

THE DESIGN, IMPLEMENTATION, AND FORMATIVE EVALUATION OF A
PROGRAM FOR WAITLISTED CAREGIVERS OF INDIVIDUALS WITH
DEVELOPMENTAL DISABILITIES
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ABSTRACT

This dissertation focused on the process of utilizing Maher's (2000) program planning and evaluation framework to design, implement, and conduct a formative evaluation of a waiting list program for caregivers waiting to receive parent-training services. The literature on waiting lists suggests that waitlisted individuals are generally provided with limited or no support while waiting for services. A waiting list program was designed in an attempt to provide support to families who had been waiting for parent training services for more than one-and-a-half years. Participants of the waiting list program received one home-based session, as well as monthly educational worksheets about topics related to caring for an individual with a developmental disability. The program was implemented for five months, followed by a formative program evaluation. Based on results from the formative evaluation, it was determined that the waiting list program was implemented according to design. In addition, the formative evaluation results suggest that the information contained in the worksheets provided caregivers with an opportunity to review previously learned information and be exposed to new information. Participants varied in regard to their satisfaction with the waiting list program, from being dissatisfied to highly satisfied. Caution should be used when interpreting these results due to the small sample size and low response rate of evaluation materials. Based on the evaluation of the program evaluation, it was determined that the evaluation plan was successfully implemented. In addition, the client reported that the information will be useful for future program planning purposes. Recommendations regarding potential adjustments to the design, implementation, and evaluation of the program are provided.

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CHAPTER I

Introduction, Overview, and Statement of the Dissertation Task

Abstract

This chapter provides an overview of the dissertation task that is described throughout this dissertation. Contextual information is included to provide the reader with background knowledge related to the purpose for carrying out this task. An initial explanation of the dissertation task is also provided.

Rationale for the Design, Implementation, and Formative Evaluation of a Waiting List Program for Caregivers of Individuals with Developmental Disabilities

Designing, implementing and conducting a formative evaluation of a waiting list program has relevance to the literature on waiting lists and also with respect to services provided to individuals on waiting lists. Individuals seeking mental health services are often met with lengthy waiting lists and are not provided with support during their wait. Services for individuals with a developmental disability and their families are no exception. As the number of children diagnosed with a developmental disability continues to grow, the length of time to access these services will also continue to increase (CDC, 2009). This dissertation examined the process of designing,

implementing and evaluating a waiting list program for caregivers waiting to receive parent-training services.

Dissertation Context

The purpose of this dissertation was the design, implementation and formative evaluation of a waiting list program for caregivers waiting to receive parent-training services. The parent-training program provides caregivers with information regarding effective behavior management strategies, as well as opportunities to receive feedback about the implementation of these strategies. Two behavior specialists are responsible for implementing the program in each caregiver's home. The behavior specialists work with the caregiver(s) for one hour each week for approximately one year. Training begins following a comprehensive assessment, which the behavior specialists conduct to gather information about the child, the caregivers, the environment, and the system. The information gathered during the assessment informs the behavior specialists of the relevant training topics and the types of behavioral interventions that will be utilized.

In general, caregivers are trained on data collection methods, reinforcement procedures, and planned ignoring and extinction. Although all caregivers are exposed to the same information, the behavior specialists individualize the depth and breadth of the material based on the specific needs of the family. Once all of the topics have been discussed, caregivers and behavior specialists work collaboratively to develop trial behavior management plans. Once a trial plan has been implemented, caregivers are provided with constructive feedback and suggestions for improving the plan. At the end of the one-year consultation, a behavior management plan is developed, when

appropriate. The behavior specialists follow up with the caregivers one month, three months, and six months following the final training session.

The organization is funded by New Jersey's Division of Developmental Disabilities (DDD), which allows for the program to be free of cost to the caregivers. However, in order to access parent-training services through this organization, caregivers have to endure a waiting time of approximately one-and-a-half to two-years, based on the official records of the organization. Historically, these caregivers have been provided with minimal contact from the organization during their wait. However, recently the organization's administrators decided that it was important to determine a way to provide support to caregivers on the waiting list. In an attempt to provide this support, a member of the organization designed a program for the waitlisted caregivers (Callaghan, 2008). A needs assessment was conducted to determine the specific needs of the caregivers on a waiting list in a particular region of the state of New Jersey (Callaghan, 2008). Caregivers on the waiting list in that particular region were selected to participate in the needs assessment because the waiting list in that region had the most members and the members had been waited the longest out of the three lists. The results of the needs assessments suggested that caregivers were interested in learning more about behavior management concepts, methods for managing their emotions related to caregiving, ways to access services through DDD and other agencies, and ways to access social support and social/leisure activities (Callaghan, 2008).

After Callaghan (2008) designed the original waiting list program, this investigator was given the opportunity to customize the program design so that the program could be implemented, with a formative evaluation to follow shortly thereafter.

The formative evaluation was intended to allow for judgments to be made about the potential benefits of this waiting list program.

Dissertation Task

An administrator of the organization expressed an interest in the design, implementation, and formative evaluation of a waiting list program for caregivers on the organization's waiting list. In order to accomplish this task, the focus of this dissertation became the design, implementation and formative evaluation of a waiting list program. Maher's (2000) program planning and evaluation framework was utilized, as it provides guidelines for all of the elements related to the four phases of program development: Clarification, Design, Implementation, and Evaluation and a description of all four phases can be found in Chapter III. In addition, more detailed information about the activities involved in the design, implementation and formative evaluation of this program are provided in Chapter III and Chapter IV.

According to Maher (2000), the purpose of the Design Phase is to document all of the essential program design elements. While Callaghan (2008) created a program design for a waiting list program, the design was revised and customized by this investigator to reflect the current contextual factors and to increase the likelihood of successful implementation. Once the program was redesigned, this investigator implemented the waiting list program.

The purpose of the Implementation Phase is to assure that the program operates according to its design. As the person responsible for all activities in the Implementation

Phase, this investigator was a participant-observer, which allowed her to have direct knowledge of the implementation process.

During and following implementation of the waiting list program, a formative program evaluation was conducted so that judgments could be made about the potential value of the waiting list program. These formative judgments will inform future program development and improvement. Three program evaluation questions were included in the evaluation plan, which can be found in Chapter IV:

1. Who participated in the waiting list program?
2. To what extent was the program implemented as designed?
3. What have been reactions of caregivers to the program?

In order to address these questions, program evaluation protocols were developed and they have been included as part of the Program Evaluation Plan in Chapter IV.

These protocols included the program evaluation question, data collection variables, data collection methods, instruments, and procedures, methods and procedures for data analysis, and personnel and responsibilities. Evaluation data were collected through a permanent product review as well as survey instruments and tracking forms that were created specifically for the waiting list program. The results of the formative program evaluation, as well as a review of the evaluation of the program evaluation will be discussed in Chapter V. Recommendations and conclusions based on the program evaluation can be found in Chapter VI.

Summary

This chapter provided an introduction to the design, implementation, and formative evaluation of a waiting list program for caregivers of individuals with developmental disabilities. This dissertation task will add to the currently limited literature on services for individuals on waiting lists. The following chapter provides a context for this task through a discussion of the relevant literature.

CHAPTER II

Review of Relevant Literature

Abstract

The purpose of this chapter is to review literature relevant to this dissertation. Sections in this chapter include Caregivers of Individuals with Developmental Disabilities, Parent-Training Programs, Waiting Lists, and Programs for Waitlisted Individuals and Families.

The first section, Caregivers of Individuals with Developmental Disabilities, provides relevant information about differences between parents who have a child with a developmental disability and those who have a normally developing child, especially in relation to parental stress and psychopathology. In addition, differences between mothers and fathers of a child with a developmental disability are also discussed. This section is relevant to this dissertation because it provides readers with an understanding of some of the characteristics of parents of a child with a developmental disability.

The second section, Parent-Training Programs, reviews literature on various aspects of parent-training programs and the potential benefits related to participation in these programs. Parent-training programs are one example of a service that is offered to caregivers who are interested in obtaining new knowledge and skills that will allow them to become more effective in dealing with aspects of their child's disability, including

challenging behaviors and limited self-help skills. This section is relevant to this dissertation because it is important for readers to have a thorough understanding of parent-training programs because the program that is being implemented and evaluated is a program for parents waiting to be able to participate in a parent-training program.

The third section, Waiting Lists, provides information about the process of creating and managing waiting lists. This section is relevant to the dissertation because the program that is being implemented and evaluation has been developed due to the fact that there is a long waiting list for services.

The final section, Programs for Waitlisted Individuals and Families, provides information about services available to people on waiting lists, as well as examples of specific programs that have been developed to support individuals on waiting lists. Readers will gain an understanding of the range of services that can be offered to individuals waiting for mental health services.

Caregivers of Individuals with Developmental Disabilities

A review of the literature on caregivers of children with a developmental disability (e.g. autism, brain injury, mental retardation) revealed a wide range of information regarding parenting-related characteristics for this population of children. A general trend in the research suggests that the child with a developmental disability is often seen as a source of stress for the parents and family system (Boyd, 2002). While most research focuses on the child's characteristics as a source of stress (Dumas, Wolf, Fishman, & Culligan, 1991), recently, a systems approach has become more common, with a focus on how each family member, not just the disabled child, has an impact on

the well-being of each other and the family unit (Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005).

Parental Stress

Boyd (2002) conducted an extensive literature review which revealed that parents of children with developmental disabilities tend to experience higher levels of stress related to parenting than do parents of typically developing children (Dumas et al., 1991). Although parenting-related stress is normal, a combination of variables, including child's diagnosis, severity of the disability and behavioral challenges, parental well-being, family resources, and social-contextual factors (e.g., socioeconomic status) were found to contribute to higher parental stress for parents of a child with a developmental disability (Dumas et al., 1991; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009). It is important to note that, while many parents of children with disabilities have been found to experience elevated levels of stress, all parents of a child with a developmental disability do not experience high stress (Davis and Carter, 2008). In addition, differences in reported levels of stress have been found based on the child's specific developmental disability (Dumas et al., 1991).

Dumas et al. (1991) investigated differences in parenting stress for parents of children with different developmental disabilities (i.e., autism, behavior disorder, and Down syndrome) and typically developing children. They found that parents of children with autism and behavior disorders experience significantly higher levels of parenting stress than either parents of children with Down syndrome or typically developing children (Dumas et al., 1991). For parents of a child with autism or a behavior disorder,

elevated scores were only significant on the child domain (not the parenting domain), suggesting that increased stress is a factor of the child's characteristics as opposed to the parents' sense of competence (Dumas et al., 1991). Davis and Carter (2008) also found that the child's individual characteristics, including their social and communication deficits, as well as their challenging behavior, can have a negative impact on the quality of family life and parental psychopathology.

Many researchers have found that, in general, parents of children with developmental disabilities report higher levels of stress than parents without a disabled child (Wolf, Noh, Fisman, & Speechley, 1989; Dumas et al., 1991); however, it should be acknowledged that traditionally, mothers have been the primary participants in research studies on parental stress (Hastings, 2003). While there is a substantial amount of research supporting higher levels of stress for mothers of children with developmental disabilities than mothers of typically developing children, there is less information about the differences between fathers (Dumas et al., 1991). However, at least one study has found fathers of disabled children to report more stress than fathers of non-disabled children (Wishart, Bidder, & Gray, 1981).

Research on whether there are differences between the stress levels of mothers and fathers of children with developmental disabilities has been inconclusive. Some researchers have found mothers to report higher levels of stress and/or other negative effects (e.g., depression, anxiety) than fathers (Bristol, Gallagher, & Schopler, 1988; Hastings and Brown, 2002), while others have found little or no difference between mothers and fathers (Wolf et al., 1989; Hastings, 2003; Davis and Carter, 2008). When differences in stress levels have been found, researchers have tended to attribute the

results to the traditional differences in parenting roles of mothers and fathers, with more caregiving burdens placed on mothers (Davis and Carter, 2008).

Parental Psychopathology

Similar trends have been found in regards to reporting symptoms of psychopathology, with parents, specifically mothers, with a child with a developmental disability reporting more symptoms of psychopathology compared to parents with typically developing children. Mothers of autistic children have been found to report dysphoria more often than mothers of children with mental retardation, behavior disorders, or typical development (Dumas et al., 1991; Wolf et al., 1989). Mothers have also been found to be more likely to describe themselves as mildly depressed (Dumas et al., 1991) and to report significantly more symptoms of depression than mothers of typically developing children (Wolf et al., 1989). Researchers suggest that the differences in psychological symptoms between mothers with and without a child with a developmental disability are more a function of parenting stresses related to caring for a child with a developmental disability than an indication of a true depressive disorder (Wolf et al., 1989; Dumas et al., 1991). Although differences between mothers have been found, no significant differences in reported symptoms of psychopathology have been found between fathers (Wolf et al., 1989; Dumas et al., 1991).

When comparing mothers and fathers with a child with a developmental disability, most researchers have found that mothers report more symptoms of both depression and anxiety than fathers (Hastings et al., 2005). In addition, mothers have

been found to be more likely to identify themselves as being mildly depressed than fathers (Dumas et al., 1991).

Variables Related to Stress and Psychopathology

In terms of predictive variables, a child's behavior problems have been found to have a greater impact on parental stress and psychopathology than the severity of the child's disability (Hastings, 2002). However, while parental stress has been found to be positively correlated with the child's behavior problems for mothers, the same relation has not been reported for fathers (Hastings, 2003; Hastings et al., 2005). Both maternal and paternal stress, however, have been found to be positively correlated with their partner's depression (Hastings, 2003, Hastings et al., 2005). In addition, the quality of the marital relationship, the child's adaptive skills, the physical care demands of the child and restricted opportunities for social support outside of the family have all been found to be correlated with the presentation of psychological symptoms for mothers and fathers (Hastings, 2003).

Differences in predictive variables may be related to distinctions in parental roles, with mothers generally having greater involvement in daily caretaking activities as compared to fathers (Konstantarea and Homatidis, 1992). Research results suggest that having a lower level of involvement and being generally less affected by their child's behavior problems may account for fathers' lower levels of reported stress (Bristol et al., 1988; Konstantarea and Homatidis, 1992). In addition, it is possible that the coping strategies fathers utilize to deal with their child's behavior problems may help to reduce the impact of these behaviors on their well-being (Hastings et al., 2005).

Positive Perceptions

While there is substantial information about the negative effects of parenting a child with a developmental disability, less information exists about these parents' positive experiences. The majority of information about parents' positive experiences of raising a child with a developmental disability has been anecdotal; however, a few empirical studies have been conducted on this topic (Taunt and Hastings, 2002; Hastings et al., 2005).

According to Taunt and Hastings (2002), parents who are able to acclimate to the role of caring for a child with a developmental disability are often able to report positive perceptions and experiences. Abbott and Meredith (1986) conducted a study comparing 30 married couples with and without a child with mental retardation and found that parents of a child with mental retardation were less critical of each other and perceived fewer family problems. In addition, the majority of the parents with a child with mental retardation reported at least one positive outcome (family grew closer and stronger) (Abbott and Meredith, 1986). Being able to accept their child's disability and perceive their situation in a positive way, as well as having support from family and friends, contributed to these families ability to adapt (Abbott and Meredith, 1986).

Scorgie and Sobsey (2002) also investigated significant, positive experiences of parents with a child with a disability. Interviews with 15 parents revealed common themes, which became the basis of a rating scale that was given to 80 parents. The majority of these parents reported numerous positive changes in their lives due to their experiences of caring for their child with a disability (Scorgie and Sobsey, 2002). Examples of positive experiences included opportunities to function in new roles, a

stronger marriage, expanded friendship network, and being able to make the most of each day. Overall, the positive experiences reported by these parents were similar to those reported in other published research (Taunt and Hastings, 2002).

According to Taunt and Hastings (2002), having positive perceptions contributes to successful coping for parents with a child with a developmental disability. Although both mothers and fathers have been found to be generally positive about the future (Taunt and Hastings, 2002), mothers have been found to report significantly more positive perceptions than fathers (Hastings et al., 2005). While a correlation between the mothers' perceptions and either child or father variables has not been found, the fathers' perceptions have been found to be negatively correlated with maternal depression (Hastings et al., 2005). Therefore, the mother's well-being appears to have a direct impact on the fathers' report of positive experiences.

Although the research provides varying results regarding parental stress and psychological symptoms, it appears clear that parents, and especially mothers, with a child with a developmental disability tend to have elevated levels of stress and symptoms of psychopathology as compared to parents of typically developing children. A variety of variables have been identified as having an impact on parent characteristics, including spousal stress and psychological symptoms, marital support, and the child's behavioral characteristics; however, the extent to which each of these variable affects a parent has been found to vary.

Parent-Training Programs

Caring for a child with a developmental disability can be very challenging. This challenge is exacerbated when the child exhibits severe behaviors (e.g., kicking, biting, self-injury) in the home setting and/or in the community. In order to be able to effectively take care of a child with a developmental disability and challenging behaviors, caregivers often seek support from professionals. While most interventions are aimed at specifically helping the child, such as medication and special education programs, comprehensive programs for parents of these children have also been developed (Johnson, Handen, Butter, Wagner, Mulick, Sukhodolsky, Williams, Swiezy, Arnold, Aman, Scahill, Stigler, McDougle, Vitiello, & Smith, 2007).

Parent-training services are one type of program that is available to parents with a child who exhibits behavioral challenges (McIntyre, 2008). Participation in a parent-training program provides caregivers with the opportunity to learn new skills that will help them to become effective behavior managers so that their child can remain in the home until adulthood (Petronko, Harris, & Kormann, 1994). Prior research suggests that the inclusion of parents in intervention programs is critical to the success of the program (Symon, 2005).

Philosophical Foundation

Parent-training programs are based on a combination of theories and behavioral principles, including social learning theory, operant conditioning, and behavior modification (McIntyre, 2008). While each specific program has a different theoretical

foundation, the majority of the programs have a strong base in applied behavior analysis (ABA) (Johnson et al., 2007) and focus on teaching parents specific procedures for working directly with their child (Symon, 2005).

More traditional parent-training programs have focused on parents with children with conduct problems and antisocial behavior, with the focus helping them learn to decrease their child's challenging behaviors (McIntyre, 2008). However, parent-training programs have also been designed for parents of a child with a developmental disability, with a greater focus placed on increasing adaptive behaviors and self-help skills (McIntyre, 2008). Due to the co-morbidity of many developmental disabilities and behavior problems, parents with a child with a developmental disability can often benefit from programs that incorporate both types of training. Therefore, more recently, training programs have been designed to meet the needs of parents with children with developmental disabilities who also exhibit behavioral challenges (McIntyre, 2008).

Program Delivery and Elements

Parent-training programs have historically been provided mainly to groups of parents in outpatient and group settings (Johnson et al., 2007). Studies investigating the differences between group and individual training in behavior modification have found them to be similarly effective for parents of children with a behavior problem, regardless of the child's intellectual ability (Brightman, Baker, Clark, & Ambrose, 1982). When parent training is provided to groups of caregivers, the service is more cost-effective and provides participants with opportunities to seek peer support and discuss their experiences with each other; however, there is often not enough time or available staff to

allow for individualization of techniques and treatment plans (Brightman et al., 1982). Providing services to individual families is less cost-effective, but allows service providers to individualize certain elements of the program to meet the specific needs of that family. Due to the chronic nature and severity of behavioral challenges in children with developmental disabilities, individualized parent-training programs that can be provided in the home setting may be more appropriate for this population. By providing individual services, there can be greater flexibility in terms of the types of techniques taught as well as individualization of the treatment plans (Brightman et al., 1982).

Although there are differences in the way that the program is provided in a group or individualized setting, both types of parent-training programs commonly share many of the same elements (Johnson, et al., 2007). However, some programs provide more basic training, while others are more comprehensive. Multiple modes of teaching can be utilized in parent training, including “written or videotaped instruction, role play, in situ prompts, performance feedback, and live or video-taped modeling” (Lerman, Swiezy, Perkins-Park, & Roane, 2000). Ideally, all of these modalities should be utilized, especially in group settings, as there will most likely not be an opportunity to determine each of the parents’ individual learning style. In addition, while some skills may be amenable to learning through instruction only, others may require more dyadic learning opportunities for mastery (Lerman et al., 2000). While some researchers have found that more basic, inexpensive training programs can be as effective as more comprehensive programs (Brightman et al., 1982), others have found basic programs providing only verbal and/or written instructions do not effectively teach parents behavior management skills (Lerman et al., 2000).

Although the methods used to teach parents about behavior management may differ across programs, the information and techniques taught are generally the same. The main topics focused on in parent-training programs for parents with a child with a developmental disability are methods of data collection, identification of antecedents, behaviors, and consequences, and techniques for increasing and decreasing behavior. Parents are taught methods of data collection so that they can collect data in between parent-training sessions. In addition, they are taught how to identify the antecedents and consequences of a child's behavior so that they can gather information about the environmental factors related to the target behavior. This information is crucial for determining the function of the behavior, a necessity for choosing an appropriate method for increasing or decreasing that behavior (Johnson et al., 2007). Parents also learn how to utilize behavior modification techniques, including prevention and antecedent strategies, in order to modify their child's behavior after the function of the behavior has been identified (Johnson et al., 2007). Additional information is provide on the use of positive and negative reinforcement and punishment, extinction, and other techniques to increase and reduce behavior (Johnson et al., 2007).

Research has produced mixed results in regards to whether the specific skills taught in the training have a direct impact the outcome. Some researchers have found there to be no difference in outcome based on the type of information provided during the parent training (O'Dell, Flynn, & Benlolo, 1977). However, Baker and Brightman (1984) found that, in general, parents who were either taught skills to manage behavior problems or to help them become more effective advocates, displayed program specific gains. While some skills related to behavior management, such as the use of

reinforcement or advocacy skills, may be susceptible to vicarious acquisition, other skills, such as data collection methods and development of behavior plans, often require direct training (Baker and Brightman, 2004).

Obstacles

Although parent-training services are often effective, obstacles can impact the training outcome (Baker, Heifetz, & Murphy, 1980). Parents have reported that the amount of time that training is provided can be the biggest obstacle (Baker et al., 1980). Although parent-training programs vary significantly in their length (i.e. from a few hours to a few years), the amount of time direct services are provided are often limited due to budgetary constraints. Programs that provide training for a substantial amount of time are able to place a greater focus on incidental training, as well as way to utilize newly learned techniques during real world situations (Baker et al., 1980). Applied training opportunities have been found to increase the effectiveness of consultation and improve parents' motivation (Baker et al., 1980). The severity of their child's behavior problems and their lack of skills were child-related obstacles reported by parents, especially those with children with limited self-help skills (Baker et al., 1980). Being able to provide more training on motivation techniques and behavior management skills could help parents feel more equipped to work with their child (Baker et al., 1980). Parents also reported feeling as though they were unable to effectively utilize the techniques and needed additional support (Baker et al., 1980). Programs that individualize the specific training techniques that are taught may be able to increase

parents' confidence by providing support with regards to implementing the new techniques they will be most likely to utilize.

Effectiveness and Factors Related to Positive Outcomes

Despite these obstacles, parent training programs have been found to be an effective intervention for teaching parents techniques that can be used to reduce challenging behaviors and increase adaptive skills in the home setting (Lerman et al., 2000; Symon, 2005). Parents have been found to be able to learn and apply new behavioral skills after as few as 20 hours of training (Johnson et al., 2007) and retain their knowledge of program principles for at least one year following participation in behavioral training (Baker et al., 1980).

Studies have identified a variety of factors related to positive outcomes following participation in parent-training programs. Clark, Baker, & Heifetz (1982) found that a mother's post-training knowledge of behavioral principles was the most important factor associated with a positive outcome. Therefore, whenever possible, it is important to ensure that the parents have a thorough understanding of behavioral principles before training services are terminated. In addition, McIntyre and Phaneuf (2007) identified parental stress and parent-child interactions as important indicators of treatment outcome. Organizational staff should assess parental stress prior to the start of parent-training services in order to determine if it is appropriate to commence with training. Information about parent-child interactions could also inform decisions about appropriateness of starting services.

Benefits and Concerns

Although participation in a parent-training program can be stressful and time-consuming, researchers have found there to be many associated benefits, not just for the child with the developmental disability, but for the entire family (Petronko et al., 1994). Following participation in a parent-training program, families reported having more time for recreation and leisure, spending less time on assisting their child with activities of daily living, having a decrease in depressive mood and perceived stress, and an increased satisfaction with the family's ability to adapt (Koegel, Schreibman, Johnson, O'Neill, & Dunlap, 1984 as cited in Petronko et al., 1994; Baker (1989) as cited in Petronko et al., 1994). In addition, parent-training services help parents become more effective behavior managers, increasing the likelihood that the child will be able to remain in the home setting (Baker, Landen, & Kashima, 1991).

Although there are many benefits to participating in parent training, it is important that potential risks are considered. Parents who exhibit symptoms of psychopathology, or who are too distressed about their child's diagnosis to focus on their role in the family system, may need other types of interventions before they would be ready to participate in parent training (Petronko et al., 1994). Additionally, Petronko et al., (1994) found that families from lower socioeconomic status, single parents, and families with previous histories of psychopathology needed additional support. While parent-training services can be beneficial to families, it is important that service providers make a reasonable attempt to ensure that parents are ready and willing to put forth the time and effort that is necessary for a successful outcome.

The studies reviewed found parent-training programs to have positive effects on families with a developmentally disabled child. Although programs can differ greatly on the setting, format, and modalities used to train parents on new techniques, they all tend to be focused on the same general goals of helping parents become more effective reducing their child's challenging behaviors and improving their adaptive skills. Although there are many different training programs, the waiting time for these services is often astronomical due to a lack of funding and is only expected to increase as the number of children diagnosed with a developmental disability continues to grow.

Waiting Lists

Waiting for Mental Health Services

Currently, there is a lack of objective information regarding the length of time that children and parents wait for mental health services. Miller, Armstrong, Masse, Klassen, Shen, and O'Donnell (2008) attempted a systematic literature review on waiting for child developmental and rehabilitation services, which revealed there to be a dearth of information regarding waiting times, procedures, and effective interventions. Their review revealed two studies that focused on the waiting times for children seeking developmental and rehabilitation services, though neither were mental health services. According to Feldman, Champagne, Korner-Bitensky, & Meshefedjian (2002), children with developmental delays and disabilities waited an average of five months to receive physiotherapy and four months for occupational therapy. Another sample revealed that half of the consumers waited more than seven months for physiotherapy and 11 months for occupational therapy (Feldman et al., 2002). Both of these studies found that longer

waiting times were related to the age of the child (older children had longer wait times), as well as residence in the suburbs (Feldman et al., 2002).

Since so little information was revealed regarding waiting lists for developmental and rehabilitation services for children, Miller et al. (2008) compiled a review on waiting times for health services in general. Surveys in Canada revealed that people seeking health services do not expect immediate access, considering a few months of waiting time to be acceptable (Miller et al., 2008). Studies have also shown that while many people are able to receive services in what they consider to be a reasonable amount of time, there are still people who wait an unacceptably long amount of time before being able to access services, even within a facility (Miller et al., 2008).

In regards to solutions to the lengthy waiting times, there is also a dearth of information in the literature. The research that does exist suggests approaches such as implementing prioritization strategies, increasing flexibility in the usage of clinical staff, and providing supports to families while they are waiting (Miller et al, 2008). The following literature review provides additional information on these strategies, with the main focus on how organizations can support individuals who are waiting for services.

Overview of the Use of Waiting Lists

Waiting lists are employed when an organization is unable to meet consumer demands. There are waiting lists for new videogame systems, season tickets to sporting events, and even prestigious pre-schools, to name a few. While waiting for these services may be frustrating, the waiting period does not usually have any significant negative

effects on the consumer. Having to wait for medical treatment or mental health services, however, can often be more debilitating.

Brown, Parker, and Godding (2002) acknowledge that waiting lists are often designed without much forethought. However, since the length, format, cost, and efficiency of treatment have a great impact on the waiting list, it is imperative that service providers carefully consider the design and implementation of a wait list in order to reduce costs and maximize benefits, for both the consumer and provider (Brown et al., 2002). External constraints often inhibit the ability to design and implement the most effective waiting list procedures; however, effortful attempts should be made at creating procedures that aim to reduce the length of the waiting list and maximize consumer benefits.

Waiting List Policies and Procedures

Although focusing on ways to decrease the length of waiting lists appears to be an obvious solution to the increasingly long waiting times, researchers have expressed concerns about attempts at doing so (Brown et al., 2002). Organizations that attempt to reduce waiting time by providing quicker treatment may compromise the integrity of the service they are providing and ultimately increase waiting times due to recidivism (Brown et al., 2002). If an organization decides to increase employee workload in order to serve more consumers, there is often a decrease in employee satisfaction, which can lead to an increase in employee turnover and consumer dissatisfaction (Brown et al., 2002). Based on these potential negative outcomes, an emphasis on determining severity

of need and appropriate services, while providing alternative services during the waiting period, appears to be the best approach at this time.

While careful planning and organization of a waiting list can be time-consuming, it is important that formal policies and procedures are implemented (Brown et al., 2002). Unfortunately, there has been very little research to support any specific recommendations or strategies regarding waiting list procedures (Brown et al., 2002). The research does suggest that a universal solution to address all of the issues related to the implementation of waiting lists does not exist. Based on their knowledge and experience, Brown et al. (2002) offer their opinion on appropriate, effective waiting list procedures, while highlighting the importance of considering the unique context of each organization when making decisions regarding the waiting list.

Once a service provider has made an initial contact with a consumer, their responsibility to that individual begins. During this first contact, the consumer should be provided with an honest estimate of how long they should expect to be waiting for services so they can make informed decisions in regards to seeking alternative services (Lakin, 1998). They should be informed of their exact number on the waiting list and an approximate date for when they should expect to start receiving services (Lakin, 1998).

Brown et al. (2002) suggests that screening procedures be utilized when contact is first made. Screening procedures can be a useful tool for finding out information about potential waitlisted members. While it is important to consider the related costs (e.g., the consumer's personal time, financial costs, necessary staffing), the information gained from screening procedures often outweighs the costs. Screenings can be quick and simple, such as a single request for a presenting problem, or can include extensive intake

evaluations (Brown et al., 2002). For individuals seeking mental health services, comprehensive screening procedures can often be considered a type of brief intervention, since they can receive beneficial information or experiences that lessen their need for intensive treatment (Brown et al., 2002).

When considering the use of a screening procedure, it is important to determine when the procedures will occur, as well as the type of information to be obtained. In general, screenings should take place within a few days after the first contact is made (Brown et al., 2002). The screening procedures should help practitioners quickly make decisions in regards to the severity of the consumers' needs, as well as who may not be able to benefit from the organization's services (Brown et al., 2002). Individuals who are unlikely to benefit should be referred to more appropriate organizations in a timely manner (Brown et al., 2002). The screening procedure, therefore, provides the organization with a more accurate list of people who can benefit from the service (Brown et al., 2002).

Screening procedures can also be useful in determining the type of services that a consumer needs. It is necessary to consider a range of variables in order to make appropriate decisions about treatment necessity (Brown et al., 2002). When possible, a triage procedure should be included in the waiting list procedures (Brown et al., 2002). Triage refers to the process of assessing the severity of an individual's needs in order to determine the urgency for services (Brown et al., 2002). Due the subjective nature of determining criteria for the need for immediate care, the usage of triage procedures has been under scrutiny; however, utilizing standardized protocols instead of clinical judgment can reduce subjectivity for making decisions regarding need (Brown et al.,

2002). By using a triage procedure, the service providers can determine which individuals need crisis services and which individuals will be less affected by spending time on a waiting list.

If a triage procedure is used, consumers who are new to the waiting list may be provided with services before those who have been waiting, due to the severity of their needs. Therefore, it is important that organizations allocate time for providing services to consumers in crisis. When triage procedures are not used, or a consumer does not need crisis services, waiting list procedures are more straightforward (Brown et al., 2002). Often, services for individuals who are not in crisis are provided in a “first come, first serve” manner, with the person at the top of the waiting list being provided with services once available.

Following the initial contact, the service provider should periodically contact waitlisted members with updates on their waiting list status and obtain updated consumer contact information, monitor their motivation, and help them feel prepared for participation in the service (Brown et al., 2002). Additionally, consumers should be provided with information on how to contact the organization throughout the waiting period.

Service providers have an ethical obligation to support consumers on the waiting list by providing them with some type of alternative service during this period (Brown et al., 2002). When appropriate, brief interventions, such as providing advice, educational or self-help material, a follow-up letter or telephone consultation, and/or waiting list group should be available to consumers on waiting lists (Brown et al., 2002). Waitlisted individuals should be provided with opportunities to discuss their experiences with each

other, as these types of experiences have been found to help individuals gain strength in their ability to become active participants in their treatment (Lakin, 1998).

Procedures for contacting consumers once services can be provided should also be clearly stated (Brown et al., 2002). Commonly, organizations will contact the person at the top of the list once a treatment slot is available and treatment will begin shortly with the next available provider. Organizations should make a reasonable attempt to contact a waitlisted member before moving on to the next person on the list.

Organizations should have clear policies that state the definition of a reasonable attempt so that a vacant spot is not left open indefinitely (Brown et al., 2002). Some organizations allow consumers to choose to continue waiting after they have reached the top of the list in order to work with a particular service provider or a service provider of a certain age, gender, or race (Brown et al., 2002). The potential benefits of allowing consumers to continue waiting for a particular service provider should be weighed against the expense of further prolonged treatment.

While providers have many responsibilities to consumers on waiting lists, it is important that consumers are also held accountable during the waiting period. Consumers should be expected to initiate contact with the provider, read relevant materials about the organization, and monitor their own needs (Brown et al., 2002). Consumers are also responsible for contacting providers to update contact information or to inform them of a decision to withdraw from the waiting list. If a service provider requires particular information at the start of treatment, consumers should be made aware of this while on the waiting list and should make reasonable attempts to collect any relevant information or documents prior to the initial treatment session (Brown et al.,

2002). Consumers' effort during the waiting period can inform providers about their interest and commitment in receiving treatment (Brown et al., 2002).

Provider Benefits and Costs

Although waiting lists are often considered undesirable, researchers have suggested that employing them can be beneficial to service providers. As mentioned above, when individuals are on a waiting list, service providers can conduct more comprehensive screening procedures to determine the specific needs prior to the start of treatment. Waiting lists also often deter people who do not have an urgent need for treatment, thereby, acting as a rationing system to decrease inappropriate demand (Brown et al., 2002). Waiting lists can also be used to help organizations create treatment groups, by providing them with the flexibility to choose individuals with particular characteristics for a specific group (Brown et al., 2002). In addition, lengthy waiting lists can serve as evidence that there is a need for the organization's services, which in turn increases providers' sense of job security (Brown et al., 2002).

Unfortunately, service providers sometimes use a waiting list in order to delay treatment for consumers who receive services at reduced or no cost (Brown et al., 2002).

While there are many benefits, maintaining a waiting list can be costly, as staff must be allocated time to spend on tasks such as computer entry, answering/initiating telephone calls, drafting letters, providing treatment information, and screening individuals in order to ensure proper maintenance (Brown et al., 2002). Time spent on these activities reduces the amount of available time devoted to actively treating consumers. Organizations that employ waiting lists may also lose the opportunity to

provide treatment to some individuals, since long waiting times can lead people to seek treatment from providers with shorter waiting periods (Brown et al., 2002). Although this can help reduce waiting times, consumers may not receive the most appropriate service if they are unwilling to wait.

Consumer Benefits and Costs

Although consumers often complain about lengthy waiting lists, waiting can be beneficial if the time is effectively utilized through learning about and reflecting on the alternative treatment options (Lakin, 1998). Consumers who actively seek to become more educated about treatment options may choose alternatives, saving themselves, as well as the provider, time and money (Brown et al., 2002). Oftentimes, consumers who independently seek out alternatives become more confident in their ability to make appropriate decisions about their treatment (Brown et al., 2002).

In addition to actively seeking alternatives, some individuals may inadvertently and independently engage in activities that improve their symptoms, such as seeking social support or taking up a hobby (Brown et al., 2002). Others may experience a significant decrease in their problems without a direct intervention. Many researchers disagree that “spontaneous recovery” can occur, instead contributing the reduction in symptoms to participation in a brief intervention, such as an intake interview or short-term group (Brown et al., 2002). Regardless of the reason, if symptoms can be reduced during the waiting period, these individuals do not have to endure the costs, monetarily and/or timely, related to participation in intensive interventions and provide an opening for an individual who requires more intensive treatment (Brown et al., 2002).

Unfortunately, individuals on waiting lists are often unable to effectively manage their placement on the list and endure continual suffering as they wait to receive treatment (Brown et al., 2002). Many consumers who experience a delay in mental health treatment endure a variety of personal costs, including an increase in emotional distress, danger to self/others, and physical health risks (Brown et al., 2002). Time spent on a waiting list can lead to the need for even more intensive interventions, as symptoms may worsen during this time. In addition, if these individuals do not receive mental health services when they are needed, there is an increased likelihood that they will engage in drug use and/or criminal behaviors, which can have a major affect on society (Brown et al., 2002).

Currently, there is little research on how waiting for services impacts the likelihood of accessing services with waiting lists in the future, as well as participation in the service once access becomes available. One study found that individuals who have been on long waiting lists in the past may be increasingly reluctant to access similar services in the future (Brown et al., 2002). In addition, as the waiting period increases, individuals may be less likely to enter treatment once available (Tucker and Davison, 2002 as cited in Brown et al., 2002). Although most of the research focuses on negative impacts of waiting lists, some researchers believe that individuals actually become more motivated to participate in services after being on a waiting list because they “endured the rigors of waiting” (Brown et al., 2002). More research is necessary to obtain a clear understanding of the effects of waiting lists on eventual treatment acquisition; however, at the current time, providers can focus on providing as much support as possible to

waitlisted members in an attempt to increase the likelihood that they will participate in treatment once it is available (Brown et al., 2002).

Programs Aimed at Reducing Waiting Times

Although reducing waiting time is not always the most appropriate approach to help individuals seeking services with waiting lists, researchers have conducted a few studies on programs that aimed to reduce the amount of time individuals had to wait for services. The following interventions were successful in reducing waiting times, but should be considered as being for illustrative purposes only based on the limited data available (Miller et al., 2008).

At a specialist referral center in British Columbia, Canada, that provided assessments (approximately 200 per year) for individuals with autism spectrum disorder, 12 to 18 months was the average waiting period for an assessment (Kalynchuk, personal communication 2008 as cited in Miller et al., 2008). In order to be able to provide assessment services sooner, a province-wide autism assessment network was established. The network included newly formed, trained regional assessment teams that developed and utilized evidence-based standards and guidelines for assessment (Miller et al., 2008). Following the implementation of this new system, the average wait time for an assessment was reduced by between 6 and 12 months, to less than 6 months (Rockett, personal communication, 2008, as cited in Miller et al., 2008). While this intervention did not address the needs of the individuals on the waiting list, it significantly reduced the amount of time they had to wait for an assessment.

In Hillingdon, United Kingdom, the Speech and Language Therapy Department of the Hillingdon PCT NHS Trust took another approach to reducing waiting time. They decided to change their target population from children with speech and language deficits to the parents of children with these deficits. Instead of working directly with the children with speech deficits, the service providers trained parents to be able to work directly with their child(ren) (Rockett, personal communication, 2008, as cited in Miller et al., 2008). In addition, the organization reorganized their service delivery model to focus on group, rather than individual, therapy sessions (Rockett, personal communication, 2008, as cited in Miller et al., 2008). After these changes were implemented, the waiting time for an initial assessment decreased from 4 months to 4 to 6 weeks (Rockett, personal communication, 2008, as cited in Miller et al., 2008). For therapy services, the wait time decreased from 12 months to 6 to 12 weeks (Rockett, personal communication, 2008, as cited in Miller et al., 2008). By changing the target population and the service delivery method, the waiting time for assessment and therapy services decreased significantly.

In South Carolina, a pediatric tertiary care referral center revised their referral procedures for individuals seeking comprehensive developmental-behavioral assessments. The goal of the new referral procedures was for the organization to be able to gain more information about the referred individuals so that they could make appropriate referrals for additional evaluations or interventions (Kelly, 2007 as cited in Miller et al., 2008). These new, more comprehensive referral assessments were conducted by a nurse practitioner and social worker (Kelly, 2007 as cited in Miller et al., 2008). During pilot testing for the new referral procedures, the waiting times for the

developmental-behavioral assessment decreased from 168 to 26 days (Kelly, 2007 as cited in Miller et al., 2008).

Programs for Waitlisted Individuals and Families

For over 50 years, researchers have been concerned with meeting the needs of individuals who are on waiting lists to receive mental health services. While procedural adjustments can sometimes be made to reduce waiting times, generally, a waiting list still remains. It is important that programs that utilize waiting lists incorporate supports to meet the needs of the individuals who are waiting for services.

Brief Therapeutic Interventions

Based on a review of the literature, brief therapeutic interventions (e.g., brief waiting-list groups) appear to be one of the most popular types of interventions that are provided for waitlisted members. However, few studies about this type of intervention have been conducted (Hotkins, Kriegsfeld, & Sands, 1958; Stone and Klein, 1999). In general, the research has shown that brief therapeutic interventions have been found to improve patient outcomes (Brown et al., 2002). Unfortunately, while patient outcome may improve, these interventions do not seem to increase the likelihood that an individual will participate in treatment once it becomes available (Brown et al., 2002). Even though treatment participation may not increase following participation in a brief intervention, service providers should consider implementing this type of service to meet some of the needs of waitlisted individuals.

At a university-affiliated mental health facility, individuals who sought treatment were given the option of participating in a weekly waiting list group, known as the preliminary process group (Stone and Klein, 1999). During a pilot study, approximately 13% (35 out of 262) of the individuals who did not receive immediate care (and were placed on the waiting list) chose to participate in at least one of the nineteen 75-minute process-oriented group sessions (Stone and Klein, 1999). The individuals who chose to participate were characterized as generally being older and less educated than the people who chose to remain on the waiting list (Stone and Klein, 1999). Of the 35 people who participated in the group, 18 attended more than one session (Stone and Klein, 1999). Stone and Klein (1999) found no significant differences between the individuals who attended the preliminary process group and those who did not, in terms of attending additional treatment, with approximately 80% of individuals in each group entering treatment. However, individuals who participated in the group were more likely to enter group therapy (25% vs. 4.8%; Stone and Klein, 1999). Therefore, the results of this study suggest that participation in a brief intervention while on a waiting list may not have an impact on the decision to participate in services once they become available.

Another study that focused on the likelihood of participating in treatment following a brief intervention found similar results. Individuals waiting to receive intensive inpatient substance abuse treatment at a VA medical center were given the choice of participating in a waiting list group. Results showed no statistical difference in eventual treatment access rates between participants in the group and individuals who chose not to participate (Parker, unpublished data, January 1997 as cited in Brown et al., 2002). To date, these studies appear to be the only studies that focus on the affect of brief

interventions on mental health-related treatment access for individuals who were on a waiting list (Brown et al., 2002).

Educational Interventions

The following is the only study that was found during a literature review search for interventions for parents with children on a waiting list for mental health-related services. Hotkins et al. (1958) created an educational group for parents of children on a waiting list for mental health services. Since a screening procedure would have cost them additional time and money, the researchers developed the group with little initial information about the potential participants (Hotkins et al., 1958). They did have background knowledge that the members of the community generally lacked an understanding of family dynamics and children's emotional needs and had been uncooperative, even to the point of sabotage, in relation to treatments for their children (Hotkins et al., 1958).

The main objective of the parent group was to increase parental understanding of their children's emotional and behavioral difficulties, while attempting to relieve some of the stress related to waiting for a long period of time to receive services (Hotkins et al., 1958). Additionally, the researchers wanted to determine if the type of information gained from this type of group could lead to shorter intake studies of the families, while providing enough information to determine who could benefit from therapeutic groups and who might need individual attention, which families would be appropriate for their services, and to get a better idea the families' needs and accessibility to treatment (Hotkins et al., 1958).

The parents of all 59 children on the waiting list were contacted and invited to attend a meeting to discuss how the center could help them during the waiting period (Hotkins et al., 1958). At least one parent of 26 of the children attended one or more of the 12 one-and-a-half hour sessions, while parents of 13 children attended the majority of the sessions (Hotkins et al., 1958). During the first three meetings, parents expressed considerable doubt and disappointment about the purpose of the group, focusing on the fact that the children alone had the problems (Hotkins et al., 1958). However, as the discussions were directed toward recognition of their reactions to each other and to their children, the group became more comfortable in realizing that they were all having similar experiences (Hotkins et al., 1958). Over time, the parents examined their own roles in the family unit and were able to share feelings of guilt, self-blame, and disappointment in themselves for being unable to solve their children's problems (Hotkins et al., 1958).

Although the researchers were unable to determine the effectiveness of this type of group, the parents who participated in the group did express feelings of gratitude for the experience and indicated through their words and behavior that there had been positive changes at home since the initial session (Hotkins et al., 1958). The parents also expressed experiencing relief through the process of sharing their problems and learning that other people had similar experiences (Hotkins et al., 1958).

The researchers' approach at meeting the needs of parent's on the waiting list helped them to gain additional information about the needs of the families and to reduce the waiting list, by removing those who were no longer interested in services or were not appropriate for services (Hotkins et al., 1958). The diagnostic information gained from

the group exceeded that from the usual intake process and was beneficial in determining appropriate alternative treatments that were available immediately, as well as how they should proceed once treatment became available (Hotkins et al., 1958). While this type of group requires organizational resources, it appears to be a beneficial intervention, as it meets some of the needs of the individuals who are waiting for services, while also providing the organization with additional information that could not be sought through a brief intake procedure.

Programs for Waitlisted Families with Children with Developmental Disabilities

Tens of thousands of individuals with developmental disabilities are waiting for services, and in most states those numbers are growing (Lakin, 1998). Specific statistics regarding the number of families of individuals with developmental disabilities who are waiting for in-home supports are not dependably recorded, but the long waiting list for these services stands as a testament for the demand. Even as the number of people receiving services increases, the waiting lists continue to grow, at least partially due to the fact that individuals with developmental disabilities are living longer than ever before and therefore require the use of services for more years (Lakin, 1998). Additionally, in the last decade or so, the demand for services has increased as people are actively seeking out services more than in the past (Lakin, 1998).

In order for waiting times to be effectively reduced, it is essential that organizations that provide services to families with children with developmental disabilities focus on supporting families in their homes and keeping children and youth with their families (Lakin, 1998). It is important for organizations to be realistic in

regards to the types of services they can provide and what they can do to shorten the waiting time. Service providers should maintain comprehensive data records that include information that can inform the planning and prioritizing of services, such as data on the client's current needs and circumstances, available supports, the specific service they are waiting for, when the service is needed, and the person's priority level for the service (Lakin, 1998). This information can be used to determine appropriate supports that can be provided while the families are waiting.

While many aspects related to the increasingly long waiting times cannot be controlled, there are some changes that service providers can make to improve the despairing situation. Service providers have a commitment to their clients to acknowledge their need for treatment and to provide support while they are waiting to access services (Lakin, 1998). How this support is provided and the type of support will differ based on the needs of the clients and the amount of resources the service providers can make available to them. Regardless of the type of support, efforts must be made to minimize potential negative aspects and maximize the potential positive aspects of waiting to receive services (Lakin, 1998).

Summary

The information contained in this literature review provides the reader with background knowledge about topics related to this dissertation. First, information was provided about parents of children with a developmental disability. Research has shown that parents, especially mothers, of a child with a developmental disability report higher levels of parental stress and symptoms of psychopathology. While, mothers and fathers

of a child with a developmental disability generally report similar levels of stress, mothers report more symptoms of psychopathology. The child's behavior problems, as well as the partner's depression, were found to be related to elevated levels of stress, while the quality of the marital relationship, the child's adaptive skills, the physical care demands of the child and restricted opportunities for social support outside of the family were all found to be correlated with the presentation of psychological symptoms.

Parent-training programs are one type of service that is offered to parents of a child with a developmental disability interested in obtaining new knowledge and skills that will allow them to become more effective in managing aspects of their child's disability. The main goal of these programs is to reduce challenging behaviors and increase adaptive behaviors; however, a reduction in parental stress and psychopathology has been found to occur following participation.

Unfortunately, due to the increasingly high number of children diagnosed with a developmental disability, the waiting lists for these programs can be extremely long. Historically, individuals on waiting lists have been provided with limited or no support while waiting for services. A review of the few studies that have been conducted regarding programs developed for individuals on waiting lists was provided.

The purpose of this dissertation is to extend current research and provide services to caregivers waiting to receive parent-training services. Following Maher's (2000) program planning and evaluation framework, this dissertation will provide information about the design, implementation, and formative evaluation of a waiting list program that was designed to meet the needs of these caregivers.

CHAPTER III

Description of the Waiting List Program

Abstract

Maher's (2000) program planning and evaluation framework was designed to be applied to human services programs. The program planning and evaluation process includes gathering, analyzing, and interpreting information so that value judgments can be made in regards to the merit of a program. The framework includes four main tasks: Clarification, Program Design, Implementation, and Program Evaluation. During each of these phases, there are a number of components and activities that should occur. Each of the phases is described below. Following the description of the framework, the remainder of the chapter focuses on the second phase, Program Design.

The Program Planning and Evaluation Framework

Clarification Phase

In order to plan a program that may add value to a group of people, it is necessary to have a clear understanding of the current situation that is of concern to a client and relevant stakeholders. The purpose of the Clarification Phase is to gather information related to a specific target population to determine if it is appropriate to design and implement a human services program for that population based on the needs and the

relevant context. During this phase, there are three main activities: specify the target population, determine the needs of the target population that may be addressed by a human services program, and delineate the relevant context in which the needs are embedded. These activities are sequential, interrelated, and reflexive, in that one activity must follow the other, with information gathered from one activity guiding the process for the next activity, as changes to the next activity may be necessary based on the previously completed activity.

During the first activity, the target population, or group of people to whom a program can be designed and implemented, is specified. Relevant information about the target population, including the size of the target population and their relevant characteristics (i.e., demographic information, social-community characteristics, educational characteristics, psychological characteristics, and physical characteristics) is obtained through interviews, permanent product reviews, and/or questionnaires. Once this information has been analyzed and interpreted, consideration should be made in regards to segmenting the population, or dividing the target population into meaningful groups. All of the information collected and analyzed should be documented in a table, graph, narrative, and/or through oral discussion.

During the second activity, the information gained during the first activity guides the process of determining the needs of the population. For program planning purposes, a need is the discrepancy between the current state of affairs and the desired state of affairs in regards to the psychological or educational functioning of the target population. In order to determine the needs, a needs assessment is conducted to gather, analyze, and

interpret information about the target population and their needs so that value judgments can be made in regards to the nature, scope, and extent of the needs.

Once the needs assessment has been conducted, it is important to determine the organizational context in which the target population's needs are embedded. An "A VICTORY" (i.e., eight factors: ability, values, ideas, circumstances, timing, obligation, resistance) approach should be used to obtain contextual information in a step-by-step manner. All of this information, which can be obtained through interview, questionnaire, permanent product review, and/or participant observation, can inform the organization's readiness to engage in the program planning process.

Program Design Phase

The purpose of the second phase, Program Design, is to use information gained during the Clarification Phase to document the program in terms of essential program design elements. Documentation of all essential elements ensures a clear understanding of the program, which helps to keep the program planning and evaluation process under control. The four main activities during this phase are to describe the purpose of the program and the program goals, consider program design alternatives, develop the program, and document the program design.

The purpose of the program should address the following questions:

Who is to receive the program?

How will they be provided with the program?

What value is expected from participation in the program?

The program goals should reflect the outcomes that will ensue for members of the target population due to their participation in the program. These goals should be derived from the needs of the target population and linked to anticipated knowledge, skills, and abilities of the target population following participation in the program. The program goals should be SMART, meaning that they are Specific, Measurable, Attainable, Relevant, and Time-framed.

Once the program goals have been delineated, program design alternatives should be considered. Considering various program designs increases the probability that the program will be designed according to the needs of the target population and the purpose and goals of the program. Next, the program should be developed, with consideration to the available or necessary resources for successful implementation. Finally, all of the essential elements should be documented so that the program can be implemented successfully and in a manner that will lead to valuable program outcomes. The program design includes the following 12 elements: program purpose and SMART goals; eligibility standards and criteria; policies and procedures; methods and techniques; materials; equipment; facilities; components, phases and activities; budget; personnel; incentives; and program evaluation plan.

Implementation Phase

The purpose of the implementation phase is to monitor the implementation process to make sure that it is implemented as designed and that modifications to the design are made as appropriate. If there is no documentation of the implementation process, then the contributions of the program to the outcome cannot be made. In order

to document the program that was actually implemented, there are three main activities, which are sequential, interrelated, and reflexive in nature. The three activities include: a review of the program design, facilitation of the implementation of the program, and program process monitoring.

The purpose of reviewing the program design is to determine if the program is still relevant to the target population, their needs, and the relevant context. All of the program elements should be evaluated to determine if they are still relevant. It is necessary to determine if the program was developed to the extent that it can be implemented as it was designed and if there are other factors that could influence how the program is actually implemented. Once the program design has been adequately reviewed, program implementation can begin. During implementation, the process should be monitoring through data collection about the actual implementation of the program design elements. Monitoring the implementation increases the likelihood that the program will be implemented with integrity and considered worthwhile. The program activities should be documented as implemented so that the program can be evaluated appropriately.

Program Evaluation Phase

The final phase of the framework is the program evaluation phase. The purpose of this phase is to ensure that data related to the program evaluation questions are gathered and analyzed so that value judgments can be made about the program. This phase begins during the Program Design Phase, when a program evaluation plan is formulated as one of the design elements, and continues through the Evaluation Phase,

when a sound program evaluation is conducted to allow for continuous program improvement.

A sound program evaluation includes four qualities: practical, useful, proper, and technically defensible (Maher, 2000). First, the evaluation should be *practical* in that the plan can be implemented by individuals in the organization in a way that is not disruptive to the organizational routines. Second, the evaluation should be *useful* in that the information generated provides clients and other relevant stakeholders with the ability to make effective decisions about the program and ways to improve it. Third, the evaluation should be *proper* in that the process occurs in adherence to relevant ethical and legal standards. Finally, the evaluation should be *technically defensible*, including methods, procedures, and instruments that can be justified as to their reliability, validity, and accuracy.

The program evaluation process includes 12 activities that are sequential, interrelated, and reflexive. These activities will be discussed in Chapter IV.

Description of the Program Design

Callaghan (2008) designed a waiting list program for an organization that provides parent-training services to caregivers of individuals with developmental disabilities. The purpose of the program was to provide support to caregivers while on they were waiting for services through the dissemination of monthly educational worksheets on topics related to caring for an individual with a developmental disability. Based on previous contact with this organization, this investigator was given the opportunity to revise and customize Callaghan's (2008) program design to reflect the

organization's current contextual factors and to increase the likelihood of successful implementation. The original program design was reviewed and modifications to the design were made as appropriate.

While the purpose of the waiting list program remained the same, modifications to the program design were necessary due to major limitations in the number of personnel available to participate in the program planning and evaluation process. This investigator assumed the responsibility for the redesign, implementation, and formative evaluation of the waiting list program. Therefore, adjustments to the depth and breadth of the program were necessary in order for the program planning activities to be feasible.

Target Population

The target population of the waiting list program was 10 members of a waiting list in a particular region of the state of New Jersey. All members of the waiting list were caregivers of an individual with a developmental disability who were waiting to receive parent-training services.

Statement of Purpose

The purpose of the waiting list program was to provide waitlisted caregivers with information related to caring for an individual with a developmental disability while they were waiting to receive parent-training services. Support was provided in the form of monthly educational worksheets on topics related to caring for an individual with a developmental disability, as well as opportunities for the participants to request additional information relevant to their specific needs. Through participation in this program, the

caregivers were expected to have access to information that could make them more knowledgeable about behavior management concepts, ways to manage their own emotional reactions, and how to access services through DDD and other agencies. The only change to the original purpose was that information about opportunities for social support was no longer included in the program due to time constraints.

Program Goals

The following program goals were chosen based on the results of a needs assessment conducted by Callaghan (2008).

1. Caregivers will gain new knowledge about behavior management concepts.
2. Caregivers will gain new knowledge about managing their emotions related to their caregiving role.
3. Caregivers will gain new knowledge about accessing services through DDD and other agencies.
4. Caregivers will be satisfied with the information provided through the program.

Eligibility Standards and Criteria

In order for an individual to be eligible to participate in the waiting list program, he or she had to be a caregiver on the parent-training waiting list for one of the regions of the state of New Jersey. This investigator contacted caregivers on the waiting list, starting with the caregiver who had been on the waiting list for the longest amount of time. The first 10 caregivers on the list who agreed to participate in the program were

eligible as long as they were still living in the same region of New Jersey and were still interested in receiving parent-training services.

Policies and Procedures

Policy one. Members of the waiting list who were waiting for the longest amount of time were informed about the waiting list program until 10 members agreed to participate in the program. Informed consent to participate was obtained from each of the waiting list members who agreed to participate. Only waiting list members who consented were able to participate in the program. Participants could withdraw their consent from the program at any time without penalty.

Procedure for policy one. This investigator attempted to contact members of the waiting list by telephone to schedule one home-based visit. Contact attempts were made until 10 caregivers agreed to participate. At the home-based visit, this investigator explained the nature of the program, including the potential benefits to the waiting list member and the responsibilities of both the waiting list member and this investigator. An informed consent form was given to each member who expressed continued interest in participating.

Policy two. Participation or refusal to participate in the waiting list program had no effect on the members' right to participate in the full parent-training program. In addition, their participation did not affect their status on the waiting list.

Procedure for policy two. The informed consent form included information explaining that the member's decision to participate or not participate in the waiting list

program would not affect his or her eligibility for parent-training services or his or her status on the waiting list.

Policy three. Information in the educational worksheets was current and technically defensible.

Procedure for policy three. All of the educational worksheets were developed based on current research and/or from expert opinions of the organization's staff or other appropriate experts. The information was reviewed periodically to ensure that it remained current.

Policy four. The educational worksheets were sent out regularly and in a timely manner.

Procedure for policy four. The educational worksheets were mailed out on a specified date of each month by this investigator.

Policy five. This investigator was to notify the organization's administration of any adverse caregiver reactions and/or potentially harmful situations within the caregiver's household.

Procedure for policy five. This investigator had to report any such incidences to the organization's administration in a timely fashion, either by telephone or in person. If necessary, the organization's administration was to provide the investigator with guidance regarding the appropriate clinical, ethical, and/or legal steps that should be taken at that time (e.g., contacting the waiting list member, contacting DDD, and/or reporting the incident to other relevant authorities).

Policy six. If a waiting list member made a complaint about the appropriateness of the content on an educational worksheet, the worksheet was to be reviewed by this

investigator and the organization's administration to determine if it should be removed from the program or revised.

Procedure for policy six. If a complaint was filed, this investigator and an administrator would have reviewed the worksheet prior to the next mailing. If necessary, the worksheet would have been removed from the program or revised. If the worksheet contained out-of-date or erroneous content, a follow-up letter indicating the necessary corrections would have been delivered with the next set of worksheets.

Policy seven. A program evaluation occurred once all participants received each of the educational worksheets.

Procedure for policy seven. This investigator included a program evaluation form with the fifth educational worksheet. This investigator analyzed and interpreted the data and collaborated with the organization's administration in order to make value judgments about the program and to determine if the program should be revised.

Methods and Techniques

This investigator conducted one home-based session with each caregiver, during which the waitlisted member was provided with a brochure to inform her about the parent-training program as well as information about the waiting list and the waiting list program. This investigator also explained informed consent to participate in the waiting list program and obtained consent as appropriate. The investigator also asked the caregivers to provide information about the family in general as well as information about the individual with a developmental disability, allowed caregivers to express any

frustrations regarding their wait, and responded to any questions or concerns about the waiting list program and/or the organization's full service program.

This investigator also provided the participants with the educational worksheets. The educational worksheets were designed to educate the waiting list members about managing emotions associated with their caregiving role, behavioral techniques, accessing services, and opportunities for social support. A total of five worksheets were mailed or emailed to the participants on a monthly basis, along with a worksheet survey. Participants were to review the worksheets in their home at their convenience.

This investigator provided the participants with the worksheet surveys each month along with the educational worksheets. During the fifth month, participants also received the program evaluation form. The worksheet surveys and program evaluation form provided the waiting list members with the opportunity to review, clarify, and/or question the information provided in the educational worksheets. In addition, participants were provided with the opportunity to request information about services. The surveys and evaluation form provided members of the organization with program evaluation information.

Materials

The following materials were used during the in-home session:

- The informed consent form
- The organization's brochure
- The Four Factor Model Worksheet (Petronko, Anesko, Nezu, & Pos, 1998)

- This worksheet explains the organization's basic approach to assessing and intervening with individuals with developmental disabilities.

The following materials were used throughout the program implementation and formative evaluation:

- Five educational worksheets
 - Worksheet 1: Welcome- Applied Behavior Analysis and the Four Factor Model
 - Worksheet 2: Crisis Management
 - Worksheet 3: Effects of Providing Care on the Caregiver
 - Worksheet 4: Navigating the System- DDD and Advocacy
 - Worksheet 5: Working with Schools System
- Caregiver Response/Evaluation Survey Form (Appendix A)
- Program Evaluation Survey (Appendix A)

The following materials were used for data collection:

- Participant Characteristics form (Appendix A)
- Child Characteristics form (Appendix A)
- Program Implementation Tracking Form (Appendix A)
- Participant Reactions on the Worksheet Surveys form (Appendix A)
- Participant Reactions on the Program Evaluation Survey form (Appendix A)

Equipment

The equipment required during the design, implementation, and formative evaluation of this program included a phone (i.e., to contact members on the waiting list),

a computer (i.e., to generate the worksheets and forms and email them to the participants), a photocopier (i.e., to produce copies of the worksheets and forms), and a vehicle (i.e., for transportation to the caregivers' homes).

Facilities

The facilities included the caregivers' homes, the organization's office space, and this investigator's home. This investigator met the caregivers in their home for a time period of approximately one hour. The participants also likely read the worksheets and responded to the worksheet surveys and evaluation form in their own home. The office space was used to make copies of materials and to meet with the client to make adjustments to the program design and to discuss implementation and evaluation of the program. This investigator's home was used when contacting caregivers, creating program materials, and mailing/emailing the worksheets and forms to participants.

Components, Phases, and Activities

Phase one: Initial contact. This investigator contacted members of the waiting list to determine which members were interested in participating. All members on the waiting list were contacted until 10 members expressed interest in the program. Caregivers who had been waiting the longest were contacted first. Each caregiver was contacted three times before contact attempts were ended. A reasonable attempt was made to obtain updated contact information when the phone number was disconnected or incorrect. Caregivers were provided with an estimate of their waiting time. Caregivers were also provided with information about the waiting list program and the

organization's full service program. This investigator scheduled a home-based session with the members who were interested in participating in the program.

Phase two: Home-based session. During the home-based session, this investigator explained the waiting list program and the full program in more detail to the participants and provided them with the organization's brochure. Informed consent was obtained from caregivers interested in participating. This investigator explained confidentiality and assured the participants that identifying information would not be included in the dissertation. This investigator also obtained demographic information from the participants by way of an informal interview. At the end of the session, this investigator provided the participants with the first worksheet and survey form.

Phase three: Educational worksheets and survey forms. This investigator mailed or emailed an educational worksheet and survey form to each participant monthly. The scope and sequence of the worksheets is presented below:

Worksheet 1: Welcome-Applied Behavior Analysis and the Four Factor Model

Worksheet 2: Crisis Management

Worksheet 3: Effects of Providing Care on the Caregiver

Worksheet 4: Navigating the System- DDD and Advocacy

Worksheet 5: Working with School Systems

If the participant did not return the survey form within a month, he or she was sent a reminder to return the previous survey at his or her earliest convenience. When a completed survey was returned, this investigator reviewed the form to determine if the participant requested additional information. A reasonable attempt was made to provide participants with the information they requested along with the following month's

worksheet. This investigator was to contact the organization's administration if a participant had a concern about the material contained in the worksheets.

Phase four: Program evaluation. The final phase involved collecting data from the worksheet survey forms and the evaluation forms that were delivered with the final worksheet.

Budget

Table 1 provides a description of the budget, which reflects an estimate of the costs for all four phases of the program planning and evaluation framework.

Table 1
Waiting List Program Budget

Clarification Costs	
Salaries x Employee Benefits – Staff	\$500
Meals, travel, incidental expenses	-----
Office Supplies and Expenses	\$100
Printing and Reproduction	\$20
Outside Services	-----
Equipment Expenses	-----
Registration Fees	-----
General Overhead Allocation	-----
Other Miscellaneous Costs	-----
<i>Total Clarification Costs</i>	<i>\$620</i>
Program Design Costs	
Salaries x Employee Benefits – Staff	\$200
Meals, travel, incidental expenses	-----
Office Supplies and Expenses	-----
Printing and Reproduction	\$10
Outside Services	-----
Equipment Expenses	-----
Registration Fees	-----

Continued-- Waiting List Program Budget

General Overhead Allocation	-----
Other Miscellaneous Costs	-----
<i>Total Program Design Costs</i>	<i>\$210</i>
Program Implementation Costs	
Participant Costs	-----
Program Materials and Supplies	\$50
Participant Replacement Costs	-----
Lost Production	-----
Instructor Costs	-----
Salaries and Benefits	-----
Meals, Travel, Incidental Expenses	\$75
Outside Services	-----
Facility Costs	-----
Rental	-----
Facilities Expense Allocation	-----
General Overhead Allocation	-----
Other Miscellaneous Expenses	-----
<i>Total Implementation Costs</i>	<i>\$125</i>

Continued-- Waiting List Program Budget

Evaluation Costs	
Salaries x Employee Benefits – Staff	\$200
Meals, travel, incidental expenses	-----
Office Supplies and Expenses	\$10
Printing and Reproduction	\$10
Outside Services	-----
Equipment Expenses	-----
Registration Fees	-----
General Overhead Allocation	-----
Other Miscellaneous Costs	-----
<i>Total Evaluation Costs</i>	<i>\$220</i>
<i>Total Program Costs</i>	<i>\$1175</i>

Personnel

This investigator was responsible for:

- obtaining the list of waitlisted members and contacting them to determine their interest in the waiting list program.
- scheduling and conducting the home-based sessions.
- mailing or emailing the educational worksheets to the participants each month.
- providing participants with additional information as requested.
- collecting the survey forms and contacting participants.
- contacting participants who do not return the forms within one month of receipt.
- analyzing the data from the worksheet surveys and evaluation forms to determine if any adjustments should be made to the program design.

The client was responsible for:

- working collaboratively with this investigator to redesign and evaluate the program.
- assuming responsibility for the implementation and evaluation of the program at the completion of the formative program evaluation.

Following the completion of this pilot program, this investigator was to dissolve her affiliation with the organization. At that time, the client will assume responsibility for delineating the roles and responsibilities across his staff and overseeing the program. The roles and responsibilities delineated in the original program design can be used as a guide (Callaghan, 2008). The client will also be responsible for conducting future program evaluations so that additional adjustments can be made to the program design to reflect the needs of the target population.

Incentives

The personnel incentives included the opportunity to design, implement, and conduct a formative evaluation of a waiting list program as a dissertation task and permission to use the information gained through the program planning and evaluation process in this dissertation. Additional personnel incentives included educational experience and personal satisfaction from helping members of the target population. The main incentive for the client was access to program evaluation information that was used to assess the effectiveness of the program and may guide future program development.

The participant incentives included a potential to gain increased knowledge about methods for managing their emotions, behavior management techniques, accessing services, and opportunities for social support. In addition, participants were given the opportunity to obtain information regarding additional topics and services.

Program Evaluation Plan

(See Chapter IV for the revised Program Evaluation Plan)

Summary

Callaghan's (2008) program design was reviewed and customized based on current organizational contextual factors. Modifications to the design were made in an attempt to increase the likelihood that the program could be implemented successfully. The design elements described above were important to the design of the program and were clearly described in order for the program to be implemented according to design. The next chapter contains the Program Evaluation Plan.

CHAPTER IV

Program Evaluation Plan

Abstract

This chapter provides information about the program evaluation plan for the formative evaluation of the waiting list program. This plan was used during the formative evaluation to determine the potential benefits of the waiting list program. According to Maher (2000), the program evaluation plan should be included as part of the program design, prior to program implementation. The program evaluation plan included the program evaluation protocols, guidelines for communication and the use of program evaluation information, and a plan for the evaluation of the program evaluation plan.

Introductory Information

Target Population

The target population for the waiting list program was 10 caregivers of an individual with a developmental disability who were waiting to receive parent-training services in a particular region in the state of New Jersey. All of the participants were mothers of a male child between the ages of five and 15 who had been previously diagnosed with autism, pervasive developmental disorder (PDD), or traumatic brain

injury (TBI). All of the mothers were married, except for one woman who was a widower.

Client

The client for this program evaluation was an administrator in an organization that provides in-home behavior management training services to caregivers of individuals with developmental disabilities. The client, a licensed clinical psychologist, as well as a New Jersey certified school psychologist, has been working in the organization for over 25 years. He is responsible for conducting staff and parent trainings in behavior management, is a behavioral consultant to multiple school districts, and supervises some of the behavioral specialists who provide in-home parent-training services.

Relevant Stakeholders

The organization's administration and the behavior specialists who work for the organization were relevant stakeholders in the waiting list program. The administration had expressed their interest in, as well as what they feel is their ethical obligation, to provide support to caregivers on the organization's waiting list. Members of the administration were considered relevant stakeholders, since with the exception of the client, they did not have direct involvement in the program planning and evaluation process for the waiting list program, but could benefit from the potential success of the program.

The organization's staff members were relevant stakeholders in the waiting list program because if the program continues, many of them will become involved in the

implementation of the program. The various activities that the investigator was responsible for would likely be delineated across the organization's staff in order to for the responsibilities related to this program to be manageable and maintainable. Reference to the original program design could be helpful in delineating these roles (Callaghan, 2008).

Organization

The organization was a behavioral consultation and training program for caregivers of individuals with developmental disabilities who exhibit challenging behaviors. Behavior specialists are responsible for training caregivers on how to create and maintain a therapeutic home, with a focus placed on improving the caregivers' understanding of behavioral principals so that they can utilize behavioral techniques that will increase the likelihood that the individual is able to remain in their natural home.

Overview of the Program Evaluation Plan

Client's Evaluation Needs

The client was interested in obtaining information about the potential value of providing caregivers on the waiting list with services while they were waiting. After a program was designed, the client also became interested in learning if the waiting list program would be implemented in accordance to the program design. Specifically, the client wanted to know who participated in the waiting list program, how the actual implementation differed from the design, and what the potential benefits were to the participants, as measured by the participants' reports of increased knowledge regarding

topics related to caring for an individual with a developmental disability. The program evaluation plan was drafted to provide the client with formative information on all three of these topics, with the intent that the information would be able to guide future adjustments to the program design, implementation, and evaluation. The formative evaluation allowed for formative value judgments to be made about the waiting list program.

Timeframe

The formative program evaluation was designed to be conducted at the completion of the waiting list program (i.e., after the participants read the fifth (and final) worksheet).

Description of the Program to be Evaluated

A description of the waiting list program was provided in Chapter III.

Purpose and Goals of the Program

The purpose of the waiting list program was to provide support to waitlisted caregivers by providing them with information on topics related to caring for an individual with a developmental disability and by giving them the opportunity to request additional information based on their specific needs.

The specific program goals were:

1. Caregivers would gain new knowledge about behavior management concepts.
2. Caregivers would gain new knowledge about managing their emotions related to their caregiving role.
3. Caregivers would gain new knowledge about accessing services through DDD and other agencies.
4. Caregivers would be satisfied with the information provided through the program.

Program components, phases, and/or sequence of program activities

In order to obtain participants, the investigator contacted members of one of the organization's three waiting lists. The investigator contacted members who had been on the waiting list for the longest amount of time first. Members of the waiting list were contacted until 10 caregivers expressed interest in participating in the program by scheduling the home-based session.

During the initial contact, the first phase of the program, the investigator explained the purpose of the waiting list program, as well as the program they were waiting for, the parent-training program. The investigator also explained that some of the information collected throughout the program would be used for this dissertation. After the initial contact, the waiting list program included three phases: home-based session, educational worksheets, and data collection.

The second phase involved participation in a home-based session. During this session, the investigator explained the waiting list program and the parent-training

program in more detail. The investigator also explained that the program was being implemented and evaluated as a dissertation task and that information would be used in this dissertation. The investigator explained confidentiality and ensured the participants that identifying information would not be included in the dissertation. Then, the investigator obtained informed consent from the participants for their participation in the waiting list program and for participation in the dissertation task. Relevant participant and child information was obtained by way of an informal interview.

The third phase began at the end of the home-based session, when the investigator provided participants with the first worksheet and survey form and explained the process and timeframes for reading the worksheets and returning the forms. After the home-based session, the remaining four educational worksheets and accompanying survey forms were disseminated in one-month increments either by mail or email, according to the participant's preference. The participants were expected to read the worksheet and return a completed survey form within one month of receipt. If a participant did not return a survey form within one month, the participant was sent a reminder with the next worksheet that they should return the previous survey at their earliest convenience. When a participant requested additional information on a survey form, a reasonable attempt was made to provide the information with the following worksheet. The scope and sequence of the worksheets is presented below:

Worksheet 1: Welcome-Applied Behavior Analysis and the Four-Factor Model

Worksheet 2: Crisis Management

Worksheet 3: Effects of Providing Care on the Caregiver

Worksheet 4: Navigating the System- DDD and Advocacy

Worksheet 5: Working with School Systems

For the final phase of the waiting list program, participants were asked to complete a program evaluation form that asked for their feedback regarding their overall experience participating in the program. The form was delivered to the participants with the final worksheet and survey form. This form was used to collect information for the formative program evaluation.

List of Program Evaluation Questions

1. Who participated in the waiting list program?
2. To what extent was the waiting list program implemented as designed?
3. What have been the reactions of the participants to the waiting list program?

Program Evaluation Protocols

Protocol 1

Program evaluation question 1. Who participated in the Waiting List Program?

Data collection variables. The data collection variables included relevant characteristics about the caregivers who participated in the waiting list program and their child with a developmental disability. The parent-related characteristics included: county of residence, gender, marital status, length of time on the waiting list, previous services utilized and feelings and/or opinions about the waiting list. The child-related characteristics included: age, gender, diagnosis, age of diagnosis and referral behavior(s) (i.e., challenging behaviors).

Data collection methods, instruments, and procedures. The data collection methods included a record review and informal participant interviews conducted during the home-based session. The record review consisted of reviewing information provided by the child's case manager, which the organization obtains when the caregiver is placed on the waiting list. The record review was conducted to obtain contact information, information about county of residence, length of time on the waiting list and the child's gender current age, and diagnosis. The participant interviews were conducted to obtain information about the participants' marital status, their thoughts and feelings about the waiting list, their use of other behavioral services, the child's age when diagnosed and the child's most challenging behaviors. Data collected about the caregivers was recorded on

Instrument 1.1, the Participant Characteristics form (Appendix A). Data collected about the child was recorded on Instrument 1.2, the Child Characteristics form (Appendix A).

Methods for procedures for data analysis. The data analysis units included statistics of the relevant participant and child characteristics. Frequencies, means and percentages were calculated for each quantitative variable. Qualitative information was provided on the participants' thoughts and feelings related to the waiting list. Data is displayed in two tables, Table 1, Characteristics of the Caregivers and Table 2, Characteristics of the Children.

Program evaluation personnel, responsibilities, and timeline. The investigator was responsible for collecting the data and placing the information in Instrument 1.1, the Participant Characteristics form (Appendix A) and 1.2, the Child Characteristics form (Appendix A). In addition, the investigator was responsible for analyzing the data, placing the results in tables, and explaining the results.

Protocol 2

Program evaluation question 2. To what extent was the waiting list program implemented as designed?

Data collection variables. The data collection variables included information related to the actual execution of the waiting list program, in terms of adherence to the program design. Information about each program phase was included.

Data collection methods, instruments, and procedures. The investigator completed Instrument 2, the Program Implementation Tracking Form (Appendix A) to document how the program activities, methods, and procedures were actually implemented and how many caregivers participated in each of the program phases.

Methods for procedures for data analysis. The data analysis units included frequencies and percentages of the number of caregivers who participated in each of the program activities. This data is displayed in a table. In addition, qualitative information is provided in regards to how the program implementation differed from the program design. This information is also provided in narrative form.

Program evaluation personnel, responsibilities, and timeline. The investigator was responsible for collecting and analyzing the data and completing the Program Implementation Tracking form. In addition, the investigator provided information about how the actual program implementation differed from the program design.

Protocol 3

Program evaluation question 3. What have been the reactions of the participants to the waiting list program?

Data collection variables. The data collection variables included the participants' responses on the worksheet survey forms and the program evaluation form. Some responses were quantitative while others were qualitative.

Data collection methods, instruments, and procedures. The data collection method included the distribution and collection of Instrument 5, Caregiver Response/Evaluation Survey (Appendix A) and Instrument 6, Program Evaluation Survey (Appendix A). The information from these instruments was placed on Instrument 3, the Participant Reactions on the Worksheet Surveys form (Appendix A) and Instrument 4, the Participant Reactions on the Program Evaluation Survey form (Appendix A).

Methods and procedures for data analysis. The data analysis units were the caregivers' responses on the worksheet surveys and the program evaluation form. Some items on these instruments required caregivers to provide ratings on a 4-point scale, while others items could be responded to in a narrative form. For the items that utilized a rating scale, descriptive statistics were used in the data analysis and interpretation. This information is displayed in a table. For the other items, written descriptions of the responses are provided.

Program evaluation personnel, responsibilities, and timeline. The investigator was responsible for distributing the worksheet survey forms each month and the evaluation form at the end of the program. In addition, the investigator was responsible for analyzing the data on the returned forms and placing the data in Instrument 3, the Participant Reactions on the Worksheet Survey form and Instrument 4, the Participant Reactions on the Program Evaluation Survey form.

Guidelines for Communication and Use of Program Evaluation Information

After a reasonable attempt was made to obtain all of the completed survey forms and program evaluation forms, the investigator analyzed the data and produced a report. The report was provided to the client one week prior to a meeting that was held approximately one month after the program had ended. The report included information about the purposes, procedures, and findings of the formative program evaluation. At the meeting, the investigator presented the preliminary findings from the evaluation and provided recommendations. The investigator and the client discussed potential adjustments to the program design, implementation, and evaluation plan that could be made in an attempt to increase the potential value of the program.

Evaluation of the Program Evaluation

After information from the formative program evaluation was analyzed, the program evaluation process was also evaluated. The investigator and the client made judgments about how the program evaluation plan could be modified in the future so that more useful information could be gained during the process. During this discussion, the following questions were addressed, as they were related to the four elements that reflect a decent program evaluation: practicality, utility, propriety, and technical defensibility (Maher, 2000):

1. To what extent was the program evaluation conducted in a way that allowed for its successful accomplishment? (Practicality)
2. In what ways was the resulting program evaluation information helpful to people?
Which people? (Utility)

3. Did the program evaluation occur in a way that adhered to legal strictures and ethical standards? (Propriety)
4. To what degree can the evaluation be justified with respect to matters of reliability and validity? (Technical Defensibility)

Summary

This chapter provided information about all 12 of the elements that are involved in a program evaluation. For the waiting list program, a formative evaluation was conducted at the termination of the program so that judgments could be made about the potential value of the program. After the program was evaluated, the program evaluation plan was evaluated to determine how the process could be improved in the future.

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CHAPTER V

Results of the Program Evaluation

Abstract

This chapter describes the results of the formative program evaluation that was conducted at the completion of the initial implementation of the waiting list program. The formative program evaluation was carried out according to the program evaluation plan that was written prior to program implementation. The procedures and instruments described in the program evaluation protocols were utilized to gain information related to each of the evaluation questions. The results provide formative information related to the potential value of the waiting list program. Results of the evaluation of the program evaluation are included at the end this chapter.

Results of Program Evaluation Question 1

Who participated in the waiting list program?

The first program evaluation question focused on relevant characteristics of the participants and their child with a developmental disability. To answer the first program evaluation question, the investigator reviewed records maintained by the organization's administrative staff. The records included information about the caregivers on the waiting list and their child with a developmental disability. Specific information relevant

to this evaluation included contact information, information about county of residence, length of time on the waiting list, and the child's gender, current age and diagnosis. In addition, the investigator gathered information through an informal interview with the caregiver during the home-based session. Relevant information obtained about the caregivers included marital status, thoughts and feelings about the waiting list, and their previous use of other behavioral services. Relevant information obtained about the child included age when the child was diagnosed with a developmental disability and the child's most challenging behaviors.

Relevant characteristics of the caregivers. Relevant information was obtained for the nine caregivers who participated in a home-based session. There was at least one participant from each county in the region in which the program was implemented. Three participants (33%) lived in Essex County, one (11%) in Mercer County, four (44%) in Somerset County, and one (11%) in Union County. The participants were all female (100%). Eight of the participants (89%) were married and one (11%) was widowed. All of the participants had been on the waiting list for more than one-and-a-half years when contacted about the waiting list program. One participant (11%) had been on the waiting list for between one-and-a-half and two years, two participants (22%) for between two and two-and-a-half years, four participants (44%) for between two-and-a-half and three years, and two participants (22%) for more than three-and-a-half years. Six of the participants (67%) reported having previous experience with behavioral services (e.g., Applied Behavior Analysis, behavioral consultation), whereas three of the participants (33%) reported having no previous experience with these services. When asked to share their feelings or thoughts about the waiting list, six participants (67%)

shared negative feelings, whereas three (33%) shared neutral or positive feelings. Some examples of the negative statements included “it’s way too long”, “it’s of no use to me whatsoever”, “it’s scary”, “depressing as time goes by”, “I hate the waiting list”, and “he needs help now, in his young years”. Some examples of positive or neutral statements included “it’s OK because the services are long”, “it’s OK because (my son is) young now”, “nice that it’s free”, and “It’s understanding. There’s a big need for others”. Data on the caregivers’ relevant characteristics are presented in Table 2.

Table 2
Characteristics of the Caregivers

Variable	Frequency	Percentage
County of Residence		
Essex	3	33%
Mercer	1	11%
Somerset	4	44%
Union	1	11%
Gender		
Female	9	100%
Male	0	0%
Marital Status		
Married	8	89%
Widowed	1	11%
Time of Waiting List		
1.5 to 2 years	1	11%
2 to 2.5 years	2	22%
2.5 to 3 years	4	44%
3 to 3.5 years	0	0%
3.5 to 4 years	2	22%
Previous Behavioral Services Utilized		
Yes	6	67%
No	3	33%
Negative Feelings/Opinions of Waiting List		
Yes	6	67%
No	3	33%

Relevant characteristics of the children. Information about the participants' child with a developmental disability was obtained through the record review and informal participant interviews. All of the participants' (100%) had a male child with a developmental disability. These children ranged in age from five to 15, with two children (22%) between the ages of five and seven, five (55%) between the ages of eight and 10, and two (22%) between the ages of 14 and 16. Five of the children (56%) had been previously diagnosed with autism, three (33%) with pervasive developmental disorder (PDD), and one (11%) with traumatic brain injury (TBI). One child (11%) was diagnosed before one year of age, two (22%) between one year and two years, two (22%) between two years and three years, three (33%) between three years and four years and one (11%) between four years and five years. The most challenging behavior(s) reported by the participants were collapsed into seven different categories: aggression (44%), adaptive/self-help skills (22%), noncompliance (33%), perseverative behaviors (11%), sensory integration disorder/dysfunction (22%), social skills deficits (11%) and tantrum behaviors (44%). Data on the children's relevant characteristics are presented in Table 3.

Table 3
Characteristics of the Children

Variable	Frequency	Percentage
Gender		
Female	0	0%
Male	9	100%
Current Age		
5 to 7	2	22%
8 to 10	5	55%
11 to 13	0	0%
14 to 16	2	22%
Diagnosis		
Autism	5	56%
PDD	3	33%
TBI	1	11%
Age When Diagnosed		
< 1 year	1	11%
1 to 2 years	2	22%
2 to 3 years	2	22%
3 to 4 years	3	33%
4 to 5 years	1	11%
Challenging Behaviors		
Aggression (self and/or others)	4	44%
Adaptive/Self-Help Skills	2	22%
Noncompliance	3	33%
Perseverative Behaviors	1	11%
Sensory Integration Disorder/Dysfunction	2	22%
Social Skills	1	11%
Tantrum Behaviors	4	44%

*PDD= Pervasive Developmental Disorder

*TBI= Traumatic Brain Injury

Results of Program Evaluation Question 2

To what extent was the waiting list program implemented as designed?

The second program evaluation question focused on gaining information about how the program was actually executed and the extent to which the implementation adhered to the program design. This information was important for making judgments about the program that would contribute to future program development and improvement. In order to answer this question, the investigator collected data related to each of the phases of the program and documented the information on Instrument 2, the Program Implementation Tracking Form (Appendix A).

Initial contact. The investigator attempted to contact 25 caregivers on the organization's waiting list for a particular region of New Jersey. Fifteen of the 25 caregivers (60%) were reachable by phone. At least three attempts were made to reach the remaining 10 caregivers, but they could not be reached either due to a change in contact information (n = 3; 30%) or because they did not return the investigator's calls (n = 7; 70%). Ten of the caregivers (67%) reached by phone agreed to participate in the waiting list program and scheduled the home-based session. Five of the caregivers (33%) were not interested in participating because they had moved (n = 1; 20%), had already received similar services (n = 1; 20%), the child was going to a residential placement (n = 1; 20%), the child's behavior was manageable (n = 1; 20%), or the caregiver felt that she already had sufficient knowledge related to caring for an individual with a developmental disability (n = 1; 20%). Data related to the initial contact phase can be found in Table 4.

Table 4
Initial Contact

To What Extent was the Initial Contact Phase of the Program Implemented as Designed?		
<u>Initial Contact</u>	Frequency	Percentage
Contact attempts	25	N/A
Caregivers who were reached by phone	15	60%
Caregivers reached by phone who agreed to participate (by scheduling a home-based session)	10	67%
Caregivers reached by phone who declined to participate	5	33%
<u>Reasons for Declining Participation</u>	Frequency	Percentage
Moved	1	20%
Received previous behavioral services	1	20%
Child going to residential placement	1	20%
Behavior was manageable	1	20%
Sufficient Knowledge	1	20%

Home-based session. After the participants were obtained, the investigator facilitated one home-based session with each caregiver. Nine of the ten caregivers (90%) who agreed to participate in the program participated in the home-based session. All of the home-based sessions occurred in either August 2009 or September 2009. During the home-based session, all of the activities described in the program design were implemented as planned. These activities included providing a description of the waiting list program, a description of the parent-training program, disseminating the organization's brochure, explaining confidentiality, obtaining informed consent, conducting an informal interview, and disseminating the first worksheet and survey form. Data related to the home-based session phase can be found in Table 5.

Table 5
Participation in the Home-Based Session

To What Extent was the Home-Based Session of the Program Implemented as Designed?		
	Frequency	Percentage
Caregivers who scheduled a home-based session and participated in the home-based session	9	90%
Caregivers who agreed to continue participation at the home-based session	9	100%
Caregivers given a description of waiting list program	9	100%
Caregivers give a description of parent-training program (with brochure)	9	100%
Caregivers explained confidentiality	9	100%
Caregivers who signed the informed consent form	9	100%
Caregivers who participated in an informal interview	9	100%
Caregivers who received Worksheet 1: Welcome- ABA and the Four-Factor Model (with the survey form)	9	100%

* Since one participant withdrew prior to the home-based session, the total number of participants was adjusted from 10 to nine.

Educational worksheets. Approximately one month after the home-based session, the investigator sent the second worksheet and survey form via mail or email to the nine participants (100%). Each additional worksheet and accompanying survey form was provided to all nine participants (100%) in one-month increments thereafter. All participants were sent the final worksheet by the end of January 2010. Participants were expected to read the worksheet and return the completed survey form to the investigator within one month. Participants who did not return a completed survey form within one month were given a reminder when the next educational worksheet and survey form was disseminated. Data related to the dissemination of the educational worksheets can be found in Table 6.

Table 6
Dissemination of the Educational Worksheets and Survey Forms

To What Extent was of the Educational Worksheet Phase of the Program Implemented as Designed?		
	Frequency	Percentage
Caregivers who were sent Worksheet 2: Crisis Management (and survey form)	9	100%
Caregivers who were sent Worksheet 3: Effects of Providing Care on the Caregiver (and survey form)	9	100%
Caregivers who were sent Worksheet 4: Navigating the System- DDD and Advocacy (and survey form)	9	100%
Caregivers who were sent Worksheet 5: Working with School Systems (and survey form)	9	100%

The return rate for the survey forms was low. Five participants (56%) returned the first and third survey forms, four participants (44%) returned the fourth and fifth survey forms and only three participants (33%) returned the second survey form. Data related to the returned worksheet survey forms can be found in Table 7.

Table 7
Returned Survey Forms

To What Extent Did the Caregivers Return Completed Survey Forms?		
	Frequency	Percentage
Worksheet 1: Welcome-ABA and the Four Factor Model	5	56%
Worksheet 2: Crisis Management	3	33%
Worksheet 3: Effects of Providing Care on the Caregiver	5	56%
Worksheet 4; Navigating the System- DDD and Advocacy	4	44%
Worksheet 5: Working with School Systems	4	44%

Program evaluation. The final component of the program was the program evaluation. Each participant was sent a program evaluation form with the final educational worksheet. When the program evaluation form was sent, three of the participants (33%) had returned the first four survey forms, three participants (33%) had

not returned any survey forms, two participants (22%) had only returned one survey form and one participant (11%) had returned all but one survey form. Since the program design did not include any policies or procedures for contacting participants who did not return completed survey forms even after being given a reminder, the investigator had to make a decision as to how to proceed. The investigator decided to make one final attempt to contact these participants, either by mail or email, to ask them to inform the investigator of their decision to either continue participating in the program or to end their participation. Participants were asked to provide a reason for their withdrawal. Only one of the six participants (17%) who did not complete all of the survey forms responded to the final reminder. She indicated that she did not have enough time to participate. Only four participants (44%) returned a completed evaluation form. Data related to the program evaluation phase can be found in Table 8.

Table 8
Program Evaluation Phase

To What Extent was the Program Evaluation Phase Implemented as Designed?		
	Frequency	Percentage
Program Evaluation Forms Disseminated	9	100%
Program Evaluation Forms Completed	4	44%

Results of Program Evaluation Question 3

What have been the reactions of the participants to the waiting list program?

The third program evaluation question focused on the participants' thoughts, opinions, and judgments of the waiting list program. The method for data collection was the distribution and collection of Instrument 5, the Caregiver Response/Evaluation Survey (Appendix A) and Instrument 6, the Program Evaluation Survey (Appendix A).

Caregiver Reactions on the Worksheet Survey Forms

On the worksheet survey forms, participants were requested to indicate if they had read the worksheet, to what extent the worksheet increased their knowledge on the topic (on a four-point scale: greatly increased my knowledge; increased my knowledge; mainly targeted information I had already learned, but I found the review helpful; I have not learned anything new), at least one thing that they learned, and to indicate their satisfaction with the worksheet (on a four-point: highly satisfied; moderately satisfied; neither satisfied nor dissatisfied (neutral); dissatisfied). Participants could also list any questions or concerns about the material, request help in obtaining information about accessing other services, and provide relevant comments or ask any additional questions.

Participants were sent a worksheet survey form along with each of the five educational worksheets. Three participants (33%) returned all five survey forms, one participant (11%) returned four survey forms, two participants (22%) returned one of the survey forms, and three (33%) did not return any survey forms. Due to the low return

rate, the following results should be considered cautiously. In addition, it should be noted that these results cannot be generalized to all parents.

Worksheet one survey form. All nine participants (100%) were given the first worksheet survey form at the home-based session. Five participants (56%) returned a completed form and indicated that they had read the worksheet. One participant (20%) reported that the worksheet increased their knowledge and four participants (80%) reported that the worksheet was mainly a review of information they already knew. One participant reported that the information “confirmed that it is better to have someone work with the child and caregiver one-on-one”. Another participant reported that she learned it is important to “work with the teacher and reinforce what is done in school”. Another participant reported that she learned that it is important to “change behavior to functional behavior”. In terms of their satisfaction with the worksheet, two participants (40%) reported being highly satisfied, one participant (20%) reported being moderately satisfied, and two participants (40%) reported being neither satisfied nor dissatisfied.

Participants requested more information about respite (22%), behavioral therapists (11%), psychiatrists that take insurance (11%), summer camps (11%), after school programs (11%), toilet training programs (11%), free speech therapy (11%), free social skills program (11%), and English tutors (11%). One participant provided a comment stating that she “would like the ABA to begin as soon as possible”.

Results from the survey forms for Worksheet One can be found in Table 9.

Table 9
Worksheet One Survey Form

To What Extent Did Caregivers Participate?		
	Frequency	Percentage
Reported reading the worksheet	5	100%
To What Extent Did Caregivers Report Increased Knowledge?		
Reported that the worksheet greatly increased their knowledge	0	0%
Reported that the worksheet increased their knowledge	1	20%
Reported that the worksheet was mainly a review	4	80%
Reported that the worksheet did not increase their knowledge	0	0%
To What Extent Did Caregivers Report Satisfaction with the Worksheet?		
Reported being highly satisfied with the worksheet	2	40%
Reported being moderately satisfied with the worksheet	1	20%
Reported being neither satisfied nor dissatisfied with the worksheet	2	40%
Reported being dissatisfied with the worksheet	0	0%

Worksheet two survey form. All nine participants (100%) were sent the second worksheet survey form. Three participants (33%) returned a completed form and indicated that they had read the worksheet. Two of the participants (67%) reported that the worksheet greatly increased their knowledge and one participant (33%) reported that the worksheet was mainly a review of information they already knew. One participant wrote that the worksheet taught them about DDD hotlines, while another participant learned about crisis agencies.

In terms of their satisfaction with the worksheet, two participants (67%) reported being highly satisfied and one participant (33%) reported being neither satisfied nor dissatisfied. One participant commented that the “information will greatly help (her) as (her) son gets older”. No new requests for information were provided.

Results from the survey forms for Worksheet Two can be found in Table 10.

Table 10
Worksheet Two Survey Form

To What Extent Did Caregivers Participate?		
	Frequency	Percentage
Reported reading the worksheet	3	100%
To What Extent Did Caregivers Report Increased Knowledge?		
Reported that the worksheet greatly increased their knowledge	2	67%
Reported that the worksheet increased their knowledge	0	0%
Reported that the worksheet was mainly a review	1	33%
Reported that the worksheet did not increase their knowledge	0	0%
To What Extent did Caregivers Report Satisfaction with the Worksheet?		
Reported being highly satisfied with the worksheet	2	67%
Reported being moderately satisfied with the worksheet	0	0%
Reported being neither satisfied nor dissatisfied with the worksheet	1	33%
Reported being dissatisfied with the worksheet	0	0%

Worksheet three survey form. All nine participants were sent the third worksheet survey form. Five participants (56%) returned a completed form and indicated that they had read the worksheet. One participant (20%) reported that the worksheet increased their knowledge, three participants (60%) reported that the worksheet was mainly a review of information they already knew, and one participant (20%) reported that the worksheet did not increase their knowledge. One participant reported that she “learned that (she is) not alone in (her) feelings of stress which is helpful”. Another participant reported that she “felt understood”.

In terms of their satisfaction with the worksheet, one participant (20%) reported being highly satisfied, one participant (20%) reported being moderately satisfied, two participants (40%) reported being neither satisfied nor dissatisfied, and one participant (20%) reported being dissatisfied. One participant reported that she “did not find anything useful about the worksheet at all and found it was a waste of time”.

One participant requested information about respite and one participant requested information about speech therapy services.

Results from the survey forms for Worksheet Three can be found in Table 11.

Table 11
Worksheet Three Survey Form

To What Extent Did Caregivers Participate?		
	Frequency	Percentage
Reported Reading the Worksheet	5	100%
To What Extent Did Caregivers Report Increased Knowledge?		
Reported that the worksheet greatly increased their knowledge	0	0%
Reported that the worksheet increased their knowledge	1	20%
Reported that the worksheet was mainly a review	3	60%
Reported that the worksheet did not increase their knowledge	1	20%
To What Extent Did Caregivers Report Satisfaction with the Worksheet?		
Reported being highly satisfied with the worksheet	1	20%
Reported being moderately satisfied with the worksheet	1	20%
Reported being neither satisfied nor dissatisfied with the worksheet	2	40%
Reported being dissatisfied with the worksheet	1	20%

Worksheet four survey form. All nine participants were sent the third worksheet survey form. Four participants (44%) returned a completed form and indicated that they had read the worksheet. One participant (25%) reported that the worksheet increased their knowledge, two participants (50%) reported that the worksheet was mainly a review of information they already knew, and one participant (25%) reported that the worksheet did not increase their knowledge. One participant reported that she learned about guardianship assistance and tutoring.

In terms of their satisfaction with the worksheet, two participants (50%) reported being highly satisfied, one participant (25%) reported being neither satisfied nor dissatisfied, and one participant (25%) reported being dissatisfied.

One participant wrote that she felt “there was too much concentration and the material lectures too much on self-advocacy”. One participant requested information about school programs in different districts in her area.

Results from the survey forms for Worksheet Four can be found in Table 12.

Table 12
Worksheet Four Survey Form

To What Extent did Caregivers Participate?		
	Frequency	Percentage
Reported Reading the Worksheet	4	100%
To What Extent did Caregivers Report Increased Knowledge?		
Reported that the worksheet greatly increased their knowledge	0	0%
Reported that the worksheet increased their knowledge	1	25%
Reported that the worksheet was mainly a review	2	50%
Reported that the worksheet did not increase their knowledge	1	25%
To What Extent did Caregivers Report Satisfaction with the Worksheet?		
Reported being highly satisfied with the worksheet	2	50%
Reported being moderately satisfied with the worksheet	0	0%
Reported being neither satisfied nor dissatisfied with the worksheet	1	25%
Reported being dissatisfied with the worksheet	1	25%

Worksheet five survey form. All nine participants were sent the third worksheet survey form. Four participants (44%) returned a completed form and indicated that they had read the worksheet. One participant (25%) reported that the worksheet increased their knowledge, one participant (20%) reported that the worksheet was mainly a review of information they already knew, and two participants (50%) reported that the worksheet did not increase their knowledge.

In terms of their satisfaction with the worksheet, one participant (25%) reported being highly satisfied, one participant (25%) reported being moderately satisfied, and two participants (50%) reported being neither satisfied nor dissatisfied. One participant reported that “the resource list will be helpful” and that the “information will be good for people just starting out in the school system”.

Results from the survey forms for Worksheet Four can be found in Table 13.

Table 13
Worksheet Five Survey Form

To What Extent Did Caregivers Participate?		
	Frequency	Percentage
Reported Reading the Worksheet	4	100%
To What Extent Did Caregivers Report Increased Knowledge?		
Reported that the worksheet greatly increased their knowledge	0	0%
Reported that the worksheet increased their knowledge	1	25%
Reported that the worksheet was mainly a review	1	25%
Reported that the worksheet did not increase their knowledge	2	50%
To What Extent Did Caregivers Report Satisfaction with the Worksheet?		
Reported being highly satisfied with the worksheet	1	25%
Reported being moderately satisfied with the worksheet	1	25%
Reported being neither satisfied nor dissatisfied with the worksheet	2	50%
Reported being dissatisfied with the worksheet	0	0%

Overall Results

At least one participant reported an increase in knowledge after reading each of the worksheets. One participant (20%) reported an increase in knowledge about ABA and the Four-Factor Model, two participants (67%) reported an increase in knowledge about Crisis Management, one participant (20%) reported an increase in knowledge about Effects of Providing Care on the Caregiver, one participant (25%) reported an increase in knowledge about Navigating the System- DDD and Advocacy, and one participant (25%) reported an increase in knowledge about Working with School Systems.

At least two participants reported being satisfied with each of the educational worksheets. Three participants (60%) reported satisfaction with Worksheet 1: ABA and the Four Factor Model, two participants (67%) reported satisfaction with Worksheet 2: Crisis Management, two participants (40%) reported satisfaction with Worksheet 3: Effects of Providing Care on the Caregiver, two participants (50%) reported satisfaction with Worksheet 4: Navigating the System- DDD and Advocacy, and two participants (50%) reported satisfaction with Worksheet 5: Working with School Systems.

Overall results can be found in Table 14.

Table 14
Overall Results of the Worksheet Survey Forms

Reported an Increase in Knowledge about the Worksheet Topic	Frequency	Percentage
ABA and the Four-Factor Model	1	20%
Crisis Management	2	67%
Effects of Providing Care on the Caregiver	1	20%
Navigating the System- DDD and Advocacy	1	25%
Working with School Systems	1	25%
Reported Satisfaction with the Worksheet	Frequency	Percentage
ABA and the Four-Factor Model	3	60%
Crisis Management	2	67%
Effects of Providing Care on the Caregiver	2	40%
Navigating the System- DDD and Advocacy	2	50%
Working with School Systems	2	50%

* Only participants who returned a completed survey form were included (n=3 to n=5)

Caregiver Reactions on the Program Evaluation Form

On the Program Evaluation form, participants were requested to indicate the extent to which the program increased their knowledge about methods or services that could assist them if they experienced any unpleasant emotions associated with their caregiving role, behavior management concepts, and accessing services through DDD or other agencies (on a four-point scale: greatly increased my knowledge; increased my knowledge; mainly targeted information I had already learned, but I found the review helpful; I have not learned anything new). For each of these topics, participants were also given space to provide additional feedback or suggestions. Participants were also asked to indicate their general level of satisfaction with the overall program (on a four-point scale: highly satisfied, moderately satisfied, neither satisfied nor dissatisfied; or dissatisfied). Four of the nine participants (44%) returned a completed form. As with the worksheet survey forms, due to the low return rate, the following results should be considered cautiously and cannot be generalized to all parents.

Item one. The first item asked caregivers to rate the extent to which the worksheet increased their knowledge about methods or services that would assist them if they experienced any unpleasant emotions associated with their caregiving role. One participant (25%) indicated that the program increased [their] knowledge, two participants (50%) indicated that the program mainly targeted information that they already learned, but they found the review helpful, and one participant (25%) indicated that they did not learn anything new from the waiting list program on this topic. Results for Item 1 can be found in Table 15.

Table 15
Results for Program Evaluation Form: Item 1

Please circle/bold the response that best describes the extent to which the program has increased your knowledge about methods or services that would assist you if you experienced any unpleasant emotions associated with your caregiving role.				
Qualifier	Greatly Increased	Increased	Mainly a Review	Did Not Increase
Frequency	0	1	2	1
Percentage	0%	25%	50%	25%

Item two. The second item asked caregivers to rate the extent to which the program increased their knowledge about behavior management concepts. One participant (25%) indicated that the program increased [their] knowledge, two participants (50%) indicated that the program mainly targeted information that they already learned, but they found the review helpful, and one participant (25%) indicated that they did not learn anything new from the waiting list program on this topic. Results to Item 2 can be found in Table 16.

Table 16
Results for Program Evaluation Form: Item 2

Please circle/bold the response that best describes the extent to which the program has increased your knowledge about behavior management concepts.				
Qualifier	Greatly Increased	Increased	Mainly a Review	Did Not Increase
Frequency	0	1	2	1
Percentage	0%	25%	50%	25%

Item three. The third item asked caregivers to rate the extent to which the program increased their knowledge about accessing services through DDD or other agencies. One participant (25%) indicated that the program increased [their] knowledge, two participants (50%) indicated that the program mainly targeted information that they already learned, but they found the review helpful, and one participant (25%) indicated

that they did not learn anything new from the waiting list program on this topic. Results to Item 3 can be found in Table 17.

Table 17
Results for Program Evaluation Form: Item 3

Please circle/bold the response that best describes the extent to which the program has increased your knowledge about accessing services through DDD or other agencies.				
Qualifier	Greatly Increased	Increased	Mainly a Review	Did Not Increase
Frequency	0	1	2	1
Percentage	0%	25%	50%	25%

Item four. The fourth item asked caregivers to chose the response that best described their general level of satisfaction with the program. One participant (25%) reported being highly satisfied, one participant (25%) reported being moderately satisfied, one participant (25%) reported being neither satisfied nor dissatisfied, and one participant (25%) reported being dissatisfied. Results to Item 4 can be found in Table 18.

Table 18
Results For Program Evaluation Form: Item 4

Please circle/bold the response that best describes your general level of satisfaction with the program.				
Qualifier	Highly Satisfied	Moderately Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied
Frequency	1	1	1	1
Percentage	25%	25%	25%	25%

Anecdotal Comments

For each of the four items, caregivers were informed that they could provide additional feedback or suggestions that could guide program development. Two participants (50%) provided feedback. The participant that reported being highly satisfied with the program wrote that “overall the program provided (her) with some information which (she) didn’t know about and this is always helpful. Any new information (she) learns can always help (her) and (her) son. (She) appreciate(d) it”. The participant that reported that she was dissatisfied with the program wrote that she “found the (educational worksheets to be) a waste of time. It is better to have a therapist come in and work one-on-one as each individual situation is different”.

Summary of Results

Ten of the caregivers (67%) reached by phone agreed to participate in the waiting list program and scheduled the home-based session. Nine of the ten caregivers (90%) actually participated in a home-based session. Therefore, the waiting list program had a total of nine participants, all of who were mothers of male children diagnosed with autism, pervasive developmental disorder, or traumatic brain injury. The majority of the children was under the age of 10 and had been diagnosed with a developmental disability by age four. All of the caregivers had been on the waiting list for between one-and-a-half and four years. When asked to share their feelings or thoughts about the waiting list, six participants (67%) shared negative feelings, whereas three (33%) shared neutral or positive feelings.

The response rate for the worksheet survey forms was low. Five participants (56%) returned the first and third survey forms, four participants (44%) returned the fourth and fifth survey forms and only three participants (33%) returned the second survey form. Three of the participants (33%) returned all five survey forms, one participant (11%) returned four survey forms, two participants (22%) returned one of the survey forms, and three participants (33%) did not return any of the survey forms. Only four participants (44%) returned a completed program evaluation form.

Due to the low return rate, the results should be considered cautiously. These results cannot be generalized to all parents of children with a developmental disability. However, the information provides insight into these caregivers' experiences participating in the waiting list program. The results indicate that at least one participant reported an increase in knowledge after reading each of the educational worksheets and at least two participants reported satisfaction with each of the educational worksheets. On the program evaluation form, only one participant (25%) reported that they gained knowledge related to each of the three topics. Two participants (50%) reported overall satisfaction with the waiting list program.

Communication of Program Evaluation Information

After all of the analyses were completed, the investigator provided the client with a comprehensive report that included relevant program evaluation information. Information about each of the three program evaluation questions was included in the report. After the client read the report, the investigator and the client met to collaboratively review the results of the program evaluation and to discuss adjustments

that could be made to the program design. Following that meeting, the client was expected to meet with relevant stakeholders (e.g., current staff members) to present them with the information provided in the report and to discuss how future implementation of the waiting list program.

Evaluation of the Program Evaluation

The investigator evaluated the program evaluation in order to determine how the program evaluation could be improved so that the information gathered and analyzed could be more meaningful in guiding future program planning activities. By evaluating the program evaluation, key stakeholders are able to utilize information about the program to make judgments about the program's worth, which helps them to proceed with program planning activities. The following questions were used to facilitate the program evaluation discussion:

1. To what extent was the program evaluation conducted in a way that allowed for its successful accomplishment? (Practicality)
2. In what ways was the resulting program evaluation information helpful to people? Which people? (Utility)
3. Did the program evaluation occur in a way that adhered to legal strictures and ethical standards? (Propriety)
4. To what degree can the evaluation be justified with respect to matters of reliability and validity? (Technical Defensibility)

Practicality

The first question focused on the success of conducting the program evaluation. Although the program evaluation was implemented according to the program design, a lack of completed program evaluation forms inhibited the program evaluation process. Although the response rate for the program evaluation was low, since all of the caregivers who participated fully in the program returned evaluation forms, the investigator and the client were satisfied with the amount of information gained.

Since the evaluation was mainly based on written responses by the participants, it was difficult to gain additional information regarding their thoughts and feelings about the waiting list program. In the future, it may be helpful for the caregivers to participate in a phone conversation or another home-based session at the end of the program, but due to budgetary constraints, the practicality of this additional contact will need to be considered.

Utility

The second evaluation question focused on how useful the program evaluation information was to the individuals involved with the program. Although the investigator and the client were the only people directly involved in the gathering and analyzing of information about the potential worth of the program, the additional stakeholders will be able to benefit from this information as they proceed with program planning activities.

The program evaluation information will also be important for the organization to have so that they can provide documentation of the potential worth of a waiting list program to the state in order to obtain funding. The client explained that the state

recognizes the significance of the waiting list and that the program evaluation information can provide support for the importance of providing services to people who are waiting.

The program evaluation information will also be useful to the behavior specialists, because it should give them a better understanding of the type of information that the caregivers have already been exposed to. While assumptions cannot be made about the potential affects of the waiting list program on the caregivers' parent-training experience, having this information may help guide the behavior specialists in choosing topics to focus on during parent-training. Information gathered during the program evaluation can also help behavior specialists gain a better understanding of the caregivers' thoughts and opinions about caring for an individual with a developmental disability, as well as what they are interested in learning more about. Having this information before parent-training services begin may help the behavior specialists be better prepared to address the caregivers' individuals needs.

Propriety

The third program evaluation questions focused on whether the program evaluation occurred in a way that adhered to legal and ethical standards. Prior to the implementation of the program evaluation, legal and ethical concerns were considered. Participants had been assured that their identifying information would be kept confidential. The investigator collected and recorded all program evaluation information in a way that ensured participant confidentiality.

Technical Defensibility

The final program evaluation question focused on the reliability, validity, and accuracy of the methods, procedures, and instruments utilized during the program evaluation. There was some concern in regards to the technical defensibility of the program evaluation, especially due to the low response rate. Since only a limited amount of information regarding the potential worth of the program could be obtained, the results should not be considered to represent the actual potential worth of the program.

Another concern was that although the participants were ensured that their responses would not affect their status on the waiting list, it is possible that they were cautious when deciding how to respond because they were worried that their responses would reflect poorly on their ability to succeed in the parent-training program.

Additionally, although the participants were encouraged to expand on their responses by providing a written response, all of the participants did not choose to do so. If the program evaluation is conducted in person or over the phone during future implementations of the program, additional information may be able to be obtained to will support their responses and provide more clarity.

As mentioned above, this program evaluation was formative in nature and should be considered only a first attempt in trying to determine the potential value of waiting list programs. Since the participants were not a random sample, and few caregivers participated fully in the program, the results should be interpreted with caution. The results from the program evaluation should be considered to have potential validity only for the specific population of individuals who participated in the program.

Summary

The program planning and evaluation process concluded with the evaluation of the program evaluation. The information gained from this evaluation allows for future program planning decisions to be made. The four questions related to the qualities of a sound human services program were used to obtain information about the program evaluation through a discussion with relevant stakeholders and a review of the program evaluation data.

In evaluating the program evaluation, it was determined that the evaluation was implemented in a practical manner. In addition, the program evaluation was found to be useful since it provided information that could be used to make future adjustments to the design and implementation of the waiting list program, as well as to inform changes to the evaluation plan. It was also determined that the program was implemented in strict adherence to legal and ethical standards. Lastly, the results of the program evaluation were found to be reliable and valid for the specific population that the program served. The results from this program evaluation cannot be generalized to other waiting list programs or populations.

CHAPTER VI

Overall Conclusions and Recommendations

Abstract

This chapter includes conclusions and recommendations based on the formative evaluation of the waiting list program. The formative program evaluation provided information related to the design of the waiting list program as it was actually implemented and the potential benefits of the program for the caregivers. Following the conclusions, there is a discussion of the limitations of the dissertation and recommendations for improvements to the waiting list program.

Findings of the Program Evaluation

Based on the information gained through the program evaluation, three main conclusions can be made. First, the investigator implemented the waiting list program according to the design. Second, caregivers were exposed to new information and some reported that they gained new knowledge related to caring for an individual with a developmental disability. Third, some caregivers were satisfied with their experience participating in the waiting list program.

Based on the self-report of the investigator as well as documentation of each of the program phases, it was determined that the program was implemented according to

design. During each phase, the investigator documented completion of each activity and acknowledged any changes that occurred based on the original program design. Overall, the program was implemented according to design. A few additional procedures were added during the implementation, including a procedure for contacting the caregivers who did not return the worksheet survey forms in a timely manner. The caregivers' level of cooperation in returning the survey forms was found to be the main obstacle; however, implementation continued as planned, with the addition of reminders to return the forms at their earliest convenience.

The second conclusion was that caregivers were exposed to new information and some caregivers reported that they had gained new knowledge related to caring for an individual with a developmental disability. This conclusion was based on the caregivers' responses on the worksheet survey forms and the program evaluation form. The worksheet on crisis management (Worksheet 2) was most frequently reported as having led to an increase in the caregivers' knowledge ($n = 2$; 67%). Only one caregiver reported an increase in knowledge for each of the three main topics.

The third conclusion was that some caregivers were satisfied with the waiting list program. This conclusion was based on the caregivers' responses on the worksheet survey forms and the program evaluation forms. The caregivers most frequently reported satisfaction with Worksheet 1: ABA and the Four-Factor Model ($n = 3$; 60%) and Worksheet 2: Crisis Management ($n = 2$; 67%). Level of satisfaction for the overall program ranged from dissatisfied to highly satisfied.

After conducting the formative program evaluation of the waiting list program, it was concluded that the evaluation plan was practical and useful for the key stakeholders.

However, due to the low response rate on all instruments related to the program evaluation, the client expressed the need for changes to be made in regards to the implementation of the evaluation plan. Even though the response rates were low, the evaluation was conducted successfully and the client reported that the program evaluation information will be useful in guiding the process of making improvements to the program.

Limitations of the Dissertation

The main constraints of this dissertation were related to the small sample size and the low response rate for the worksheet survey forms and the program evaluation form. The sample size for the dissertation was nine caregivers; however, only four of the nine caregivers participated fully in the waiting list program. Therefore, only a limited amount of information was obtained regarding the caregivers' increased knowledge and satisfaction with the waiting list program. Since these participants were not randomly selected, the results should be considered to be valid only within the context of this waiting list program and for this specific population.

Another limitation was that the target population was caregivers who had already been waiting for services for at least one-and-a-half years. Therefore, they may have been frustrated with the lack of support they had received up until the time they were contacted about the waiting list program. Their frustration may have impacted their level of participation in this program. In addition, it is likely that these caregivers had already made attempts to gain information about topics related to caring for an individual with a developmental disability. Therefore, the information provided in the worksheets may

have been redundant, which possibly contributed to some of the caregivers' decisions to not participate in the program after the home-based session. If the program continues to be implemented, changes in the implementation of the program should be made in an attempt to increase the level of participation. If caregivers are provided with support when they are first placed on the waiting list, their level of frustration and their fund of knowledge related to caring for an individual with a developmental disability will likely be lower than that of the participants in this dissertation.

Another limitation of this dissertation was that the evaluation was formative in nature due to contextual and temporal constraints. Since only five worksheets were included in the implementation of the program, the program's potential benefit for the caregivers may extend beyond the current results. During future implementations, when more worksheets will be included, the program evaluation will provide more information about the potential value of participation in the full waiting list program.

Recommendations

Since following the completion of this dissertation this investigator will no longer be involved in the implementation and evaluation of the waiting list program, it is recommended that the client delineate the various program implementation and evaluation roles to different members of the organization. Each member of the organization should become knowledgeable about their specific role, as well as the other roles, and should be careful to implement the program with integrity. It will be important for all members involved in the waiting list program to meet on a consistent basis to

discuss the program planning and evaluation process. Refer to Callaghan's (2008) program design for suggestions on delineating the different roles.

It is recommended that all members of each of the organization's waiting lists be provided with the opportunity to participate in the program. All waitlisted members should be provided with the initial home-based session so that relevant information can be disseminated and informed consent can be obtained. Following the initial home-based session, the 20 caregivers who have been waiting the longest should be provided with at least semi-annual home visits so that information related to their participation in the program can be obtained and additional support can be provided. During these semi-annual visits, the information that was obtained through the worksheet survey form and program evaluation form will be obtained. The worksheet survey forms will no longer be used due to the low response rate. However, participants should still be able to request information about other topics and provide feedback as necessary through email, mail, or by phone. The program evaluation form will still be utilized, but will be supplemented by information gained during the final semi-annual visit for members who were on the waiting list for the longest amount of time.

Strong consideration should be made to including at least 10 of the educational worksheets that were constructed as part of the original design of the waiting list program. If 10 worksheets are included, the program will have a 10-month duration. Therefore, participants will be exposed to a greater breadth of information while they are waiting, which may better prepare them for participation in the parent-training program. In order to determine which worksheets should be included, it will be necessary to review

the information to ensure that it is current and still relevant. It may be useful to combine related topics.

Overall Summary and Conclusions

This dissertation focused on the process of designing, implementing and conducting a formative evaluation of a program for caregivers waiting to receive parent-training. Maher's (2000) program planning and evaluation framework was utilized to redesign the program and program evaluation plan, implement the program, and conduct a formative program evaluation. The information gained through the formative program evaluation will be used to make adjustments to the program design and implementation, as well as the evaluation plan.

Based on the formative evaluation, three main conclusions were made. First, the waiting list program was implemented according to the program design, with the addition of a few procedures that were included to attempt to increase participation. Second, the caregivers were provided with information related to caring for an individual with a developmental disability that either was a review of information they already knew, or provided them with new knowledge. Third, the caregivers were generally satisfied with the waiting list program. Due to the small sample size and low response rates, these results should be reviewed with caution.

Several recommendations were presented for the continued implementation and evaluation of the waiting list program. These recommendations include delineating responsibilities across the organization, providing all members of the waiting lists with the opportunity to participate, discontinuing the use of the worksheet survey form,

providing at least semi-annual home-visits to the 20 members who have been waiting the longest, and combining the initial 15 worksheets into a total of 10 worksheets after reviewing the information to ensure that it is current and relevant.

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APPENDIX A
PROGRAM INSTRUMENTATION

Instrument 1.1_
Participant Characteristics

This form was created to gather information about the caregivers who participated in the waiting list program. The form is to be completed by this investigator for all caregivers who participated in the program. The organization's records should be reviewed in order to obtain contact information, information about county of residence, and length of time on the waiting list. Additional participant information (gender, marital status, thoughts and feelings about the waiting list, use of other behavioral services) should be obtained during the participant interviews. The relevant information should be recorded so that the data can be used during the program evaluation.

Variable
County of Residence
Essex
Mercer
Somerset
Union
Gender
Female
Male
Marital Status
Married
Widowed
Time of Waiting List
1.5 to 2 years
2 to 2.5 years
2.5 to 3 years
3 to 3.5 years
3.5 to 4 years
Previous Behavioral Services Utilized
Yes
No
Negative Feelings/Opinions of Waiting List
Yes
No

Instrument 1.2
Child Characteristics

This form was created to gather information about the children of the caregivers who participated in the waiting list program. The form is to be completed by this investigator for the caregivers' child with a developmental disability. The organization's records should be reviewed to obtain information about the child's gender, current age and diagnosis. Additional information about the child (age at time of diagnosis, current challenging behaviors) should be obtained during the participant interview. The relevant information should be recorded so that the data can be used during the program evaluation.

Variable
Gender
Female
Male
Current Age
5 to 7
8 to 10
11 to 13
14 to 16
Diagnosis
Autism
PDD
TBI
Age When Diagnosed
< 1 year
1 to 1 year, 11 months
2 to 2 years, 11 months
3 to 3 years, 11 months
4 to 4 years, 11 months
Challenging Behaviors
Aggression (self and/or others)
Adaptive/Self-Help Skills
Noncompliance
Perseverative Behaviors
Sensory Integration Disorder/Dysfunction
Social Skills
Tantrum Behaviors

Instrument 2
Program Implementation Tracking Form

This form was created to document the frequency and percentage of caregivers who participated in each of the phases of the waiting list program. This form will be completed by the investigator at the end of each phase. This information will be used during the program evaluation.

To What Extent was the Initial Contact Phase of the Program Implemented as Designed?		
	Frequency	Percentage
Contact attempts		
Caregivers who were reached by phone		
Caregivers reached by phone who agreed to participate (by scheduling a home-based session)		
To What Extent was the Home-Based Session Implemented as Designed?		
	Frequency	Percentage
Caregivers who scheduled a home-based session and participated in the home-based session		
Caregivers who participated in the home-based session and agreed to continue participation		
Caregivers given a description of waiting list program		
Caregivers give a description of parent-training program (with brochure)		
Caregivers explained confidentiality		
Caregivers who signed the informed consent form		
Caregivers who participated in an informal interview		
Caregivers who received Worksheet 1: Welcome- ABA and the Four-Factor Model (with the survey form)		

Continued-- Program Implementation Tracking Form

To What Extent was the Educational Worksheet Phase of the Program Implemented as Designed?		
	Frequency	Percentage
Caregivers who were sent Worksheet 2: Crisis Management (and survey form)		
Caregivers who were sent Worksheet 3: Effects of Providing Care on the Caregiver (and survey form)		
Caregivers who were sent Worksheet 4: Navigating the System- DDD and Advocacy (and survey form)		
Caregivers who were sent Worksheet 5: Working with School Systems (and survey form)		
To What Extent was the Program Evaluation Phase Implemented as Designed?		
	Frequency	Percentage
Program Evaluation Forms Disseminated		
Program Evaluation Forms Completed		

Instrument 3

Participant Reactions on the Worksheet Surveys

This form will be utilized to record the frequency and percentage of caregivers' responses to each of the worksheet survey forms. The form will be completed by this investigator. The information will be used during the program evaluation.

To What Extent did Caregivers Participate?		
	Frequency	Percentage
Reported reading the worksheet		
To What Extent did Caregivers Report Increased Knowledge?		
Reported that the worksheet greatly increased their knowledge		
Reported that the worksheet increased their knowledge		
Reported that the worksheet was mainly a review		
Reported that the worksheet did not increase their knowledge		
To What Extent did Caregivers Report Satisfaction with the Worksheet?		
Reported being highly satisfied with the worksheet		
Reported being moderately satisfied with the worksheet		
Reported being neither satisfied nor dissatisfied with the worksheet		
Reported being dissatisfied with the worksheet		

Instrument 4

Participant Reactions on the Program Evaluation Survey

This form will be utilized to record the frequency and percentage of caregivers' responses on the Program Evaluation Survey. The form will be completed by this investigator. The information will be used during the program evaluation.

To What Extent did Participants Report Having Read the Worksheet?		
	Frequency	Percentage
ABA and the Four-Factor Model		
Crisis Management		
Effects of Providing Care on the Caregiver		
Navigating the System- DDD and Advocacy		
Working with School Systems		
To What Extent did Participants Report Increased Knowledge on the Worksheet Topic?		
ABA and the Four-Factor Model		
Crisis Management		
Effects of Providing Care on the Caregiver		
Navigating the System- DDD and Advocacy		
Working with School Systems		
To What Extent did Participants Report Being Satisfied with the Content of the Worksheet?		
ABA and the Four-Factor Model		
Crisis Management		
Effects of Providing Care on the Caregiver		
Navigating the System- DDD and Advocacy		
Working with School Systems		

Instrument 5
Caregiver Response/Evaluation Survey Form

Caregiver Response/Evaluation Survey – Worksheet Evaluation

Every month we ask that you take a few minutes to respond to our survey about the worksheet that you have just read. Your responses will help us tailor the waiting list program to include content that is most beneficial to the waiting list clients. Even if you were not interested in this topic or did not have time to read the materials, please respond to Question One, as this will provide us with information that can be used in the evaluation of this program. The questions were developed from a needs assessment that was completed with waiting list members in your area. Your responses to the survey also provide you with the opportunity to ask specific questions about the content that you have read and/or about other services. We hope that you find the waiting list program interesting and helpful and we thank you for your participation.

Worksheet Title: _____ (Insert Worksheet Title)

1. Please circle or bold the response that best describes your use of this information:
 - a. I was able to read the current worksheet.
 - b. I did not read the current worksheet because I was not interested in the topic.
 - c. I did not read the current worksheet because I did not have time.

Continued--Caregiver Response/Evaluation Survey Form

2. Please circle or bold the response that best describes the extent to which this worksheet increased your knowledge about (Insert Worksheet Topic).
- a. This worksheet greatly increased my knowledge about (Insert Worksheet Topic).
 - b. This worksheet increased my knowledge about (Insert Worksheet Topic) and I learned at least one new concept.
 - c. This worksheet allowed me to review information that I had already learned about (Insert Worksheet Topic) and I found the information was helpful.
 - d. I did not learn anything new about (Insert Worksheet Topic) from this worksheet and did not find it helpful.
3. Please list below what you learned in this worksheet that may be helpful to you in your caregiving role.

Continued--Caregiver Response/Evaluation Survey Form

4. Please circle or bold the response that best describes your general level of satisfaction with this worksheet.

- a. I was highly satisfied with this worksheet.
- b. I was moderately satisfied with this worksheet.
- c. I was neither satisfied nor dissatisfied (i.e., neutral).
- d. I was dissatisfied with this worksheet.

5. Please list any questions or concerns that you have about the material in the space below.

6. Please let us know of any services that you are having difficulty obtaining (e.g., physicians, therapists, transportation, respite, camps, day programs.) Although we will not always be able to help you, we do have some limited resource information that may be helpful. If we have any relevant information, we will forward it to you with your next worksheet. (Please include your name and address (or email) below so we can forward relevant materials).

Continued--Caregiver Response/Evaluation Survey Form

7. Please use the space below to ask any additional questions or provide relevant comments.

Instrument 6
Program Evaluation Survey

Program Evaluation Survey

Thank you for participating in the waiting list program. Please fill out this survey and return it by mail or email to our offices so that we can evaluate and improve our services to you. The questions listed on this survey were developed from a needs assessment that was completed with waiting list members in your area. We know that you are busy and appreciate any time that you can take to complete this survey.

1. Please circle or bold the response that best describes the extent to which this program has increased your knowledge about methods or services that would assist you if you experienced any unpleasant emotions associated with your caregiving role.
 - a. The wait list program has greatly increased my knowledge.
 - b. The wait list program has increased my knowledge.
 - c. The wait list program has mainly targeted information that I had already learned but I found the review helpful.
 - d. I did not learn anything new from the wait list program about methods or services that could assist me if I experience any unpleasant emotions associated with my caregiving role.

Continued-- Program Evaluation Survey

Please provide additional feedback or suggestions that may guide our program development.

2. Please circle or bold the response that best describes the extent to which this program has increased your knowledge about behavior management concepts.
- a. The wait list program has greatly increased my knowledge.
 - b. The wait list program has increased my knowledge.
 - c. The wait list program has mainly targeted information that I had already learned but I found the review helpful.
 - d. I have not learned anything new from the wait list program about behavior management principles or strategies that would assist me with managing the challenging behaviors of my relative.

Please provide additional feedback or suggestions that may guide our program development.

Continued-- Program Evaluation Survey

3. Please circle or bold the response that best describes the extent to which this program has increased your knowledge about accessing services through DDD or other agencies.
- a. The wait list program has greatly increased my knowledge.
 - b. The wait list program has increased my knowledge.
 - c. The wait list program has mainly targeted information that I had already learned but I found the review helpful.
 - d. I have not learned anything new from the wait list program about behavior management principles or strategies that would assist me in accessing services through DDD or other agencies.

Please provide additional feedback or suggestions that may guide our program development.

Continued-- Program Evaluation Survey

4. Please circle the response that best describes your general level of satisfaction with the program.
- a. I am highly satisfied with the program.
 - b. I am moderately satisfied with the program.
 - c. I am neither satisfied nor dissatisfied (i.e., neutral).
 - d. I am dissatisfied with the program.

Please provide additional feedback or suggestions that may guide our program development in the space below.
