	4	5

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me
	1	2	3	4	5
15. Since receiving the diagnosis, I feel that I am the only one who can help my child.	1	2	3	4	5
16. Without my child having this disability, my life would not have a purpose.	1	2	3	4	5
17. Someone else noticed my child was having problems before I did and told me.	1	2	3	4	5
18. When my child was diagnosed with a disability, I researched everything I could.	1	2	3	4	5
19. I worry about other people judging me as a parent of a child with special needs.	1	2	3	4	5
20. Being able to express myself and talk to others about my emotions helps me to cope with my child's diagnosis.	1	2	3	4	5
21. I do not have much hope for my child's future.	1	2	3	4	5
22. I have created routines that help me to meet my child's needs.	1	2	3	4	5
23. I get so confused and at a loss when I try to talk about my child's disability.	1	2	3	4	5
24. I continue to do what I have to do to help my child each day.	1	2	3	4	5
25. I blame myself for causing my child's disability.	1	2	3	4	5
26. My child's diagnosis has never bothered me.	1	2	3	4	5
27. I am angry with the professionals who diagnosed my child.	1	2	3	4	5
28. Observing what my child does helps me to understand my child better.	1	2	3	4	5
29. I stay focused on learning everything I can about the diagnosis to help me support my child.	1	2	3	4	5
30. I feel more positive now about my child's diagnosis.	1	2	3	4	5
31. My child was given a disability to help me with my own personal growth.	1	2	3	4	5
32. I waited to get my child diagnosed because I did not think there was a problem.	1	2	3	4	5
33. I feel that by addressing my emotions after my child's diagnosis, I am better able to support my child.	1	2	3	4	5
34. I am so confused about my child's diagnosis that I don't know what to do to help my child.	1	2	3	4	5

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me
	1	2	3	4	5
35. I work with all the professionals in my child's life to understand my child's changing needs.	1	2	3	4	5
36. I feel isolated and alone since my child's diagnosis.	1	2	3	4	5
37. I try to stay current with new interventions so that I can actively help my child.	1	2	3	4	5
38. I have created self-help routines to help me get through my day.	1	2	3	4	5
39. I feel that my child's disability has been harder for me as the parent than for my child.	1	2	3	4	5
40. Thinking positively about my child's future helps me to help my child.	1	2	3	4	5
41. I feel that I am in a continual state of crisis.	1	2	3	4	5
42. I want others to be as angry as I am about my child's situation.	1	2	3	4	5
43. It is important for me to have information about my child's diagnosis.	1	2	3	4	5
44. I feel I don't need to do anything more to help my child.	1	2	3	4	5
45. I am proud of myself for how well I am helping my child.	1	2	3	4	5
46. I felt a need to grieve after my child's diagnosis.	1	2	3	4	5
47. I am overwhelmed when caring for my child.	1	2	3	4	5
48. It is important that I actively participate in helping my child make progress.	1	2	3	4	5
49. I feel powerless to help my child.	1	2	3	4	5
50. I believe my child's brilliance will make a huge difference in the world someday.	1	2	3	4	5
51. I feel that everything about my child's disability is negative.	1	2	3	4	5
52. I think it is important for me to acknowledge my success in helping my child.	1	2	3	4	5
53. I avoid thinking about my child's diagnosis.	1	2	3	4	5
54. I just cannot get myself organized and focused enough to help my child.	1	2	3	4	5

	Not at all like me	Slightly like me	Somewhat like me	Much like me	Very much like me
	1	2	3	4	5
55. My personal beliefs have helped me to come to terms with my child's diagnosis.	1	2	3	4	5
56. I believe my child's diagnosis has had no effect on our family.	1	2	3	4	5
57. I take charge of getting my child appropriate services.	1	2	3	4	5
58. I am constantly angry that my child has a disability.	1	2	3	4	5
59. I have supportive phrases I tell myself that help me get through each day.	1	2	3	4	5
60. I have found joy in raising my child.	1	2	3	4	5

Thank you for filling out this survey.

If you have any further comments, you may write them here:

**INSTRUCTIONS FOR SCORING THE PRDS-2 SCALES**  
**FOR RESEARCHERS**

Kathleen A. Brewer, M.A., and Mary B. Gruber, Ph.D., BCBA-D

California State Polytechnic University Humboldt

For a scale score, we add the respondent's ratings on each of the items in the scale, and then divide by the number of items in the scale, keeping two digits past the decimal point. This gives the parent's average rating on the scale items. It also expresses the scale score on the same 1-5 scale as the original rating scale, thus facilitating interpretation.

The item numbers for each of the Resolved scales are listed below:

Positive Feelings:	Items 1, 30, 45, and 60.
Working through Emotions:	Items 4, 20, 33, and 46.
Active Research:	Items 3, 18, 37, and 57.
Participation and Helping:	Items 6, 24, 35, and 48.
Self-Help Routines:	Items 10, 22, 38, and 59.
Broad Perspectives:	Items 14, 28, 40, and 55.
Focused Thought:	Items 12, 29, 43, and 52.

The item numbers for each of the Unresolved scales are listed below:

Emotionally Overwhelmed:	Items 9, 19, 41, and 47.
Angry Feelings:	Items 5, 27, 42, and 58.
Depressed Feelings:	Items 11, 21, 36, and 49.
Confused Feelings:	Items 8, 23, 34, and 54.
Neutralizing Unconcerned:	Items 13, 26, 44, and 56.
Neutralizing Resistant:	Items 2, 17, 32, and 53.
Negative Distortions:	Items 15, 25, 39, and 51.

The item numbers for the Positive Distortions scale are listed below:

Positive Distortions:	Items 7, 16, 31, and 50.
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For each scale score, we add the respondent's ratings on each of the four items in that scale, and then divide by four, keeping two digits past the decimal point.

For the Resolved Total score, we add the respondent's scores on each of the seven Resolved scale scores, and then divide by seven, rounding to two digits past the decimal point.

For the Unresolved Total score, we add the respondent's scores on each of the seven Unresolved scale scores, and then divide by seven, rounding to two digits past the decimal point.

As a researcher, you can enter the item responses for each parent into your data file. Then you can enter the computing commands in the format used by your statistical program, resulting in the scale scores being computed for each parent and added into your data file.

If not all of the items in a scale were answered, and you are conducting research with a group of parents, the most conservative and stable treatment of missing responses is to substitute the group's item mean for that parent's missing item, prior to calculating the scale and total scores.

If not all of the items in a scale were answered, and you are working with just one parent at the time, the parent's scale score is best calculated via prorating, by adding the parent's ratings on the answered items, and then dividing by the number of answered items.

We hope these measures can be beneficial in your research or service work.

**SCORING SHEET FOR THE PRDS-2 SCALES**  
**FOR AN INDIVIDUAL PARENT**

**Parent ID:** \_\_\_\_\_

For a scale score, we enter and add the parent's ratings on each of the items in the scale, and then divide by the number of answered items in the scale, keeping two digits past the decimal point. This gives the parent's average rating on the scale items. It also expresses the scale score on the same 1-5 scale as the original rating scale, thus facilitating interpretation.

**RESOLVED Feeling-Oriented Scales:**

**1. Positive Feelings Scale:**

\_\_\_\_\_ Item 1. I feel a strong emotional connection with my child with a disability.

\_\_\_\_\_ Item 30. I feel more positive now about my child's diagnosis.

\_\_\_\_\_ Item 45. I am proud of myself for how well I am helping my child.

\_\_\_\_\_ Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**2. Working through Emotions Scale:**

\_\_\_\_\_ Item 4. I worked through a lot of emotions about my child's diagnosis.

\_\_\_\_\_ Item 20. Being able to express myself and talk to others about my emotions helps me to cope with my child's diagnosis.

\_\_\_\_\_ Item 33. I feel that by addressing my emotions after my child's diagnosis, I am better able to support my child.

\_\_\_\_\_ Item 46. I felt a need to grieve after my child's diagnosis.

$$\text{Working through Emotions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**RESOLVED Action-Oriented Scales:**

**3. Active Research Scale:**

- \_\_\_\_\_ Item 3. I sought answers immediately when I realized that my child was having problems.  
\_\_\_\_\_ Item 18. When my child was diagnosed with a disability, I researched everything I could.  
\_\_\_\_\_ Item 37. I try to stay current with new interventions so that I can actively help my child.  
\_\_\_\_\_ Item 57. I take charge of getting my child appropriate services.

$$\text{Active Research Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**4. Participation and Helping Scale:**

- \_\_\_\_\_ Item 6. I actively participate in interventions and programs for my child.  
\_\_\_\_\_ Item 24. I continue to do what I have to do to help my child every day.  
\_\_\_\_\_ Item 35. I work with all the professionals in my child's life to understand my child's changing needs.  
\_\_\_\_\_ Item 48. It is important that I actively participate in helping my child make progress.

$$\text{Participation and Helping Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**5. Self-Help Routines Scale:**

- \_\_\_\_\_ Item 10. I schedule special time for myself to relax, rejuvenate, and restore my well-being.  
\_\_\_\_\_ Item 22. I have created routines that help me to meet my child's needs.  
\_\_\_\_\_ Item 38. I have created self-help routines to help me get through my day.  
\_\_\_\_\_ Item 59. I have supportive phrases I tell myself that help me get through each day.

$$\text{Self-Help Routines Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$



**RESOLVED Thinking-Oriented Scales:**

**6. Broad Perspectives Scale:**

- \_\_\_\_\_ Item 14. I think my child makes a positive contribution to our family.  
 \_\_\_\_\_ Item 28. Observing what my child does helps me to understand my child better.  
 \_\_\_\_\_ Item 40. Thinking positively about my child's future helps me to help my child.  
 \_\_\_\_\_ Item 55. My personal beliefs have helped me to come to terms with my child's diagnosis.

$$\text{Broad Perspectives Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**7. Focused Thought Scale:**

- \_\_\_\_\_ Item 12. I believe that the more I plan for the possibilities of each day, the more prepared I am to help my child.  
 \_\_\_\_\_ Item 29. I stay focused on learning everything I can about the diagnosis to help me support my child.  
 \_\_\_\_\_ Item 43. It is important for me to have information about my child's diagnosis.  
 \_\_\_\_\_ Item 52. I think it is important for me to acknowledge my success in helping my child.

$$\text{Focused Thought Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

- Place a dot by any of the above Resolved items which the parent rated low (1 or 2).

**RESOLVED TOTAL SCORE:**

For the Resolved Total Score, we add the parent's scores on each of these seven Resolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\text{Resolved Total Score} = \frac{(\text{PFS} + \text{WES} + \text{ARS} + \text{PHS} + \text{SRS} + \text{BPS} + \text{FTS})}{7}$$

$$= \left( \frac{\quad + \quad + \quad + \quad + \quad + \quad}{7} \right) = \frac{\quad}{7} = \boxed{\quad . \quad}$$

**UNRESOLVED Overwhelmed, Angry, Depressed, and Confused Scales:**

**8. Emotionally Overwhelmed Scale:**

- \_\_\_\_\_ Item 9. Every day I experience the same overwhelming emotions I had when my child received a diagnosis.
- \_\_\_\_\_ Item 19. I worry about other people judging me as a parent of a child with special needs.
- \_\_\_\_\_ Item 41. I feel that I am in a continual state of crisis.
- \_\_\_\_\_ Item 47. I am overwhelmed when caring for my child.

$$\text{Emotionally Overwhelmed Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**9. Angry Feelings Scale:**

- \_\_\_\_\_ Item 5. It is important to me that someone be held responsible for my child's disability.
- \_\_\_\_\_ Item 27. I am angry with the professionals who diagnosed my child.
- \_\_\_\_\_ Item 42. I want others to be as angry as I am about my child's situation.
- \_\_\_\_\_ Item 58. I am constantly angry that my child has a disability.

$$\text{Angry Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**10. Depressed Feelings Scale:**

- \_\_\_\_\_ Item 11. I am stuck in sadness about my child having a disability.
- \_\_\_\_\_ Item 21. I do not have much hope for my child's future.
- \_\_\_\_\_ Item 36. I feel isolated and alone since my child's diagnosis.
- \_\_\_\_\_ Item 49. I feel powerless to help my child.

$$\text{Depressed Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**11. Confused Feelings Scale:**

- \_\_\_\_\_ Item 8. Sometimes I think everything will be okay and then it just becomes too much to handle.
- \_\_\_\_\_ Item 23. I get so confused and at a loss when I try to talk about my child's disability.
- \_\_\_\_\_ Item 34. I am so confused about my child's diagnosis that I don't know what to do to help my child.
- \_\_\_\_\_ Item 54. I just cannot get myself organized and focused enough to help my child.

$$\text{Confused Feelings Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**UNRESOLVED Unconcerned, Resistant, and Negative Distortions Scales:**

**12. Neutralizing Unconcerned Scale:**

- \_\_\_\_\_ Item 13. I have never felt strong emotions about my child's diagnosis.  
 \_\_\_\_\_ Item 26. My child's diagnosis has never bothered me.  
 \_\_\_\_\_ Item 44. I feel I don't need to do anything more to help my child.  
 \_\_\_\_\_ Item 56. I believe my child's diagnosis has had no effect on our family.

$$\text{Neutralizing Unconcerned Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**13. Neutralizing Resistant Scale:**

- \_\_\_\_\_ Item 2. I really believe that my child's diagnosis is incorrect.  
 \_\_\_\_\_ Item 17. Someone else noticed my child was having problems before I did and told me.  
 \_\_\_\_\_ Item 32. I waited to get my child diagnosed because I did not think there was a problem.  
 \_\_\_\_\_ Item 53. I avoid thinking about my child's diagnosis.

$$\text{Neutralizing Resistant Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

**14. Negative Distortions Scale:**

- \_\_\_\_\_ Item 15. Since receiving the diagnosis, I feel that I am the only one who can help my child.  
 \_\_\_\_\_ Item 25. I blame myself for causing my child's disability.  
 \_\_\_\_\_ Item 39. I feel that my child's disability has been harder for me as the parent than for my child.  
 \_\_\_\_\_ Item 51. I feel that everything about my child's disability is negative.

$$\text{Negative Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad . \quad}$$

- Place a dot by any of the above Unresolved items which the parent rated highly (4 or 5).

**UNRESOLVED TOTAL SCORE:**

For the Unresolved Total Score, we add the parent's scores on each of these seven Unresolved scales, and then divide by seven, rounding to two digits past the decimal point.

$$\begin{aligned} \text{Unresolved Total Score} &= \frac{(\text{EOS} + \text{AFS} + \text{DFS} + \text{CFS} + \text{NUS} + \text{NRS} + \text{NDS})}{7} \\ &= \frac{(\quad + \quad + \quad + \quad + \quad + \quad)}{7} = \frac{\quad}{7} = \boxed{\quad . \quad} \end{aligned}$$

**15. Positive Distortions Scale:**

The Positive Distortions Scale is calculated separately from the Resolved and Unresolved scales.

- Item 7. My child's having this disability has been a wonderful blessing for our family.
- Item 16. Without my child having this disability, my life would not have a purpose.
- Item 31. My child was given a disability to help me with my own personal growth.
- Item 50. I believe my child's brilliance will make a huge difference in the world someday.

$$\text{Positive Distortions Score} = \frac{\text{Sum of Item Ratings}}{4} = \frac{\quad}{4} = \boxed{\quad .}$$

**Missing Responses**

If there are some missing responses, you may remind the parent that there are no right or wrong answers to the questions, and you may encourage them to fill in their best estimate for how much each item applies to their experiences. Be careful not to suggest specific answers to the parent, however. Also, be careful to respect the parent's choice to not answer all the items if the parent prefers this.

If there are still some missing responses, you may use prorating to calculate the parent's scale score, by adding the parent's ratings on the answered items, and then dividing by the number of answered items in that scale.

For example, if a parent did not answer Item 45 on the Positive Feelings scale, you may calculate a Positive Feelings scale score by adding the responses on the other three items and then dividing by three instead of four. This gives the parent's average rating on the items that they did answer.

**Positive Feelings Scale - Example with a missing response:**

- 4   Item 1. I feel a strong emotional connection with my child.
- 3   Item 30. I feel more positive now about my child's diagnosis.
- n   Item 45. I am proud of myself for how well I am helping my child.
- 5   Item 60. I have found joy in raising my child.

$$\text{Positive Feelings Score} = \frac{\text{Sum of Item Ratings}}{4 - 1} = \frac{12}{3} = \boxed{4.00}$$

**GRAPHING THE PARENT'S PROFILE  
OF SCORES ON THE PROFILE FORM**

After calculating a parent's scale scores, you can graph the parent's profile on the profile template form, shown in Figure 2. The vertical axis shows the scale score values from 1 to 5. A blank column is shown above each of the 15 scale labels. Within each scale column, draw a colored line at the height of the parent's score, and write the parent's score value above the line, as shown in the example in Figure 3.

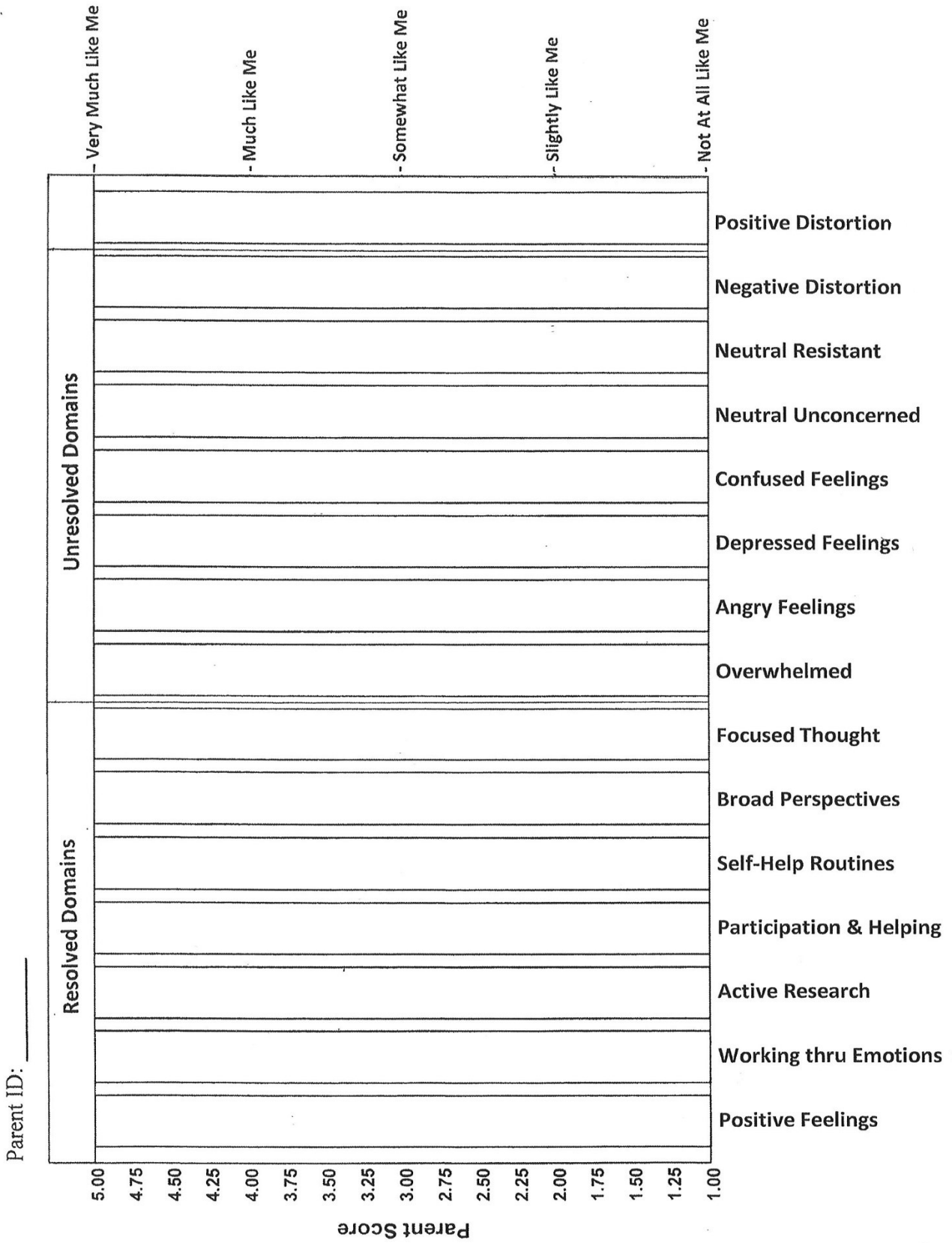


Figure 2. Profile graph form for showing the profile of scores for an individual parent.

Parent ID: 070

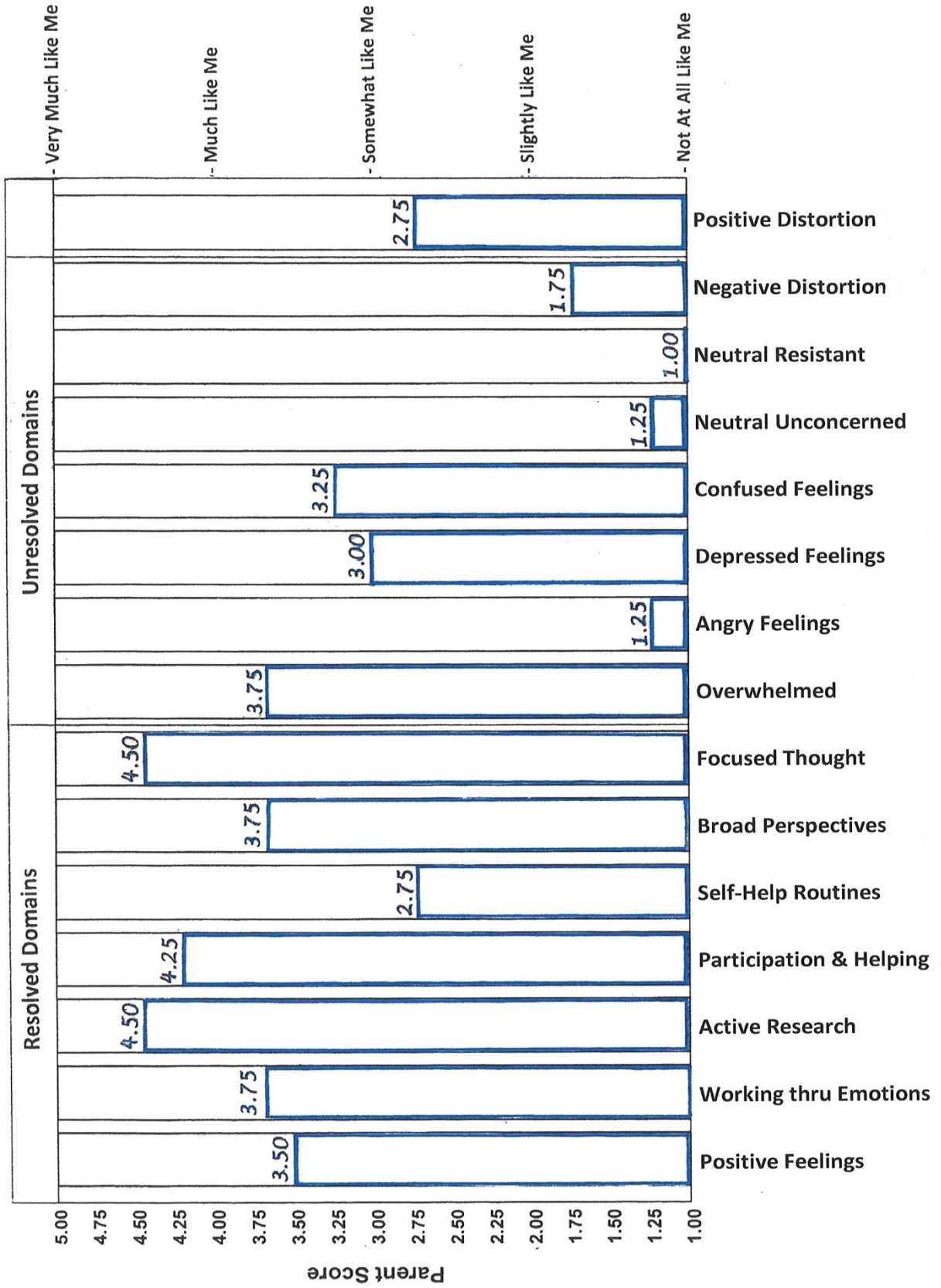


Figure 3. Profile graph showing the profile of scores for the example Parent #070.

## **SUMMARY OF TAILORED SUPPORTS**

Here we are providing a concise summary of the tailored supports that we have discussed in relation to each of the scale scores. This summary can be a helpful reference for ideas when filling out the Services Worksheet for an individual parent.

### **RESOLVED DOMAINS:**

For **high** scores (around 4-5): Praise, reflect, and congratulate the parent on these strengths.

For **medium** scores (around 3): Ask the parent whether they may value services in this area.

For **low** scores (around 1-2): Suggest resources and services tailored to these difficulties.

#### **1. Positive Feelings**

For **high** scores: Congratulate, listen, share enjoyment.

For **low** scores: Empathize with the parent; recognize and praise positive parent actions; point out parent actions to be proud of; point out things you yourself like about the child; point out positive child progress; suggest journaling about any positive experiences with child; discuss fun activities parent and child can share together; suggest enjoyable family and community activities.

#### **2. Working through Emotions**

For **high** scores: Congratulate, listen to how they have acknowledged and coped with emotions.

For **low** scores: Listen and encourage the parent to acknowledge and express their varied emotions with you; reassure feelings of grief are natural; may suggest journaling to sort out emotions; parent support groups where parents can express emotions with other more experienced parents; may suggest individual or group grief counseling.

#### **3. Active Research**

For **high** scores: Praise and offer further current, specific, and advanced information and training.

For **low** scores: Provide information on the diagnosis that is easy to understand and relevant; graduate in time to more complex information; encourage parent questions; get parent's preferences for types of information they would like; provide resources where parent can look for additional information of interest to them.

#### **4. Participation and Helping**

For **high** scores: Praise and offer further training and inclusion in their child's treatments.

For **low** scores: Invite to participate in easy tasks first; praise and gradually raise involvement; individual or group parent training; behavioral skills training; progress to more advanced skills in evidence-based treatment; encourage parent's suggestions and participation with the therapy team; point out ways their helping contributes to their child's success.



## 5. Self-Help Routines

For **high** scores: Praise and affirm that self-care activities are important for caregivers.

For **low** scores: Affirm importance of self-care activities for caregivers; help schedule respite times; create a network of extended family or friends who can help out; provide cognitive behavioral supports, relaxation, mindfulness exercises, positive self-statements; help identify and schedule times for activities that the parent used to enjoy.

## 6. Broad Perspectives

For **high** scores: Respect the parent's positive views of their child in relation to their family, culture, beliefs, and future.

For **low** scores: Suggest positive ways the child can be included in extended family, cultural, and community activities; journaling about parent observations and understanding of their child; planning for the child's transitions into the future.

## 7. Focused Thought

For **high** scores: Praise the parent's daily planning, their focus on learning about the diagnosis and helping their child, and acknowledging their own success in helping the child.

For **low** scores: Help parent devise a way to schedule and plan for possibilities of each day, to focus on learning about the disability and supporting their child, and to recognize and acknowledge their successes in parenting.

## UNRESOLVED DOMAINS:

For **high** scores (around 4-5): Suggest resources and services tailored to these difficulties.

For **medium** scores (around 3): Ask the parent whether they may value services in this area.

For **low** scores (around 1-2): Praise, reflect, and congratulate the parent on these strengths.

## 8. Emotionally Overwhelmed

For **high** scores: Listen and empathize with the parent's varying emotions; assure overwhelmed feelings are natural in parenting a child with special needs; parent support group for sharing emotions and coping strategies; practice assertive responses for when worried about others judging them; practice calming techniques; use calendar of schedules to make life more predictable; list contacts for persons they can call when overwhelmed.

For **low** scores: Acknowledge the parent's ability to manage stressors as an important strength.

## 9. Angry Feelings

For **high** scores: Listen and empathize; assure they have a highly qualified team to help them and their child; assure them that no one is responsible for causing the disability; suggest professional counseling for strong anger; any signs of possible violence or severe neglect present a mandated duty to report to child welfare services; follow up to ensure safety and family counseling.

For **low** scores: Acknowledge the parent's low degree of angry feelings as a valuable strength.

### **10. Depressed Feelings**

For **high** scores: Point out that this scale only measures sad feelings about the child's condition, and does not diagnose clinical depression; suggest parent support group to help reduce feelings of isolation and aloneness; provide parenting skills training to increase empowerment, confidence, and hopefulness; refer for professional grief counseling for intense sadness.

For **low** scores: Acknowledge a parent's low level of depressed feelings as a valuable strength.

### **11. Confused Feelings**

For **high** scores: Assure confused feelings are natural; respectfully listen and encourage the parent to state opinions and ask questions; explain rationale for each treatment; use clear language familiar to the parent; offer seminars and trainings; help parent organize by posting schedules; keeping therapy materials in one place; inviting to participate in training sessions.

For **low** scores: Acknowledge the parent's organization and clarity as important strengths.

### **12. Neutralizing Unconcerned**

For **high** scores: For an unconcerned parent, explain the importance of parent involvement for the child's success; offer initially simple parent skills training, and show the child's positive gains; if another parent has taken on the burden of caregiving, offer the more active parent additional supports; encourage the less concerned parent to increase active involvement for the child.

For **low** scores: Acknowledge and praise the parent's strong commitment to their child.

### **13. Neutralizing Resistant**

For **high** scores: For an anxious parent who resists the diagnosis, gently share a checklist of signs and symptoms; offer initially simple parent skills training to reduce anxiety and raise confidence; point out positive gains the child makes with parent help; offer a more active parent additional supports; guide parents to coordinate and celebrate their parenting activity.

For **low** scores: Acknowledge and praise the parent for actively accepting their parenting role.

### **14. Negative Distortions**

For **high** scores: Calmly listen and gently discuss negatively distorted beliefs; may point out that no one is to blame for causing the child's disability, that there are positive qualities to appreciate about the child, that there is a team to help so parent is not alone; may suggest cognitive behavioral counseling to support more realistic and constructive thoughts about themselves and their child.

For **low** scores: Acknowledge and praise the parent for their constructive viewpoints.

## **INDEPENDENT DOMAIN:**

### **15. Positive Distortions**

For **any** score (1-5): Acknowledge and respect the parent's views in this domain, and express realistic hope for the child. If the parent expresses specific concerns relating to this area, however, you may discuss services that may be of help to the parent.

**PRDS-2 SERVICES WORKSHEET**

Parent ID \_\_\_\_\_

This worksheet helps to compile suggested services to discuss with the parent. In these **Resolved** scales, services would especially benefit a parent who scores **low** (around 1-2) in a scale, or in a specific item in a scale. For scales with medium scores (around 3), ask the parent whether they may value services in this area. For Resolved scales with higher scores (around 4-5), be sure to point these out to the parent as areas of strength.

**Total Resolved Score:** \_\_\_\_\_

**Resolved Domains**

**Notes and Possible Services**

<p><b>1. Positive Feelings</b></p> <p>Score: _____</p> <p>___ Fine (4-5)</p> <p>___ Possible Services</p>	
<p><b>2. Working through Emotions</b></p> <p>Score: _____</p> <p>___ Fine (4-5)</p> <p>___ Possible Services</p>	
<p><b>3. Active Research</b></p> <p>Score: _____</p> <p>___ Fine (4-5)</p> <p>___ Possible Services</p>	

**PRDS-2 SERVICES WORKSHEET**

**Resolved Domains**

**Notes and Possible Services**

<p><b>4. Participation and Helping</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>5. Self-Help Routines</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>6. Broad Perspectives</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	
<p><b>7. Focused Thought</b></p> <p>Score: _____</p> <p>___ Fine (4-5) ___ Possible Services</p>	

**PRDS-2 SERVICES WORKSHEET**

This worksheet helps to compile suggested services to discuss with the parent. In these **Unresolved** domains, services would especially benefit a parent who scores **high** (around 4-5) in a scale, or in a specific item in a scale. For scales with medium scores (around 3), ask the parent whether they may value services in this area. For Unresolved scales with lower scores (around 1-2), be sure to point these out to the parent as areas of strength.

**Total Unresolved Score:** \_\_\_\_\_

**Unresolved Domains**

**Notes and Possible Services**

<p><b>8. Emotionally Overwhelmed</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>9. Angry Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>10. Depressed Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	

**PRDS-2 SERVICES WORKSHEET**

**Unresolved Domains**

**Notes and Possible Services**

<p><b>11. Confused Feelings</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>12. Neutralizing Unconcerned</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>13. Neutralizing Resistant</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	
<p><b>14. Negative Distortions</b></p> <p>Score: _____</p> <p>___ Fine (1-2) ___ Possible Services</p>	

**PRDS-2 SERVICES WORKSHEET**

The **Positive Distortions** scale is separate from the other scales. This scale correlates positively with Resolution rather than Nonresolution. It represents the parent's hope for their child's future. You may acknowledge and respect the parent's views in this scale (from 1-5), and express realistic hope for the child. However, if the parent expresses specific concerns relating to this area, then you may discuss services that may be of help to the parent.

**Positive Distortions Domain**

**Notes and Possible Services**

<p><b>15. Positive Distortions</b></p> <p>Score: _____</p> <p>____ Fine (1-5)</p> <p>____ Possible Services</p>	
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**Additional Notes and Available Services:**

\_\_\_\_\_ Parent's Initials

\_\_\_\_\_ Service Coordinator's Initials

\_\_\_\_\_ Date

## **SUMMARY OF STEPS FOR THE FOLLOW-UP INTERVIEW**

### **Preparing:**

- Fill out the scoring form, profile graph, and services worksheet for this parent
- Use the Summary of Tailored Supports for ideas of supports relating to the parent's specific scale scores
- Write in your ideas for support services in the services worksheet notes section
- Fill out another services worksheet with the scores, but with blank notes sections, to discuss and fill in together with the parent
- Collect specific information about the available support services

### **Greeting:**

- Greet the parent
- Ask how the parent and family are doing - listen and reflect
- Thank the parent for filling out the measure

### **Sharing:**

- Show the completed scoring form and profile graph
- Point out that these can show current areas of parent strengths and difficulties

### **Strengths:**

- Point out areas of strengths - in high Resolved scores and items (around 4-5)
- Point out areas of strengths - in low Unresolved scores and items (around 1-2)
- Celebrate these areas of strengths and invite the parent's comments on these
- Show the services worksheet with scores, but with blank note sections
- Write specific positive comments into the services worksheet notes sections

### **Difficulties:**

- Point out areas of difficulty - in low Resolved scores and items (around 1-2)
- Point out areas of difficulty - in high Unresolved scores and items (around 4-5)
- Ask about any other parent concerns, and about any medium scores (around 3)
- Show compassion and invite the parent's further comments about these areas
- Discuss and collaborate about possible supports for the family in these areas

### **Services:**

- Your supportive comments provide valuable insight and encouragement
- Available services - describe these and invite the parent's questions and opinions
- For services of interest to the parent - provide specific information and referrals
- Write each of these possible supports into the services worksheet notes sections

### **Concluding:**

- Offer the parent copies of their scoring form, graph, services worksheet, and service information
- Agree on any planned actions and referrals to do prior to the next meeting
- Arrange for the next meeting with the parent and family
- Thank the parent for their valuable involvement in parenting their child!



**NOTE TO READERS**

Standards for service providers can change over time, and no recommendation is guaranteed to be safe and effective in all circumstances. We intend our work to be a helpful resource, however it cannot serve as a substitute for appropriate training, peer review, and clinical supervision. Neither the publisher nor the authors can guarantee the complete efficacy or appropriateness of any particular recommendation for every specific situation. We hope these measures can be beneficial in your research or service work. If you have further questions or comments about these measures, we invite you to contact us at [mbg2@humboldt.edu](mailto:mbg2@humboldt.edu).

## REVIEWS

“The Parent Reaction to Autism Scale (PRADS-2) is a tool that enables researchers and service professionals to objectively measure a parent’s reaction to a child’s diagnosis of autism. The instrument takes a strength-based approach in helping parents to resolve a challenging and often stressful situation. The manual contains a comprehensive background on the development and validation of the instrument in a format that is easy to read and understand. The psychometric properties of the instrument are reported in detail, and the manual clearly outlines the relevant ethical standards which should be used to guide the application of the instrument. The administration, scoring, and graphing instructions are detailed and comprehensive. The authors offer good suggestions for building rapport and putting the parent at ease when discussing results from the assessment. The authors also provide useful recommendations on how to use results from the measure to determine the types of support and services parents and families might need based on their self-reports on the PRADS-2 instrument. The manual contains worksheets and useful suggestions on how to determine additional support services that parents might need to help them adjust to their child’s diagnosis of autism.”

**Dr. Sandra M. Harris**, Ph.D., M.Ed., is the Director of Academic Program Review at Walden University. She has a Ph.D. degree in Educational Psychology and M.Ed. degree in School Psychometry. She has scholarly publications in peer reviewed journals, and she serves as a peer reviewer and editor on the design, development, and validation of tests and assessments.

“The experiences and well-being of parents raising a child with autism spectrum disorder (ASD) can vary based on the needs of their child, family resources, and parent coping strategies. In the field of autism treatment, identifying the types of support that best fit a parent’s needs is crucial in supporting the family as a whole. Developed using actual parents’ statements about their experiences raising a child on the spectrum, the Parent Reaction to Autism Diagnosis Scale (PRADS-2) allows for the compassionate measurement of parental strengths and the challenges they face. Most importantly, the PRADS-2 provides guidance for practitioners in both celebrating parent success and tailoring support specific to a parent’s needs while taking into account their culture and family system. Any clinician who strives to provide or connect parents of children with ASD with effective support services should use this measure as a first step in orienting the parents to the available strategies, resources, and social networks that offer much-needed family support.”

**Dr. Kate E. Fiske**, Ph.D., BCBA-D, is a Clinical Associate Professor at Rutgers University at New Brunswick and the Director of Family Support Services at the Douglass Developmental Disabilities Center. She is the author of the book, *Autism and the Family: Understanding and Supporting Parents and Siblings*.