10-2020

Predictors of Positive Outcomes in Treating Individuals Diagnosed with IDD and Comorbid Psychiatric Disorders

Jacob Omondi Wasonga

Recommended Citation

Wasonga, Jacob Omondi, "Predictors of Positive Outcomes in Treating Individuals Diagnosed with IDD and Comorbid Psychiatric Disorders" (2020). *Theses & Dissertations*. 42.
https://commons.stmarytx.edu/dissertations/42

PREDICTORS OF POSITIVE OUTCOMES IN TREATING INDIVIDUALS DIAGNOSED WITH IDD AND COMORBID PSYCHIATRIC DISORDERS

APPROVED:

Carolyn Y. Tubbs, Ph.D., LMFT-S
Dissertation Advisor

Nicholas Wilkens, Ph.D., LMFT-S, LPC-S

Russell Bartee, Ph.D., LMFT-S, LPC-S

APPROVED:

Leona Pallansch, Ph.D.
Interim Dean, College of Arts, Humanities and Social Sciences

Date

PREDICTORS OF POSITIVE OUTCOMES IN TREATING INDIVIDUALS DIAGNOSED WITH IDD AND COMORBID PSYCHIATRIC DISORDERS

A

DISSERTATION

Presented to the Faculty of the Graduate School of
St. Mary's University in Partial Fulfilment
of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY
in
Marriage and Family Therapy

by

Jacob Omondi Wasonga, M.A., LMFT
San Antonio, Texas
October 2020

Abstract

PREDICTORS OF POSITIVE OUTCOMES IN TREATING INDIVIDUALS DIAGNOSED WITH IDD AND COMORBID PSYCHIATRIC DISORDERS

Jacob Omondi Wasonga, M.A., LMFT

St. Mary's University, 2020

Dissertation Advisor: Carolyn Y. Tubbs, Ph.D.

The purpose of this research was to evaluate the use of a new treatment protocol, the systemic treatment plan (STP) by identifying the predictors of positive treatment outcomes for individuals diagnosed with intellectual and developmental disabilities (IDD) and comorbid mental health conditions. This study examined the relationship between challenging behaviors, psychiatric conditions, and positive treatment outcomes for individuals with IDD and co-occurring disorders, particularly those individuals whose treatment was driven by the STP. A linear regression analysis was conducted to determine which challenging behaviors and psychiatric disorders best predict positive outcomes in systemically engaged treatment. The results from this study indicated that challenging behaviors did not act as predictors of positive outcomes in treatment. However, the results demonstrated that having a diagnosis of Autism acted as the best predictor of positive outcomes when the STP was used in treatment.

Table of Contents

List of Tables

List of Figures

Chapter I

The Problem and Justification of the Study

Individuals with intellectual and developmental disabilities (IDD) represent a unique population that has specific physical and mental health needs that are often not being met. Although the needs of this group have been broadly identified throughout literature, researchers argue that there are consistent health disparities that persist for individuals with IDD (Anderson et al., 2013). While these disparities often stem from a myriad of structural problems within the healthcare system—including the lack of trained providers to deliver care—research clearly demonstrates that there is a paucity of evidence-based practice upon which to develop and sustain treatment for this population (Singh et al., 2013; Wong et al., 2015). Consequently, those diagnosed with IDD may experience significant barriers in acquiring effective care to address their unique needs.

Statement of the Problem

Although significant challenges exist for meeting the physical and mental health needs of individuals with IDD, these issues are often further complicated by the presence of comorbid health conditions including psychopathology. Research consistently demonstrates that for individuals with IDD, the presence of comorbid mental health issues can result in a number of deleterious outcomes (Turygin, Matson, MacMillan, & Konst, 2013). Comorbid psychopathology can markedly impact the behavior of the individual with IDD, leading to the physical restriction of activities and the inability of the affected individual to engage in important social relationships (Turygin et al., 2013). These comorbidities were noted by Horovitz, Shear, Mancini, and Pellerito (2014) to have a profound impact on an individual's quality of life. According to these authors, individuals with IDD who are diagnosed with comorbid mental health issues report significantly lower quality of life scores than those with IDD that do not have comorbid mental health issues (Horovitz et al., 2014).

Further complicating outcomes for those diagnosed with IDD and comorbid psychopathology is the lack of evidence-based interventions to direct and support treatment. Arguably, the situation for individuals with intellectual and developmental disabilities and comorbid mental health issues is one that is notably complex. While research does indicate that treatment of psychiatric disorders in this population can have a remarkable impact on behavior and overall outcomes for the client (Vereenooghe & Langdon, 2013), providing mental health treatment for clients with IDD can be a challenging undertaking (Man, Kangas, Trollor, & Sweller, 2017; Whittle, Fisher, Reppermund, Lenroot, & Trollor, 2018). Many clients may lack the expressive capabilities needed to help practitioners understand when concrete improvements in mental health symptoms have occurred (McDermott et al., 2018). Additionally, many mental healthcare providers lack the experience, knowledge, and training needed to provide care for individuals with IDD (Man et al., 2017).

Based on the current issues noted regarding evidence-based treatment for individuals with IDD and comorbid psychopathology, it becomes evident that efforts are needed to determine what works to provide the most effective support for this vulnerable population. Effective interventions for this group can enhance autonomy and quality of life; factors that are imperative for improving treatment outcomes for those with IDD (Schalock & Luckasson, 2013). Given the need to examine what works and to further build an effective foundation for evidence-based practice, this study focused on the use of a quantitative approach to examine the impact of systemic engagement as a treatment method to promote positive outcomes in treatment. Through the exploration of systemic engagement and its implications on individuals with IDD and co-occurring mental health disorders; it should be possible to build a foundation for evidence-based practice that can be utilized to structure and improve treatment for this unique population throughout community mental health centers and outpatient clinics.

Purpose of the Study

The purpose of this research was to evaluate the use of a new treatment protocol, the systemic treatment plan (STP) by identifying the predictors of positive treatment outcomes for individuals diagnosed with IDD and comorbid mental health conditions. The STP is a tool that was developed by researchers within the systemic, therapeutic, assessment, resources, and treatment (START) program to assess the efficacy of treatment. This program was pioneered by the National START Center at the University of New Hampshire Institute on Disability to provide a foundation for delivering structured care for individuals with intellectual and developmental disabilities and comorbid behavioral health issues (Beasley, Kalb, & Klein, 2018). Under the model, a systems approach that emphasizes systemic communication and decision making is employed along with a client-centered focus to succinctly address the evolving needs of the client (Beasley, Klein, & Weigle, 2016). Although the START model has been widely employed in practice, there is a dearth of empirical literature quantifying the outcomes that can be achieved through the use of this model (Beasley et al., 2018). Thus, efforts are needed to demonstrate the efficacy of the model and to further facilitate the development of a solid evidence base for the treatment of individuals with IDD and co-occurring mental health disorders.

Literature Support

A review of what has been noted about the START model and systemic engagement, in general, indicates that this approach to treatment appears to have notable theoretical salience for addressing the needs of the target population. In particular, information regarding systemic engagement demonstrates that this approach to care has been linked to ecological systems theory initially developed by Urie Bronfenbrenner (Bronfenbrenner, 1979). Under this theory, practitioners are challenged to integrate a broader foundation for conceptualizing and understanding the needs of others. More specifically, Bronfenbrenner advocated for consideration of broader systems such as social institutions (schools, employment, etc.) and social milieu as part of understanding a person and determining his or her needs (Bronfenbrenner, 1986). The use of ecological systems in practice fosters the ability of the practitioner to comprehensively and holistically conceptualize the client in his or her environment. Conceptualization in this manner leads to a more complete understanding of the variables impacting the client that can be identified and addressed to enhance outcomes (Stephens, 2014).

The operationalization of systems theory in counseling practice has occurred through the development of various pragmatic approaches to client care including strategic family therapy (SFT) (Murray, 2014). Under this approach to care, the client’s behavior is addressed through an understanding of relational and communication imbalances that are present in the systems of the client (Murray, 2014). With this approach, an effort is made to ameliorate the larger systems issues impacting the client rather than focusing solely on changing the behavior of the client. In the context of the START model, strategic and systemic engagement provide a unique foundation upon which to identify the systemic elements contributing to the distress of the client and develop solutions to the problem. The model provides the opportunity to address these elements’ needs so that client autonomy, empowerment, and quality of life can be improved.

Practical Importance

The practical importance of this research can be seen when reviewing the scope and implications of the problem. Data provided by the National Association of State Directors of Developmental Disability Services [NASDDDS], (2013) demonstrate that there are currently more than 4.7 million individuals living in the United States who have been diagnosed with IDD. Additional data provided by Durbin, Sirotich, Lunsky, and Durbin (2017) indicate that of those diagnosed with IDD, as many as half suffer from some type of co-occurring mental health disorder. As previously mentioned, individuals diagnosed with IDD and comorbid psychopathology have unique health needs and further quantitative data are needed to enhance care and support because there is a paucity of data to support evidence-based treatment of this group. In addition, practitioners need a definitive and structured foundation for delivering care to those with these specific health needs.

Research Questions

The global research question for this study was, *"How do challenging behaviors and psychiatric disorders impact treatment outcomes among individuals diagnosed with intellectual and developmental disabilities who have received treatment using the STP and the START plan over a 12-week period?"* The following secondary research questions also guided the study:

1a: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the STP over a 12-week period?*

1b: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the START plan over a 12-week period?*

2: *Do stressors improve through time for individuals receiving treatment using the STP over a 12-week period?*

3a: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the STP?*

3b: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the START plan?*

Rationale or Justification for the Study

Historically, health services and clinical research for individuals diagnosed with IDD have both been greatly underdeveloped and understudied. According to Krahn, Hammond, and Turner (2006), the outpatient mental health systems in the United States has failed to meet the needs of individuals with IDD and co-occurring challenging behaviors and, to date, there are limited programs that have been developed to show effective strategies for engaging with this population. These inadequacies of effective service provision are mainly due to the over-reliance on hospital-based services as well as the stereotypes of IDD etiology by service providers (Beasley, 2002). Researchers have begun to address this oversight within the last two decades based on evidence that people with IDD experience a greater number of life events than their typically developing peers and that the current strategies are costly and somewhat ineffective in terms of decreasing challenging behaviors (Hatton & Emerson, 2004).

Social service agencies and other programs that cater to the needs of individuals diagnosed with IDD fall behind on integrated systems of care and intervention strategies are psychotropic based (Krahn et al., 2006). In addition, crisis services are mainly used as interventions once challenging behaviors come to surface and there is a need to focus on preventative measures. Although longitudinal data on effectiveness are required, programs that offer intervention before behaviors become more severe and established clearly offer potentially important evidence for the effectiveness of prevention (Allen et al., 2013). Indeed, the prevention of challenging behaviors is favorable to intervention once the behaviors are present. A small number of studies have demonstrated the effectiveness of adopting a function-based approach to early intervention with this population (Kurtz et al., 2003; Wacker et al., 1998). Of relevance is evidence that effective early intervention strategies can be delivered on the scale required to make an impact on the IDD population at large.

Research regarding the needs of individuals with IDD and co-occurring mental health disorders clearly indicates that this population can be challenging to treat (Turygin, Matson, & Adams, 2014). However, with effective treatment, the needs of this group can be met and the health and quality of life of those with these disorders can be markedly improved (Brown, Brown, & Dibiasio, 2013; Holwerda, van der Klink, de Boer, Groothoff, & Brouwer, 2013). Through the use of effective treatment supports for those with IDD and comorbid psychopathology, it will be possible to foster client independence, self-determination, and empowerment (Schalock & Luckasson, 2013). Schalock and Luckasson (2013) also add that these issues have been noted as critical to the well-being of all clients with IDD and what is essential to improving their lives is social inclusion. Through the effective treatment of mental health disorders, social inclusion can be improved for clients and further growth and development will be possible (Morisse, Vandemaele, Claes, Claes, & Vandevelde, 2013). Consequently, successful treatment of underlying mental health issues in clients with IDD is imperative to foster optimal well-being and a heightened quality of life. The intent of this study is to have its outcomes solidify the evidence base for treatment such that practitioners, especially marriage and family therapy (MFT) clinicians will have definitive support for utilizing systemic engagement for the successful treatment of individuals with IDD and comorbid psychopathology.

Understanding the impact of systemic thinking in treating cases of individuals diagnosed with IDD and co-occurring disorders in order to avoid recurrent crisis episodes or hospitalizations is a fairly new concept. However, the impact of systemic thinking is crucial and can help foster the effective provision of services by crisis programs within social service agencies as well as MFT practitioners. This study is important to mental health professionals because systems thinking, the discipline that examines the relationships between essential parts of a problem and determines how to manage those relationships to get positive outcomes, is a philosophy that orients the MFT profession. MFT's, as systemic thinkers, know that problems can have hidden, indirect causes and can spiral out from one problem to touch many. The use of systemic engagement in this study highlights the impact that systems theory already has on the field of marriage and family therapy. Furthermore, this study is important to the mental health profession since the IDD population is the most underserved population in the mental health field (Anderson et al., 2013; Krahn et al., 2006). With this in mind, clinicians will be able to understand and conceptualize the issue of developmental disorders and how having this diagnosis doesn't only affect the individual diagnosed, but the support systems involved.

Limitations

This study was exploratory in nature and it involved the use of historical data from a relatively small sample of clients with IDD and co-occurring mental health issues (*n*=93). Limitations from this study will therefore result in the inability to broadly generalize the findings to all individuals in the target population. This study was also limited by geographic area. These data were collected from a single site and included a convenience sample. Participants were selected from a population of individuals with IDD and comorbid psychopathology who were enrolled in the START program before being randomly assigned to a treatment or control group.

These methodological issues impact the internal validity of the study and also shape the generalizability of the findings. Even though participants were randomly assigned, they were not randomly drawn from all members of the target population, making it difficult to state with certainty that the sample is truly representative of all clients diagnosed with IDD and co-occurring mental health issues.

Definition of Terms

For the purposes of this research, the following terms are defined:

Developmental disability. Chronic conditions that are “attributable to a mental or physical impairment or combination of mental and physical impairments” (McDermott et al., 2018, p. 371). The condition develops before the age of 22, is expected to continue across the lifespan and results in marked functional limitations in three or more of the following areas: self-care, receptive/expressive language, learning, mobility, self-direction, independent living, and economic self-sufficiency (McDermott et al., 2018).

Intellectual disability. Disabilities that are caused by limitations in both intellectual functioning and the ability of the individual to engage in adaptive behavior (McDermott et al., 2018).

Systemic engagement. A systems linkage approach to service delivery that works to overcome broader systems challenges in access to mental health care services (Charlot & Beasley, 2013). Treatment is solution-focused with an emphasis on active communication and decision making and a better understanding of individual clinical and treatment needs (Beasley et al., 2016). Through this process, the underlying systems that support symptomatic behaviors are addressed such that the symptomatic behavior can be effectively mitigated (Murray, 2014).

Challenging behaviors. According to the Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists (2007), behavior can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion. Examples of challenging behavior include self-injurious behavior (hitting, scratching, biting, etc.), aggressive behavior (screaming, hitting others, spitting, etc.), or inappropriate sexual behavior (Schmidt et al., 2016).

Positive outcomes. Positive perceptions of treatment outcomes by individuals in the treatment team as well as clients served. These perceptions were captured through a combination of questions from a 32-item satisfaction survey which was completed at the end of the original START study. The standard mean difference of these questions was statistically significant.

Chapter II

Review of Literature

The purpose of this research was to evaluate the use of a new treatment protocol, the systemic treatment plan (STP) by identifying the predictors of positive treatment outcomes for individuals diagnosed with intellectual and developmental disabilities (IDD) and comorbid mental health conditions. The global research question that this study sought to answer was, *"How do challenging behaviors and psychiatric disorders impact treatment outcomes among individuals diagnosed with IDD who have received treatment using the STP and the START plan over a 12-week period?"* The researcher attempted to explore whether challenging behaviors and psychiatric disorders as the presenting problem play a role in predicting positive outcomes in treatment. To provide foundational support for this project, the literature reviewed here considers: the scope and impact of intellectual or developmental disabilities on the functioning of the individual; the implications of co-occurring mental/behavioral health disorders on the functioning of individuals with IDD; the central tenets of systemic engagement; and the utility of applying systemic engagement for treatment of the target population.

Scope and Impact of IDD

The most current epidemiological data indicates that as many as eight million individuals in the United States currently suffer from an intellectual or developmental disability (McDermott et al., 2018). Developmental disabilities are defined as severe, chronic conditions that are "attributable to a mental or physical impairment or combination of mental and physical impairments" (McDermott et al., 2018, p. 371). The condition develops before the age of 22, is expected to continue across the lifespan and results in marked functional limitations in three or more of the following areas: self-care, receptive/expressive language, learning, mobility, self-direction, independent living, and economic self-sufficiency (McDermott et al., 2018). Intellectual disabilities include those which are caused by limitations in both intellectual functioning and the ability of the individual to engage in adaptive behavior (McDermott et al., 2018). There are many conditions under the IDD umbrella. Some conditions are diagnosed using the second edition of the Diagnostic Manual – Intellectual Disability (DM-ID-2) while others such as the Prader-Willi syndrome are diagnosed using specialized instruments that are adapted and specially developed for their respective syndromes (Spendelow, 2011). Ideally, the chronic conditions classified under "intellectual and developmental disabilities" are broad and research to understand the behavioral phenotypes associated with specific genetic causes of intellectual disabilities is still a growing area (Cooper, Melville, & Einfeld, 2003). In addition, there are some specific groups that have been identified as meeting the criteria for IDD including those with autism, Down syndrome or cerebral palsy (McDermott et al., 2018).

Information regarding the pragmatic challenges faced by individuals with IDD indicates that these disorders impact the ability of the individual to learn and apply new information (Ross, Marcell, Williams, & Carlson, 2013). Further, IDD significantly impairs adaptive behavior and the ability of the individual to engage in social skills, self-management, and activities of daily living (ADL) (Ross et al., 2013). Due to these issues, those with IDD are less likely to seek post-secondary education or acquire gainful employment (Ross et al., 2013). These issues have systemic implications for lifespan development including the ability of the individual to access needed healthcare resources and supports (Heller, Fischer, Marks, & Hsieh, 2014). Consequently, research indicates that as individuals with IDD age, they are more likely to suffer from a wide range of chronic health conditions, further impacting their functioning and well-being (Heller et al., 2014).

The scope and implications of the challenges facing those with IDD is reviewed by Anderson et al. (2013) who argue that those with IDD experience a wide range of health disparities due to structural and institutional factors that have historically impeded the ability of this group to access needed supports to improve health. More specifically, Anderson et al. (2013) argue that these individuals often lack access to high quality care including access to providers that are equipped to meet their unique physical and mental health needs. The authors indicate that those with IDD often live in poverty and are excluded from the larger context of public health planning (Anderson et al., 2013). In short, individuals with IDD are significantly marginalized in society and often lack many of the routine healthcare supports that are typically provided to those without this diagnosis. Over time, Anderson and coworkers contend that marginalization of individuals diagnosed with IDD has a systemic impact on health which leads to shorter life expectancies and higher rates of co-occurring health issues including: psychiatric disorders, hypertension, cardiovascular disease, and gastrointestinal disorders. Kalb, Beasley, Klein, Hinton, and Charlot (2016) also described the prevalence of psychiatric hospitalization services among individuals in this population in a study of 3299 individuals with IDD (mean age= 31 years; SD=14 years) and found that 28% of the sample had at least one psychiatric inpatient stay in the prior year of the study.

The nexus of the difficulties faced by those with IDD appear to lie in the problems that arise with regard to adaptive behavior. According to Dimitriadou and Kartasidou (2017), adaptive behavior represents the combination of practical, perceptual, and social skills that enable the individual to function in the external environment. These authors argue that limitations in adaptive behavior inhibit the individual with IDD to accurately perceive and respond to external stimuli, making it difficult, if not impossible, for the individual to behave in a manner that will ensure positive outcomes in everyday tasks (Dimitriadou & Kartasidou, 2017). The problem is reinforced when the behavior of the individual results in negative reinforcement from the social environment and the inability of the individual to cope with outcomes that occur as a result of their behavior (Dimitriadou & Kartasidou, 2017). What this suggests is that while IDD has implications for internal functioning and behavior, there is a social component to these disorders which systemically impact functioning.

Comorbid Conditions

Given the concerns outlined above, it is necessary to consider how other components of IDD affect the individuals diagnosed with their ability to adapt to different environments. Research indicates that for many individuals with IDD, comorbid mental/behavioral health concerns are often present (Durbin et al., 2017). For many years, the co-occurrence of IDD and psychiatric disorders was regarded as being related directly to IDD. The current predominant view is that persons with IDD can develop psychiatric disorders additionally and not related to the pre-existing IDD condition (Holland, 1999).

Current statistics suggest that as many as half of all individuals with IDD have a co-occurring psychiatric disorder (Durbin et al., 2017). Even though IDD and comorbid mental health issues are common, scholars argue that there are often significant gaps in treatment as many of those with these co-occurring disorders have complex health needs (Durbin et al., 2017). Complicating the problem has been the process of deinstitutionalization and the shift of psychiatric care to the community (Durbin et al., 2017). Because individuals with IDD and comorbid mental health issues often have extensive health needs, most communities struggle to provide effective care that comprehensively addresses all these issues (Durbin et al., 2017).

The scope and impact of co-occurring mental/behavioral health diagnoses in individuals with IDD can be difficult to fully conceptualize under a single umbrella. Researchers have consistently demonstrated different profiles of psychiatric comorbidity for individuals with specific intellectual and developmental disabilities (Turygin et al., 2014). For instance, individuals diagnosed with autism have been shown to also struggle with depression and social anxiety (Turygin et al., 2014). They are also significantly more likely to show aggression and disruption to the environment (McClintock, Hall & Oliver, 2003).

However, in clients with other forms of intellectual disability and co-morbid conditions such as cerebral palsy, mood swings, a lack of empathy, and attention seeking behaviors may be more common (Turygin et al., 2014). Further, in adults with epilepsy and other seizure disorders, schizophrenia-spectrum and personality disorders have been shown to co-occur more frequently (Turygin et al., 2014). What these data indicate is that even though comorbid psychiatric disorders are quite common in individuals with IDD, considerable challenges exist when it comes to succinctly classifying the mental health issues that are most prevalent in this population.

Additional concerns have been noted regarding the diagnosis of co-occurring psychiatric disorders among individuals with IDD (Matson & Williams, 2014). Specifically, researchers have argued that due to the specific nature of certain intellectual or developmental disabilities, those affected may lack the cognitive or communicative capabilities to effectively express their symptoms (Matson & Williams, 2014). The diagnosis and treatment of mental disorders often employs client self-report of symptoms and distress (Turygin et al., 2014). For those with various types of IDD, expressing these concerns can be problematic (Turygin et al., 2014). In such instances, clinicians tend to depend on caregivers and direct support staff for information regarding symptoms in order to treat.

Consequently, diagnosis of comorbid psychiatric disorders is often made based on specific symptoms observed by caregivers (Matson & Williams, 2014). Differentiating symptoms of mental disorders and those directly related to IDD can be difficult (Matson & Williams, 2014). This may lead to over-diagnosing in some populations of individuals with IDD and under-diagnosing in others (Turygin et al., 2014). For instance, people diagnosed with autism are prone to struggle with constipation issues in which constipation, a biological stressor, has a correlation with challenging behaviors such as physical aggression, head-hitting, self-biting, and destruction of property. It is clearly possible for a person with IDD to display behavior such as aggression in the absence of any form of psychosis or a personality disorder. Hemmings, Gravestock, Pickard and Bouras (2006), used a symptomatic rather than syndrome-based approach to explore behavior in a sample of adults with IDD and found that self-injury and aggression were associated with affective disorders while screaming and destructiveness were linked with autism spectrum disorder rather than with more formal functional psychiatric disorders.

Despite the challenges that exist when it comes to identifying and accurately diagnosing comorbid psychiatric disorders in individuals with IDD, research does indicate that those with these co-occurring disorders often face a myriad of challenges when it comes to behavior (Turygin et al., 2013). More specifically, scholars examining outcomes for individuals with IDD who have been diagnosed with co-occurring mental health disorders argue that psychiatric comorbidity often results in the exacerbation of challenging behavior (Turygin et al., 2013). When challenging behaviors are present, individuals with IDD may be placed in a more restrictive social environment which can impede social interaction and the ability to experience outcomes such as self-determination and empowerment (Turygin et al., 2014). This restriction on behavior has further been linked to a decline in the individual's overall quality of life (Turygin et al., 2014). Clearly, the presence of comorbid psychiatric disorders for individuals with IDD can complicate overall functioning and the ability of individuals with these diagnoses to achieve desired goals for social inclusion, such as an education or full-time employment.

Challenging Behaviors

Unfortunately, for many individuals with IDD and associated comorbidities, there are additional issues of concern that impact functioning and success in achieving social inclusion goals. Schmidt et al. (2016) illustrate this point in their review of the challenging behavior that is frequently noted to accompany IDD. According to these authors, IDD often result in significant impairments in social communication skills (Schmidt et al., 2016). Consequently, individuals with IDD may become frustrated by the inability to have their basic needs met, resulting in the development of a challenging behavior. According to the Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists (2007), behavior can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive, or result in exclusion. Examples of challenging behavior include self-injurious behavior (hitting, scratching, biting, etc.), aggressive behavior (screaming, hitting others, spitting, etc.), or inappropriate sexual behavior (Schmidt et al., 2016). Some behavioral phenotypes are known to be associated with specific forms of challenging behaviors and forms of functional psychiatric disorders. People with Prader–Willi syndrome, for example, are likely to engage in skin picking at specific body sites (Thompson & Caruso, 2002) and experience psychosis (Boer et al., 2002). Individuals diagnosed with severe or profound intellectual disability are associated with frequent rates of challenging behaviors (Chadwick, Kusel, & Cuddy, 2008) as well as the presence of certain genetic conditions such as Lesch–Nyhan (Anderson & Ernst, 1994) and cri-du-chat syndrome (Collins & Cornish, 2002).

Challenging behaviors can impact the ability of caregivers to provide effective support. These behaviors also affect the client's ability to acquire needed skills to foster communication and improve coping (Schmidt et al., 2016). Further, these behaviors can markedly impact social functioning and the ability of the individual with IDD to make vital connections with others that are needed to help improve well-being (Schmidt et al., 2016).

Information provided by Richman et al. (2013) highlights the scope and impact of challenging behavior through an examination of self-injurious behavior (SIB). According to Richman et al. (2013), SIB is one of the most complex problems facing those with IDD. SIB results from the dynamic interplay of biological and environmental cues. While environmental stimuli often trigger this type of behavior, biological mechanisms reinforce the need to engage in the behavior, despite the harm that occurs (Richman et al., 2013). In some instances, those who engage in SIB can inflict permanent tissue and nerve injury, further complicating the symptoms of their diagnosis (Richman et al., 2013). Even though the specific pathophysiology of SIB has not been delineated, the biological foundations of this behavior impact the ability of caregivers to effectively control the behavior once it is triggered (Richman et al., 2013).

To further build on the dynamic interplay of biological and environmental cues, a framework that best explains the factors that contribute to recurrent challenging behaviors is the Biopsychosocial framework, developed by George Engel. Engel (1977) clearly aimed at understanding all aspects that led to the development of specific medical conditions in order to provide most efficient care and this framework is what guides this research in conceptualizing factors that contribute to challenging behaviors and inhibit achieving positive treatment outcomes. Jones, Edwards, and Gifford (2002) state that this model views clinical assessments as a combination of biological characteristics (e.g., genetic predisposition), psychological factors (e.g., lifestyle, stress, health beliefs), and social conditions (e.g., cultural influences, family relationships, social support). A practical way to view this is, an individual diagnosed with IDD and a comorbid condition struggling with a challenging behavior might be as a result of a urinary tract infection which if left untreated, could lead an individual to experience psychotic symptoms. Another cause could be from experiencing a flashback, reoccurring from a past traumatic event. Finally, the same challenging behavior could be from disturbances due to a rapid change in routine or hypersensitivity to crowded spaces especially for individuals with a comorbidity of autism.

Even though there are behavioral interventions present such as ongoing therapy, and medical interventions such as psychotropic medications, individuals diagnosed with IDD still struggle to maintain stability from challenging behaviors. Currently, psychotropic medication is the most typical intervention provided for challenging behaviors (Fleming, Caine, Ahmed, & Smith, 1996; Harper & Wadsworth, 1993; Kennedy & Meyer, 1998). The common practice is that individuals are sent to inpatient or outpatient psychiatric hospitals for treatment when behaviors have become unbearable.

The current prevailing strategy is one of “diagnose and treat,” whereby an individual receives access to intervention once the behavior or emotional problem is firmly established, and by which point considerable cost has been incurred (in terms of the quality of life of the person, their family, and in terms of the financial implications for inpatient hospitalization) and treatments are less likely to be effective (Lowe et al., 2007). Medication intervention in this case is seen as controversial mainly because these medications are designed to have specific effects on specific forms of mental health symptoms but are frequently prescribed for sedative rather than therapeutic effects. Fleming et al., (1996) conducted a study on the aspects of use of psychoactive medications on individuals diagnosed with IDD. The resulting data indicated that 69% of people were receiving psychoactive medication primarily for the control of challenging behavior and only eight percent of them had a psychiatric diagnosis (Fleming et al., 1996). These data clearly demonstrate that medications are used to suppress challenging behaviors and nothing beyond that.

Treatment Outcomes

To date, very little has been published on effective responses to stress and behavioral challenges for people with IDD. Outpatient and community mental health centers provide social services that are goal-oriented, but the common challenge is the fact that most goals end up not being attained due to the complex nature of the IDD population. Beasley et al. (2016) state that while there is a high prevalence of challenging behavior in the population, there is often a lack of effective supports to assist individuals and systems that face these challenges. It is therefore pertinent to examine cumulative strategies that will be successful in not only preventing but intervening once the challenging behaviors are present. Although the research evidence is somewhat equivocal, there are several studies that indicate that the introduction of these approaches may have beneficial impacts on rates of challenging behavior (Beadle-Brown, Hutchinson, & Whelton, 2012; Koritsas, Iacono, Hamilton, & Leighton, 2008; Toogood et al., 2009).

Social Inclusion

The challenging behaviors exhibited by those with IDD have been extensively reviewed in the context of social inclusion (Amado, Stancliffe, McCarron, & McCallion, 2013; Simplican, Leader, Kosciulek, & Leahy, 2015). Social inclusion involves the ability of the individual with IDD to be accepted and supported by others such that he or she is able to build interpersonal relationships and to participate in community life (Simplican et al., 2015). Social inclusion fosters a sense of belonging for the individual with IDD as well as provides a sense of purpose for developing meaningful roles in relationships or in the community. In many instances, those with IDD are unable to engage in behaviors that foster their ability to be socially included (Simplican et al., 2015). There is strong evidence to show that disruptive, dangerous, life-threatening, inappropriate, and socially undesirable behaviors by individuals with IDD present major difficulties for family, peers, and other community relationships (Harvey, Boer, Meyer, & Evans, 2009). These behaviors tend to be fueled by deficiencies in major life activities such as language, mobility, learning, self-help, and independent living. A combination of these factors leads this vulnerable population to not only become underserved based on their heightened need for care, but also isolated from social support systems due to frequent behavioral challenges. Generally, individuals diagnosed with IDD receive less emotional support and companionship from family members and friends in comparison to individuals that do not have the IDD diagnosis (Rosen & Burchard, 1990). These relationships are crucial in fostering emotional well-being. Yet due to this gap, individuals with IDD end up receiving much of their support through paid professionals.

This problem has given rise to a dichotomy in which many believe that efforts should be made to “normalize” the behavior of those diagnosed with IDD in order to promote social inclusion (Amado et al., 2013). While fostering behavioral adaption of individuals with IDD has become a focal point of providing care, many contend that social environments need to become more open and accepting of individuals with IDD such that significant rigorous adaption is not continually needed for the individual to be viewed as “normal” (Amado et al., 2013; Simplican et al., 2015).

All of the information regarding health disparities and social inclusion for individuals with IDD does raise questions regarding treatment approaches and interventions that can be used to address the specific needs of those with this diagnosis. Scholars reviewing this issue have noted that intervention to address the needs of those with IDD has focused on the development of planning supports to foster the highest level of social functioning for the individual (Schalock & Luckasson, 2013). More precisely, planning has focused on a myriad of client-centered programs that will enable the individual to participate in society as fully as possible through activities such as education and employment (Schalock & Luckasson, 2013). Planning supports also focuses on outcomes such as self-determination, empowerment, and personal growth with the idea that intervention will enable the individual to participate in society to the best of his or her ability (Schalock & Luckasson, 2013). Essential to the development of planning for individuals with IDD has been the integration of a systems approach in which those providing services are able to holistically assess needs to deliver interventions that are tailored to comprehensively address the needs of the client (Schalock & Luckasson, 2013). Examples include: natural resources, assistive technology, educational technology and opportunities, professional services, and personal strengths (Schalock & Luckasson, 2013).

Social support is most associated with positive outcomes for people diagnosed with IDD and some in the scientific community have turned to a position of widespread enthusiasm about the social shaping of interventions for this population. There is some evidence that showcases social factors associated with mental health and mental illness act as determinants for positive well-being (Wilkinson & Marmot, 1998). More specifically, the direct relationships between social support and psychological well-being have been examined and proven to be effective with people diagnosed with IDD (Lunsky & Benson, 2001). McGillivray and McCabe (2007) further explored this relationship with people diagnosed with IDD who struggle with depressive symptoms and showed a positive correlation as well. Moreover, Lunsky and Benson (2001) conducted a study to show that interpersonal relationships are positively associated with the well-being for people diagnosed with IDD. Horner, Vaughn, Day, and William (1996) also demonstrated how the challenging behaviors of 15 young people with severe IDD decreased after receiving positive influence and social support from their caregivers. These studies provide plenty of evidence to highlight the importance and effectiveness of systemic engagement whereby active support from the system is crucial at supporting a good quality of life.

Community Support Services and Goal Attainment

What is evident from the information provided by Schalock and Luckasson (2013) is that the specific services provided to individuals with IDD are varied based on the specific needs of the client. Hewitt, Agosta, Heller, Williams, and Reinke (2013) argue that the specific needs of individuals with IDD often vary dramatically making it imperative for communities to provide a wide range of educational, vocational, and economic supports. Hewitt et al. (2013) argue that in many communities, planning services for individuals with IDD are provided by Medicaid through programs such as the home and community based services (HCBS). Under these programs, care for the individual with IDD is provided in the home through family-centered supports that are coordinated with different providers throughout the community (Hewitt et al., 2013). The use of this approach enables providers to effectively organize various resources within the community that can be utilized to address the specific needs of the individual and to improve participation in the social environment (Hewitt et al., 2013).

Although current interventions to address the needs of individuals with IDD indicate that supports are client-focused and individualized to address unique concerns for the individual, considerable challenges exist when it comes to achieving targeted goals. Ticha, Hewitt, Nord, and Larson (2013) highlight the difficulties that can arise when it comes to achieving desired goals for the individual to participate in the community. In particular, the extent to which individuals with IDD experience success within the community is contingent upon individual-level characteristics such as age, severity of disability, and family-related factors. Ticha et al. (2013) go on to argue that systems-level factors such as the types of services available as well as the funding to support programs for individuals with IDD will also play some role in outcomes, shaping the opportunities that are available to those with this diagnosis. Based on this assessment, it becomes clear that each individual with IDD will face a unique set of challenges and obstacles that may foster or hinder their success (Ticha et al., 2013). Because of the need to tailor supports to address the unique needs of the client, there are few standardized interventions that can be applied to ensure the success of individuals seeking services.

Outcomes Based on Mental Health Counseling

Further complicating outcomes for individuals with IDD and co-occurring psychiatric disorders is the need for evidence-based treatment. Research does indicate that for individuals with IDD and comorbid mental health issues, treatment can be effective in addressing mental health issues (Vereenooghe & Langdon, 2013). However, providing mental health counseling to clients with IDD can prove challenging for a myriad of reasons. Counselors must be trained to understand the unique needs and limitations of clients with IDD (Man et al., 2017; Whittle et al., 2018). Additionally, practitioners providing care must be aware of the specific impact and side-effects of psychotropic medications when used in this population (Tveter, Bakken, Rossberg, Bech-Pedersen, & Bramness, 2016). Even though considerable challenges to providing care to those with IDD and co-occurring psychiatric disorders are present, existing evidence supporting the use of mental health treatment does overwhelmingly suggest that this intervention can be effective (Brown et al., 2013; Holwerda et al., 2013). For instance, Wigham, Hatton, and Taylor, (2011) conducted a systematic review of the literature on the effects of adverse life events or trauma on people with IDD and found that they have high rates of post-traumatic stress disorder (PTSD). Despite these high rates, there are challenges to identifying trauma reactions in people with IDD, such as diagnostic overshadowing (Reiss, Levitan, & Szyszko, 1982) and compromised communication skills, when, for example, flashbacks may be communicated as current experiences, resulting in a misdiagnosis of schizophrenia (Doyle & Mitchell, 2003). Needless to say, there are mental health treatment modalities such as eye movement desensitization and reprocessing (EMDR) that have been shown to be effective in treating trauma within this population (Mevissen, Lievegoed, & de Jongh, 2011). Trauma informed care can eventually lead to improved adaptive skills and the ability of the individual to transition into less restrictive environments in the community (Holwerda et al., 2013).

Although current evidence does suggest that treatment of mental disorders in clients with IDD can lead to positive outcomes for social inclusion and improved functioning, scholars examining treatment options for those with these comorbid conditions note that there is a paucity of evidence-based practice to help support interventions (Koslowski et al., 2016). Specifically, the current evidence base used to support mental health treatment in clients with IDD is drawn from a wide range of uncontrolled studies and case reports (Koslowski et al., 2016). The lack of methodological rigor in this evidence base makes it difficult for practitioners to locate definitive counseling supports that will ensure positive outcomes for clients (Koslowski et al., 2016). Additional challenges facing practitioners in delivering evidence-based support for this client population is the fact that research undertaken to address psychiatric comorbidity in clients with IDD has focused on a wide range of interventions with few efforts to replicate single studies employing a specific approach (Koslowski et al., 2016). Consequently, the evidence base for treatment suggests that almost any form of psychotherapy will be effective without demonstrating reliability or consistency in these approaches across multiple groups of individuals with IDD and psychiatric comorbidity.

Barriers to identifying effective evidence-based treatment for clients with IDD and mental health comorbidity shape prevailing conceptualizations of these disorders and preferred treatment methods. Morisse et al. (2013) assert that the medical model of treatment has typically dominated interventions for individuals with IDD. Morisse et al. (2013) argue that the overuse of the medical model of treatment is due to the complex physical, emotional, and behavioral issues that are typically present for those with IDD. As a result of this focus for treatment, services for those with IDD have not been extensively integrated into mainstream mental health counseling. This outcome can be seen when reviewing services for those with IDD and mental health issues (Morisse et al., 2013). In particular, specialized services are often established for individuals with IDD that present with mental health issues. Rather than offering mainstream mental health supports for those with IDD, clients with these co-occurring disorders are treated separately. This separate treatment makes it more challenging to identify what interventions will be most effective for addressing the unique needs of the individual with IDD and comorbid psychopathology (Morisse et al., 2013).

The insight provided by Morisse et al. (2013) regarding the lack of integration of services for clients with IDD and co-occurring psychiatric health issues dovetails nicely into what Whittle et al. (2018) note about barriers to accessing mental health services for individuals with IDD. According to these authors, many individuals with IDD and co-occurring psychiatric health issues fail to acquire mental health treatment due to a lack of coordinated services within the community. Whittle et al. (2018) specify that there are often a dearth of coordinated mental health supports within the community that are capable of meeting the needs of individuals with IDD. Service delivery systems continue to operate in silos where the medical, mental health, psychological, and social supports provided to individuals with IDD are not integrated (Beasley et al., 2016). The lack of integration leads to extensive gaps when it comes to providing support and intervention, significantly limiting the ability of clients and families to access needed care. These gaps in service provision are troubling in light of research which does suggest that mental health counseling can be useful for improving the function and quality of life for the individual with an intellectual and developmental disability (Brown et al., 2013; Holwerda et al., 2013).

Synthesis of these data demonstrates that there are both significant and systemic gaps in providing care for individuals with IDD and psychiatric comorbidities. Sandhu and Tomlins (2017) provide a comprehensive overview of the problem noting that, at the present time, there is a lack of consensus regarding what treatment for this population should encompass. While some support the ongoing use of specialized psychiatric services, others believe that individuals with IDD would benefit from programs that promote social inclusion in treatment (Sandhu & Tomlins, 2017). This situation is one that appears to echo the current state of concern regarding social inclusion of individuals with IDD: i.e., whether to promote their conformity or to promote a larger social environment in which acceptance is an integrated component of social norms (Amado et al., 2013; Simplican et al., 2015). What is evident is that when it comes to providing effective, evidence-based support for individuals with IDD and comorbid metal health diagnoses, there are systemic unmet needs that must be addressed in order to augment outcomes for those requiring these services.

Systemic Engagement

Systemic engagement is a concept that is typically associated with ecological systems theory first established by Urie Bronfenbrenner in 1979. Brofenbrenner proposed ecological systems theory as a means to expand the typical boundaries that are commonly used as the basis for understanding the influences that shape outcomes for an individual (Bronfenbrenner, 1986). Rather than simply examining the microsystem, a system which typically includes family, peers, neighborhood, and schools, Bronfenbrenner advocated for a broader perspective, for analysis that included the mesosystem (connections between the individual and the microsystem), exosystem (employment, media, social services) and the macrosystem (broader ideology, social attitudes). Use of ecological systems theory facilitates an understanding of systemic engagement, fostering the need to expand the boundaries of inclusion and to ensure that all components of the larger system are brought together to inform understanding of a problem and to identify solutions that will be the most efficacious (Stephens, 2014).

Systemic engagement originates from a framework called General Systems Theory (GST) which was introduced in 1949 by Ludwig von Bertalanffy, who criticized the mechanistic worldview of classical physics for its inability to explain the attributes of complex organizations like those of wholeness, evolution, self-regulation, and equifinality (Bertalanffy, 1949).

Bertalanffy (1968) conceptualized systems as different running parts that work together towards common goals (equifinality) and concluded that the whole of the system was greater than the sum of its parts. Essentially, if all stakeholders (family members, paid caregivers, therapists, psychiatrists, nutritionists, etc.) in the system of an individual diagnosed with IDD worked together and had increased engagement in order to decrease challenging behaviors, the outcomes would be greater than if the specific members of the system worked individually.

Although the concept of systemic engagement can be traced back to systems theory, the literature on various approaches to psychotherapy suggests that systemic engagement can be seen through various therapeutic methodologies employed in practice. For instance, strategic family therapy (SFT) has been shown to incorporate strategic and systems thinking to help navigate the challenges faced by couples and families (Murray, 2014). Scholars report that SFT "aims to address the underlying and inadvertent functionality of one's symptomatic behavior, addressing relational, and communicative imbalances in the interpersonal context in which symptomatic behaviors emerge" (Murray, 2014, p. 393). Focus on this approach serves to address relational and communication imbalances such that symptomatic behaviors can be nullified (Murray, 2014). Through this process, the underlying systems that support symptomatic behaviors are addressed such that the symptomatic behavior can be effectively mitigated (Murray, 2014). By employing this approach, a more comprehensive foundation for alleviating systems is employed; one that is both systemic and strategic in nature. The defining characteristics of SFT are that there is a focus on family communication patterns that serve to maintain the problem, treatment goals that derive from the problem/symptoms are presented, a belief that change can be rapid and does not require insight into the causes of the problem, and finally, the use of resistance in order to promote change by applying strategic interventions (Piercy, Sprenkle, & Wetchler, 1996).

The utility of SFT is further reviewed by Parke (2017), who notes that this approach to intervention proves useful due to the changing nature of the family and its embeddedness in a myriad of social institutions. According to Parke, the family is not a static institution; rather, it is one that is continually being reconceptualized and structured based on changing policy and social attitudes. The larger context in which the family exists must therefore be taken into consideration when providing psychotherapeutic supports (Parke, 2017). By understanding the family in this broader context, it is possible to build a more complete foundation for treatment that addresses both institutional supports and barriers that will impact the family through the process of treatment (Parke, 2017). As further demonstrated by Parke, this perspective can be challenging to embrace. However, efforts to develop treatment based on this model will help to ensure that the comprehensive needs of the family are addressed. If similar concepts are used within the social support teams of individuals diagnosed with IDD, it would result in effective treatment outcomes just as it does in psychotherapy. Nonetheless, engaging systems to create long-term changes in outcomes for not only the individual diagnosed with IDD, but their system of support can be a challenging task.

The concept of systemic engagement in counseling has been operationalized through the development of approaches such as the SFT. For the purposes of this research, it is imperative to consider how this concept can be utilized in the context of providing care for clients with IDD and comorbid psychiatric disorders. A review of the literature regarding current therapeutic approaches to address the specific needs of this population utilizing systemic engagement and strategic systems is detailed below.

Application to the Target Population

A majority of the programs that utilize systemic engagement through integrated service delivery have been developed and implemented in the United Kingdom (U.K.) and Australia. For instance, in the U.K., there is a program called the early intensive behavioral intervention (EIBI). EIBI is a treatment program that focuses on preventative measures to decrease challenging behaviors on children with autism. It integrates in-home service delivery by applied behavior analysts (ABA), trained therapists, local education authority (LEA), crucial family members and other direct care support staff. To showcase its effectiveness using a semi-structured format, Grindle, Kovshoff, Hastings, and Remington (2008) interviewed 53 parents whose children had received two years of EIBI to obtain detailed first-person accounts of the impact of EIBI on family life and support systems. In general, parents were positive about EIBI, its benefits for them, their child, and the broader family.

Koritsas et al. (2008) conducted a study to investigate the effectiveness of enhanced interactions between support workers and its impact on the decrease in challenging behaviors among individuals diagnosed with IDD. They examined 12 adults with IDD aged 27–57 years (M 37¼ years) residing in three group homes, and their support workers. The support workers completed assessments on three occasions (at baseline, post- training, and at follow-up). The results showed that residents exhibited an overall decrease in anxiety, self-absorbed behavior, disruptive behavior, and problem behavior in general. There was also an overall decrease in perceived support needs. The results from this study clearly contribute to a growing body of evidence demonstrating favorable outcomes of systemic engagement in decreasing challenging behaviors among people diagnosed with IDD. In the United States, the systemic, therapeutic, assessment, resources, and treatment (START) model has emerged as an important foundation for delivering systemic engagement services to individuals diagnosed with IDD and co-occurring mental health needs (Beasley et al., 2018; Kalb et al., 2016).

Systemic, Therapeutic, Assessment, Resources, and Treatment (START)

A general review of the START model provided by Beasley et al. (2016) indicates that the approach was first pioneered and implemented in Massachusetts in 1989 in order to improve the care of individuals with IDD and comorbid behavioral health issues. START uses what has been coined as a "systems linkage approach" to service delivery cited by the United States Surgeon General's report as a model that helps overcome disparities in access to mental health care (Charlot & Beasley, 2013). The core philosophy is that there must be an emphasis on solution-focused active communication and decision-making in the system of care, in addition to a better understanding of individual, clinical and treatment needs in order to improve service outcomes (Beasley et al., 2016). START is a best practice, evidence-informed, tertiary care program and community network that enhances capacity toward effective supports for individuals with IDD and behavioral health needs (Beasley et al., 2016).Throughout its lifespan, this program has revealed promising outcomes that include significant reduction in emergency service use as well as improvements in service experiences (Beasley, 2002). At the present time, there are START programs in 10 states across the United States, with the National START Center at the University of New Hampshire Institute on Disability serving as a center to promote education and improvements in the START model for national practice. The program adapts its treatment strategies based on the World Health Organization's (WHO) public health tertiary care model which utilizes person-centered practices, continuous training, and skill building of practitioners within the community, active participation of stakeholders, collection and analysis of data, and ongoing modification of services in response to individual and trend-related outcomes, along with the changing needs of the system (Beasley et al., 2016).

World Health Organization's Public Health Tertiary Care Model and START

The implications of this treatment approach can be seen when further reviewing the three stages of the START model and the specific areas that are targeted for enhancing the care of the client. The three stages are: the primary, secondary, and tertiary levels. These levels were adapted from the World Health Organization's public health tertiary care model (WHO, 2004) which is a framework that drives the START program. Beasley et al. (2016) provide a complete review of each of the three stages that are involved in the START model. The first stage involves prevention. However, according to Beasley et al. (2016), this stage seeks to:

> strengthen the service system's ability to successfully engage individuals with IDD by focusing on quality of life, improving access to services, identifying gaps in the system, and improving competencies for all including self-advocates, families, direct support staff, and clinically trained professionals (p. 1638).

In this level of intervention, an effort is made to offset the challenges faced by the client by building capacity within the system in which the client exists (Kalb et al., 2016). Through this process, Kalb and coauthors argue that it is possible to better understand the needs of the client and to address them in a more comprehensive manner.

The secondary stage involves the identification of the specific difficulties faced by the client to prevent exacerbation of challenging behavior (Kalb et al., 2016). Beasley et al. (2016) also add that specific changes made to care in the second stage of the START model has implications for improving outcomes for the client. In this stage of care, intervention is focused on the need to address all of the biopsychosocial factors that influence the behavior of the client

(Beasley et al., 2016). Triggers for challenging behaviors are identified through communication deficits that are present in the relationships within the client's environment (Beasley et al., 2016). Through the identification of these issues, it is possible to discern the most effective interventions that can be used to decrease the likelihood that a crisis will occur for the client.

In the tertiary stage, the stabilization of a client that has experienced an acute condition is undertaken in an effort to prevent the need for emergency care (Kalb et al., 2016). Beasley et al. (2016) argue that management is the key focus here, with the use of a cross-system intervention and prevention plan, one that is individualized for each client. This plan includes the tools and actions that will be used if a crisis emerges for the client. By having this plan in place, those providing care can respond quickly to ameliorate the crisis facing the client in a timely manner (Beasley et al., 2016). Kalb, Stuart, Mandell, Olfson, and Vasa (2017) further assert that the START model provides a useful community crisis tool that can markedly reduce the need for emergency psychiatric care for individuals with IDD.

Systemic Engagement and START

When applying the concept of systemic engagement to the known challenges faced by individuals with IDD, it is possible to theoretically link this approach to treatment to build practice. For instance, when reviewing the core deficits faced by individuals with IDD, scholars have extensively noted challenges with adaptive behavior that are impacted by the social environment of the client (Dimitriadou & Kartasidou, 2017; Holwerda et al., 2013; Ross et al., 2013). In particular, Dimitriadou and Kartasidou (2017) argued that individuals with IDD lack the capacity to appropriately respond to their external environments, leading to negative social reinforcement and challenges with coping. Viewing these issues from the standpoint of systems thinking, it becomes possible to consider elements of the social environment that may reinforce problematic behavior including the inability of the client to cope with functional limitations. The guiding principle of the START model in regard to systemic engagement is by addressing the environment as a source of treatment and engaging stakeholders in change thus altering the social experience of the individual with IDD and the behavioral outcomes that result.

Perhaps the most important emphasis of the program is that START works to fill in gaps in the system while engaging providers of primary medical, mental health, and other services to work with individuals with IDD through linkages, supports, and increased knowledge of the IDD condition. As a result, the START program improves the capacity of the community at large to effectively serve this population in a coordinated and integrated manner rather than providing a segregated system of support (Beasley et al., 2016). Beasley and coauthors also note that the ability to link in this way enhances the capacity of the entire system, and therefore improves the ability to diagnose and treat individuals with diverse levels of need, including those with more complex and/or severe impairments.

Systemic engagement, as operationalized through SFT and the START model, provides an important foundation for conceptualizing how the care of the target population is implemented and can be improved. Beasley et al. (2018) argued that improvements in behavior require a consideration of the larger context in which they develop. Murray (2014) emphasized this point in reviewing the foundations of SFT in which an acknowledgment was made that relational and communicative environments often create support for problematic behavior. By identifying and addressing these structures in practice, it is possible to change the environment of the client, which leads to improvements in challenging behavior instances (Beasley et al., 2018; Kalb et al., 2016; Murray, 2014). Systemic engagement for the START program also involves focusing on communication patterns within the system of care that are not only problematic but maintain the challenging behaviors for the individual with IDD. According to Schmidt et al. (2016), individuals with IDD often engage in challenging behaviors as a result of impairments in communication. As demonstrated by Murray (2014) when reviewing the main tenets of SFT, an emphasis on communication patterns is viewed as an essential component of changing the behavior of the client. Given that communication difficulties are commonly viewed as the root cause of challenging behaviors for individuals with IDD, interventions utilized by the START program that target communication and relational issues to alleviate problematic behaviors are executed by the START coordinator. According to Beasley et al. (2016), the START coordinator is a clinician considered to be trained and certified after completing a 55-hour course, along with a clinical practicum, in order to meet the qualifications to help navigate the different systems in achieving positive treatment outcomes.

The START coordinator engages with members of the system in either team meetings or targeted outreach. In these engagements, the START coordinator employs systemic concepts such as reframing and setting healthy boundaries. Here, the START coordinator assesses the different types of boundaries, those invisible barriers that regulate contact/communication between the members of the system. The START coordinator strives to have the team/system attain clear boundaries amongst members. The clarity of boundaries within a system solidifies the roles and responsibilities that each member of the system carries in order to achieve positive outcomes. In regard to reframing, the START coordinator emphasizes positive connotations by helping team members reinterpret either a client or fellow team member's behavior from a negative point of view to a positive one. The reinterpretation helps shape/change the image that individuals in the team have about others/behaviors. Engagements such as these by the START coordinator appear to have notable salience for enhancing treatment outcomes of those with these disabilities.

The START Model's Influence on Treatment Outcomes

Despite START's widespread expansion in providing treatment for individuals with IDD and comorbid psychiatric disorders, empirical literature demonstrating the efficaciousness of the model is somewhat limited. Even though this limitation exists, the available literature on the model does indicate that START may provide a unique and essential foundation for enhancing the care of the target population. To date, there are a number of studies that have examined START (Beasley, 2002; Beasley et al., 2018; Kalb et al., 2016; Kalb et al., 2019). Initially, there was a four-year study of 89 families using START services that showed promising outcomes, including a significant reduction in emergency service use as well as improvements in service experiences (Beasley, 2002). This study was followed by a comparative analysis conducted in the state of Tennessee (*N*=15), showed a reduction in emergency service use and associated costs among those in START when compared with a group of waitlist controls (Fahs, Weigle, Smith, & Benson, 2007).

Kalb et al. (2016), examined the efficacy of START on psychiatric hospitalization services adjusting for 11 predisposing, enabling and need factors within the Andersen model of healthcare use. Data were from 3,299 individuals with ID (mean age= 31 years; SD=14 years) who were referred to START. A random effects logistic regression model was used to examine the association between the 11 factors and caregiver report of psychiatric hospitalization within 12 months. Twenty-eight percent of the sample had at least one psychiatric inpatient stay in the prior year. The study concluded that increased psychiatric hospitalization services were associated with younger, male, more severe IDD, higher ratings of aggressive behaviors, and an increased number of psychiatric diagnoses (Kalb et al., 2016).

Kalb, Beasley, Caoili, and Klein (2019) conducted a study that examined one-year pre- and post- caregiver service experiences regarding client family member's involvement in emergency department treatment and supportive mental health services. Data were collected from individuals (*N*=116) diagnosed with IDD (Children *n*=57; Adults *n*=59). The results of this study showed improvements in all three outcomes at the level of the service user, caregiver, and system (Kalb et al., 2019). Another recent study conducted by Beasley et al. (2018) examined outcomes for 41 individuals with IDD who had been referred to START programs in Iowa. The analysis of data from this group was supplemented with a qualitative case study to evaluate outcomes as a result of using this intervention. Data provided by Beasley et al. (2018) indicated that individuals enrolled in the program experienced a significant reduction in problematic behaviors as reported by caregivers. Additionally, Beasley et al. (2018) reported that those enrolled in the program also experienced a decline in the number of psychiatric emergency room visits. Based on these results, the authors argue that research supports the use of the START program as a means to improve outcomes for individuals with IDD and comorbid psychiatric disorders.

Critical to the success of the START program in improving outcomes for clients with IDD and comorbid mental health issues is, according to Beasley et al. (2018), the role of a strengths-based biopsychosocial approach that facilitates systemic stakeholder engagement in care. The intervention does not specifically target the problematic behavior; rather, the approach targets the biopsychosocial vulnerabilities that commonly contributed to the conditions that are seen within the client (Beasley et al., 2018). This approach is similar to what is noted in SFT whereby the behavior of the client is nullified by addressing the structural systems issues that contribute to the development of behavioral challenges for the client (Murray, 2014). Consequently, what is seen through the use of the START model and systemic engagement is a paradigm shift in the way in which care for the client is conceptualized and operationalized in practice.

Enhancing Outcomes and Systemic Engagement through Goal Setting. To further broaden the scope and impact of systemic engagement on treatment outcomes for this population, researchers from a START program in the southeast region of the United States developed the Systemic Treatment Plan (STP) as seen in Appendix A. The STP is a tool that was used by the START clinical team in order to more clearly organize, articulate and measure systemic goals for each individual served by the agency (Kurland et al., 2018). The researchers hypothesized that using the STP would improve the coordinators' systemic engagement, result in more rapid systems change, and lead to less use of emergency services. Kurland and co-researchers were attempting to incorporate additional systemic engagement concepts to treatment as well as develop an individualized service plan that is not only goal-oriented but one that incorporates issues identified from the assessments conducted at intake.

Kurland and her colleagues (2018) identified their global research question as: *"What influence does systemic engagement have on the overall goal attainment for people diagnosed with IDD?"* and used the STP as the independent variable. This tool incorporated short-term goals whereby the clinician integrated strategies and objectives (similar to SFT) on how to navigate the presenting problem from a systemic point of view. The goals of the STP were broken down into three levels: primary, secondary and tertiary. These levels were adapted from the World Health Organization's public health tertiary care model (WHO, 2004). The dependent variables included service outcomes data obtained from the START Information Reporting System (SIRS) which is the START program's database system (Kurland et al., 2018). These included: 1) demographic data and data indicating the use of crisis response and other emergency services; 2) pre- and post- intervention scores from the subscales of the Aberrant Behavior Checklist (ABC); 3) pre- and post- intervention Recent Stressor Questionnaire (RSQ) scores; and 4) completion of a systemic satisfaction survey at the end of the experimental period.

This study looked at two groups (Kurland et al., 2018). The control group that received treatment using the START plan (the treatment plan used by START clinicians) and the treatment group that received treatment using the new tool, the STP (Kurland et al., 2018). Once the two certified START coordinators' (of equivalent skill level) caseloads were selected for comparison, one clinician was trained and coached in using the STP and the other was not (Kurland et al., 2018). The clinician who was trained to use the STP was placed in the treatment group while the other was placed in the comparison group (Kurland et al., 2018). Each caseload had 20 individuals who were being served in the START program which brought the total number of participants to $N = 40$ (Kurland et al., 2018). Demographic data for the sample indicated the following: age (7-12 years, 10%; 13-17 years, 20%; 18-24 years, 37.5%; 25-34 years, 17.5%; 35-44 years, 15%), race/ethnicity (20% African American, 2.5% Asian, 10% Hispanic, 62.5% White and 2.5% more than one race), severity of IDD (60% mild, 5% severe, 20% moderate and 5% normal intelligence), psychiatric condition (45% autism spectrum disorder, 40% attention-deficit/hyperactivity disorder [ADHD], 22.5% bipolar disorder, 22.5% depression and 17.5% psychotic disorder) (Kurland et al., 2018). Additionally, the authors reported two main presenting problems for the sample: 85% aggression (physical, verbal, property destruction, or threats), and 55% family or caregivers needing additional assistance (Kurland et al., 2018).

Each individual enrolled in the START program had a system (treatment team) which was comprised of either a parent/guardian, provider representative (group home manager/direct support staff/case manager), service coordinator, board-certified behavior analyst (BCBA), occupational therapist (OT), speech pathologist (SLP), therapist/counselor (LPC/LMFT/LP), and or a psychiatrist (Kurland et al., 2018). A randomized controlled between-subject research design was used to compare goal attainment over time of participants receiving treatment using the STP, compared to those who received treatment using the START plan (Kurland et al., 2018). Data were gathered within a three-month period (Kurland et al., 2018).

In addition to training the START coordinator of the treatment group to implement the STP, the coordinator was also coached by the researcher to employ several systemic engagement concepts (Kurland et al., 2018). What follows are some systemic engagement concepts that were used/adapted by the coordinator during the course of the study:

I. The coordinator was light, authentic, spontaneous and congruent during his engagement with the team members.

II. The coordinator invested initially in the joining process with the team. Joining means that the coordinator spent time building relationships with other team members in order to build trust.

III. During the initial engagement, the coordinator assessed the system's ability to accept change. The assessment was done through a series of questioning during team meetings and then the coordinator hypothesized (giving a possible but not yet proven explanation for something) on what made the system fail to adjust to changing circumstances.

IV. The coordinator challenged unproductive assumptions, which support structural problems within the team/system. These could either be biases or myths about behaviors and mental health conditions.

V. The coordinator encouraged critical analysis as well as helped the team differentiate (separate) thoughts and feelings when discussing crucial matters.

VI. The coordinator provided support, motivation, psychoeducation, guidance, and hope to the teams.

VII. The coordinator assessed and identified the homeostasis (the normal way of functioning within the system), brought it to surface and determined if it was healthy or unhealthy based on clinical impressions.

VIII. The coordinator assessed the different types of boundaries and strived to have teams attain clear boundaries amongst members.

IX. The coordinator helped clarify the different roles that each member of the system carried in order to clarify responsibilities and tasks.

X. Throughout the process of engagement with the teams, the coordinator developed a sensitivity to how culture shaped experience and infused relationship structures (Kurland et al., 2018).

Over the course of the three months, the coordinator of the treatment group was able to use systemic concepts similar to ones used in SFT to work through the objectives identified with their respective treatment goals (Kurland et al., 2018). Some of the concepts adapted from SFT include the use of paradoxical interventions (Kurland et al., 2018). A paradoxical intervention is whereby a clinician asks individuals in treatment to do something that seems in opposition to the goals of treatment (Nichols & Schwartz, 1998). One type of paradoxical intervention is prescribing the symptom, whereby some of the individuals in treatment were asked to engage in more of the same symptomatic behavior. The goal of this intervention is for the individual or the treatment team to rebel and in the process, lessen or control the symptomatic behaviors. This intervention promotes progress regardless of the response (Weakland, Fisch, Watzlawick, & Bodin, 1974). Another paradoxical intervention employed was restraining techniques, whereby select individuals in the treatment team were either warned of the dangers of change, restrained from trying to change or were asked to slowly change the dysfunctional ways of relating with other members of the treatment team. The restraint of change technique is used when the family seems ambivalent about change (Nichols & Schwartz, 1998).

Other systemic concepts adapted for use in Kurland's study was using directives (Kurland et al., 2018). At the Evolution of Psychotherapy conference in 1985, Jay Haley pointed out that directives are used to get family members to do things differently and have different experiences doing them (Zeig, 2007). He added that they are also used to involve the therapist in the treatment and intensify the relationship with the therapist (Zeig, 2007). Directives were given to team members in the form of homework in order to disrupt the malfunctioning sequences of power struggles especially between parents of individuals diagnosed with IDD and representatives from provider agencies (Kurland et al., 2018).

The START clinician who had individuals in the treatment group obtained goals that were outlined in the STP (Kurland et al., 2018). These goals were developed through an initial team meeting with all members of each individual's system (Kurland et al., 2018). The START clinician from the comparison group did not obtain any goals but did provide treatment using the

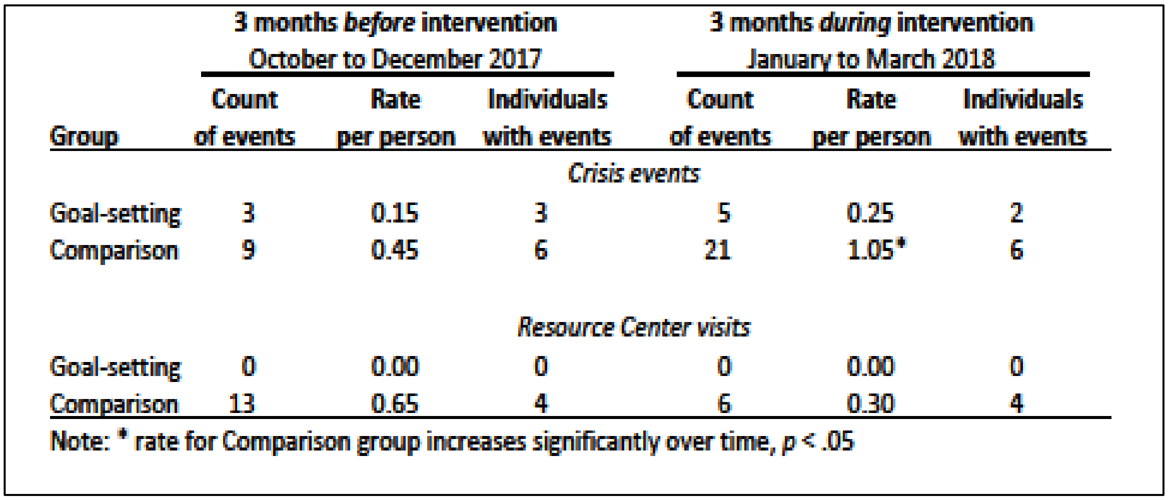
START plan (Kurland et al., 2018). Both clinicians obtained ABC and RSQ data scores from a treatment team member in the system who had the most contact with the individual diagnosed with IDD (Kurland et al., 2018).

The three-month period was chosen for the study by the researchers based on protocols for assessment of clients established by the START Center (Kurland et al., 2018). A three-month re-assessment of clients is used as a benchmark for reviewing client progress on short-term goals (Kurland et al., 2018). At the end of the three months, the START clinicians from both the treatment and control groups obtained another set of ABC and RSQ data scores from the same informants (Kurland et al., 2018). In addition, a satisfaction survey was completed by team members from both groups (*n*=53) at the end of the experimental period (Kurland et al., 2018). The post-test satisfaction survey was developed by Kurland and colleagues in order to gauge the level of satisfaction of services provided (Kurland et al., 2018). The majority of these were Likert-like items based on a scale of 1 to 5 from “totally disagree” to “totally agree” (Appendix B). 53 respondents completed the satisfaction survey and all data were collected in-person, through an online portal or over the phone (Kurland et al., 2018).

Data analysis included t-test parametric inferential statistics using quality data from the satisfaction survey which was analyzed using the IBM Statistical Package for the Social Sciences (SPSS) Grad Pack version 25.0 Premium (IBM Corp., Released 2017). The results from the study showed that the number of crisis events and Resource Center (facility that offers respite care) visits decreased for the treatment group during the three-month intervention as shown in Figure 1.

Figure 1

Crisis Events and Resource Center Visits Before and During Intervention for Goal Setting



	3 months *before* intervention October to December 2017			3 months *during* intervention January to March 2018		
Group	Count of events	Rate per person	Individuals with events	Count of events	Rate per person	Individuals with events
			Crisis events			
Goal-setting	3	0.15	3	5	0.25	2
Comparison	9	0.45	6	21	1.05*	6
			Resource Center visits			
Goal-setting	0	0.00	0	0	0.00	0
Comparison	13	0.65	4	6	0.30	4

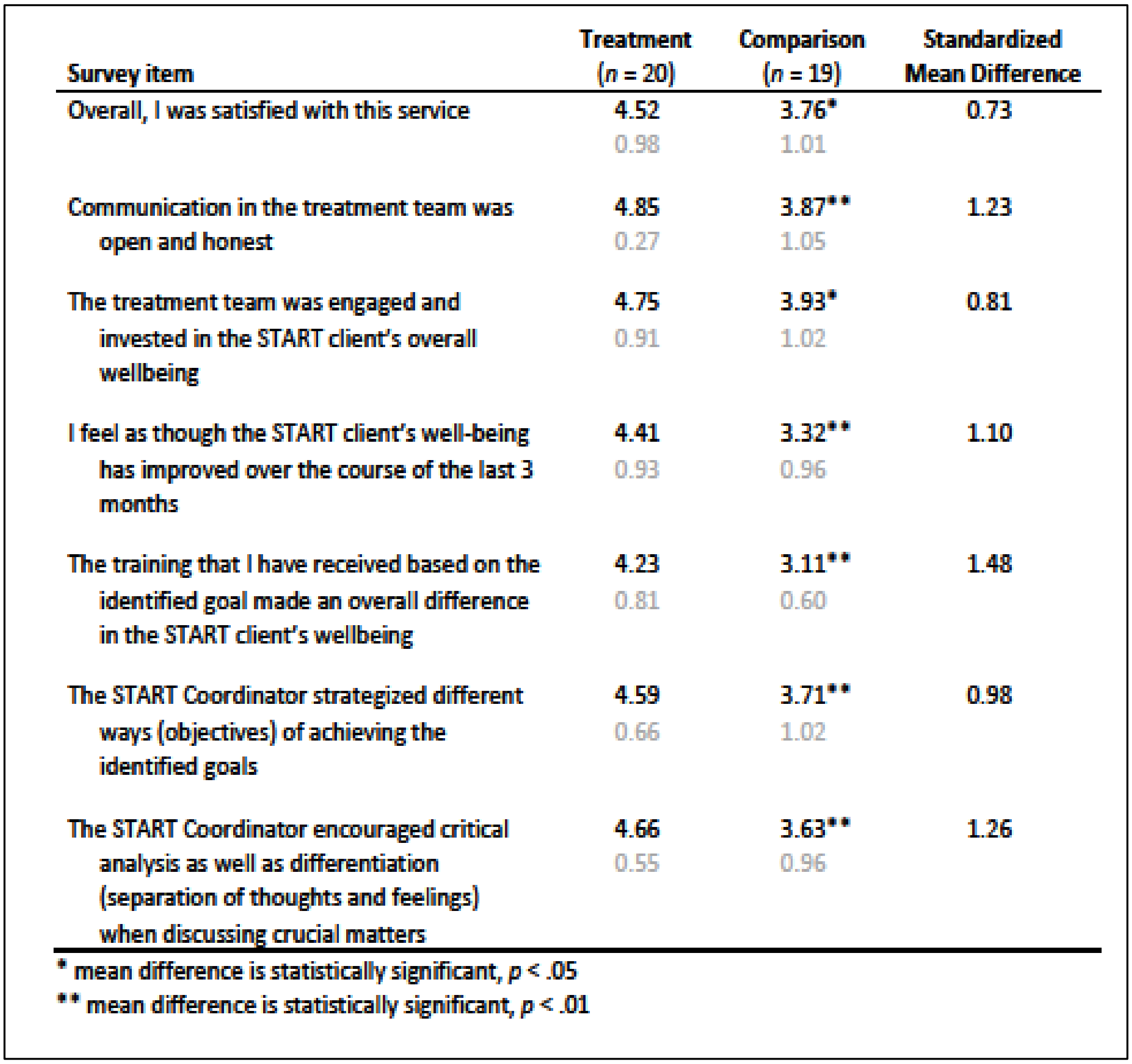
Note: * rate for Comparison group increases significantly over time, $p < .05$

Note. Image retrieved from “Enhancing outcomes and systemic engagement through goal-setting.” Kurland et al. (2018, May).

Overall, the results from the use of the STP and responses from the satisfaction survey as shown in Figure 2 indicates that the STP treatment group manifested greater goal attainment and positive outcomes than their START plan counterparts. In addition, these results also showed that the use of the STP increased communication within the treatment team and improved the perception of services provided (Kurland et al., 2018).

Figure 2

Means and Standard Deviation for Post-Test Survey Ratings: Treatment and Comparison



Survey item	Treatment ($n = 20$)	Comparison ($n = 19$)	Standardized Mean Difference
Overall, I was satisfied with this service	4.52 0.98	3.76* 1.01	0.73
Communication in the treatment team was open and honest	4.85 0.27	3.87** 1.05	1.23
The treatment team was engaged and invested in the START client's overall wellbeing	4.75 0.91	3.93* 1.02	0.81
I feel as though the START client's well-being has improved over the course of the last 3 months	4.41 0.93	3.32** 0.96	1.10
The training that I have received based on the identified goal made an overall difference in the START client's wellbeing	4.23 0.81	3.11** 0.60	1.48
The START Coordinator strategized different ways (objectives) of achieving the identified goals	4.59 0.66	3.71** 1.02	0.98
The START Coordinator encouraged critical analysis as well as differentiation (separation of thoughts and feelings) when discussing crucial matters	4.66 0.55	3.63** 0.96	1.26

* mean difference is statistically significant, $p < .05$
** mean difference is statistically significant, $p < .01$

Note. Image retrieved from "Enhancing outcomes and systemic engagement through goal-setting." Kurland et al. (2018, May).

A closer examination of systemic engagement and its application to individuals with IDD and co-occurring psychopathology does suggest that the use of this concept in practice is both feasible and practical given the specific challenges faced by those with these diagnoses. Systemic engagement not only requires all stakeholders to work cooperatively to address the needs of the client but also, this process seeks to improve the social context of treatment such that the client can more fully and actively participate in the social environment. Through the application of systemic engagement, it should be possible to change the way that clinicians approach care, facilitating their ability to address the underlying supports that are needed to build a foundation for effective care for the client served.

Summary and Conclusion

Individuals with IDD and comorbid psychiatric disorders, especially ones who struggle with challenging behaviors, represent a unique population that has specific needs which are often not adequately met through current treatment paradigms. Systemic engagement represents a useful tool for re-conceptualizing care for this target population. However, the approach does require a paradigm shift in the way in which supports for the client are employed in practice. The establishment of systemic engagement as a viable foundation upon which to build care for the target population warrants further empirical support to demonstrate the efficaciousness of this approach in practice.

As noted earlier, Kurland and her colleagues (2018) were attempting to incorporate additional systemic engagement concepts to treatment as well as develop an individualized service plan that was not only goal-oriented, but one that incorporated issues identified from the assessments conducted at intake. The results from Kurland's study clearly showcased that the use of systemic engagement was effective in aiding the clinician to navigate the presenting problem from a systemic point of view and achieve short-term goals.

Gap in the Literature

Even though systemic engagement has been shown to be effective within the IDD population, there are still gaps in care and service provision. Outpatient and community mental health centers do provide social services that are goal-oriented, but the common challenge is the fact that most goals end up not being attained due to the complex nature of the IDD population. The complex nature is based on individual-level factors such as age, psychiatric diagnoses, level of disability, social inclusion/exclusion, etc. Unfortunately, the number of research studies conducted that focus on the individual-level factors that promote positive outcomes in treatment of individuals diagnosed with IDD are limited. Further limited are studies that look at these individual-level variables between two or more groups.

Ticha and colleagues (2013) indicated that the extent to which individuals with IDD experience success within the community is contingent upon individual-level characteristics such as age, the severity of the disability, and family-related factors. Notwithstanding, Kalb and colleagues (2016) mentioned that in their study, increased hospitalization rates were associated with variables such as younger age, male gender, less severe IDD, higher caregiver ratings of aggressive behaviors, increased number of psychiatric diagnoses and diagnoses of psychotic disorders. These individual-level factors need to be explored further in order to better cater to this population. Despite Kurland and her colleagues (2018) demonstrating that systemic engagement is effective in developing positive outcomes in treatment, their study focused on quality data from the satisfaction survey and did not analyze the variables/individual-level characteristics within the population that might have had an impact on positive outcomes between the two groups.

Current Study

Given the gap in literature, the principal investigator sought to address the gap by exploring whether individual-level variables are impacted/change when utilizing two different treatment strategies (the STP and the START plan) in treatment. The individual-level factors that were examined in this study were challenging behavior scores and psychiatric diagnoses (autism, depressive disorders, psychotic disorders, anxiety disorders, [ADHD], and bipolar disorder).

The study's goal was to answer the global research question of, *"How do challenging behaviors and psychiatric disorders impact treatment outcomes among individuals diagnosed with IDD who have received treatment using the STP and the START plan over a 12-week period?"* The following research sub-questions guided the study:

1a: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the STP over a 12-week period?*

1b: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the START plan over a 12-week period?*

2: *Do stressors improve through time for individuals receiving treatment using the STP over a 12-week period?*

3a: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the STP?*

3b: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the START plan?*

Chapter III

Research Methods

The purpose of this research was to evaluate the use of a new treatment protocol, the systemic treatment plan (STP) by identifying the predictors of positive treatment outcomes for individuals diagnosed with intellectual and developmental disabilities (IDD) and comorbid mental health conditions. The researcher sought to explore the predictive relationship of challenging behaviors and psychiatric conditions on positive treatment outcomes amongst individuals with IDD in order to further assist clinicians and social service agencies catering to this vulnerable population to identify which individual factors yield positive outcomes when using systemic engagement in treatment. The results of the quantitative data analyses of the START study conducted by Kurland and her colleagues contributed to the research question posed in this study which focused on understanding how the STP influences specific outcomes for the IDD population. Based on the data collected by Kurland and her colleagues, the researcher identified succinct variables and statistical methods were used to quantify the relationship between the STP and the resulting treatment outcomes.

A randomized experimental control group research design was selected as the foundation for this research project. Quantitative studies collect and analyze numerical data for the purposes of answering a research question and/or proving a hypothesis (Creswell, 2014). The objectives of quantitative designs are met through deductive reasoning in which a hypothesis is tested, and conclusions are drawn to either confirm or reject the hypothesis (Creswell, 2014). Quantitative research seeks to precisely identify relationships between variables such that conclusions about these relationships can be made (Creswell, 2014). By utilizing a quantitative methodology, it was possible to assess the impact of the STP on specific outcomes for the individual with IDD.

Quantification of these outcomes is desirable to support the development of a reliable evidence base upon which to recommend the use of STP in the treatment of individuals with IDD and co-occurring psychiatric disorders.

The information reviewed above provides a clear explanation of why a quantitative approach to research was selected. To demonstrate that this approach is the most appropriate for this study, it is helpful to compare the quantitative approach to the qualitative tradition. Qualitative research has been identified in the literature as a naturalistic approach to inquiry in which an effort is made to understand how a phenomenon occurs in practice (Merriam & Tisdell, 2015). The approach utilizes non-numeric data and an inductive approach to data analysis in which information collected from a study is used to generate rather than prove theory (Merriam & Tisdell, 2015). While this study sought to examine the use of the STP in a real-world context, the goal of the research was not to generate theory. Instead, the goal was to prove that the theoretical tenets behind STP are effective for meeting the needs of individuals with IDD and co-occurring mental disorders. Consequently, a qualitative design was not appropriate for this study.

The benefits of utilizing a quantitative approach to research stem from the type of data that are collected and analyzed through this methodology. Scholars examining the quantitative paradigm of research assert that this approach focuses on the measurement of objective data that can be statistically analyzed (Barnighausen, Rottingen, Rockers, Shemilt, & Tugwell, 2017). This paradigm of research does not involve subjective approaches to data collection and analysis such as those used in qualitative research (Barnighausen et al., 2017). Quantitative methodologies are based on a positivist/post-positivist ontology (Barnighausen et al., 2017). Under this approach, researchers believe that it is possible to reduce phenomena to a set of empirical indicators that provide an understanding of the truth as it exists in practice

(Barnighausen et al., 2017). The quantitative approach is also rooted in empiricism and objectivity, suggesting that neutrality and reliability are inherent in the methods used for data collection and analysis (Barnighausen et al., 2017). Consequently, the benefits of using a quantitative approach in this research stem from the ability to acquire objective and empirical data that was utilized to obtain a clear understanding of the relationship between the STP and outcomes for individuals diagnosed with IDD and co-occurring mental health issues.

Research Design

The research design that was used in this investigation was a quantitative retrospective case-control approach (Gelman & Carlin, 2014). A closer examination of retrospective studies provided by Abbott, Barton, Terhorst, and Shembel (2016); Altoè, Bertoldo, Callegher, Toffalini, Calcagnì, Finos, and Pastore (2020); Dykacz (2005); and Salkind (2010) indicates that this approach to research is used to acquire data from the past in order to inform current research and practice. Abbott and colleagues go on to argue that data can be collected from medical records, databases, or from national survey data. The primary advantage of utilizing this type of study is that it provides the ability to study larger sample sizes over a longer period as well as the ability to investigate the use of new treatments in comparison to care as usual (Abbott et al., 2016; Dykacz, 2005; Salkind, 2010). The latter has notable pertinence for this study.

The decision to utilize a retrospective case-controlled design was based on the novelty of the STP and the lack of significant evidence to validate its utility in practice. As noted, there is preliminary evidence that suggests that START services do indeed have a positive impact on treatment outcomes for clients with IDD and co-occurring psychopathology (Beasley et al., 2018). In addition, the use of the STP does further impact the positive outcomes in treatment (Kurland et al., 2018). Despite these positive impacts, the use of a randomized controlled trial in which participants were not provided with care as usual, is not ethically prudent, given the lack of evidence to support the STP as a standalone approach to care. Consequently, the retrospective case-controlled design was viewed as a viable alternative to assessing the efficacy of this approach especially since the principal investigator was curious to know whether the rate of challenging behaviors identified at intake affects outcomes in treatment for this population. Psychiatric conditions (autism, attention-deficit/hyperactivity disorder [ADHD], anxiety disorders, bipolar disorders, depressive disorders, psychotic disorders) and challenging behavior scores rated by the ABC tool under the five subscales (irritability, lethargy, stereotypy, inappropriate speech, and hyperactivity) were the independent or predictor variables and the dependent or criterion variable was the positive outcomes in treatment as conceptualized by the average mean scores of three questions from the caregiver responses (questions 13, 15, and 21). Abbott et al. (2016) assert that well-designed and conducted retrospective studies that utilize reliable data and appropriate statistical methods can systemically reduce bias and produce results that are commensurate with those reported in randomized controlled trials (RCTs).

Although the use of a retrospective case-controlled design will minimize threats to internal validity, scholars do caution that several issues must be addressed when designing these studies (Abbott et al., 2016; Altoè et al., 2020; Dykacz, 2005; Salkind, 2010). Examples of methodological weaknesses for retrospective case-controlled studies include: the use of relevant and reliable data sources, appropriate data extraction and analysis procedures, and careful interpretation of results in order to ensure that the conclusions that are drawn are appropriate (Abbott et al., 2016; Altoè et al., 2020). Datasets for use in this research included client information provided by Kurland and her colleagues. Data extraction and analysis were based on standardized tools including the Participant Survey Questionnaire (PSQ), Aberrant Behavior

Checklist (ABC) and the Recent Stressor Questionnaire (RSQ). Statistical procedures were selected based on the level of data collected to ensure that appropriate conclusions regarding what the data demonstrates can be assessed.

Original Study

In the original study by Kurland and her colleagues (2018), the researchers were attempting to incorporate additional systemic engagement concepts to treatment as well as develop an individualized service plan that was not only goal-oriented but one that incorporated issues identified from the assessments conducted at intake. The researchers hypothesized that using the STP (tool used by the START clinical team to more clearly organize, articulate and measure systemic goals for each individual served) would improve the coordinators' systemic engagement, result in more rapid systems change, and lead to less use of emergency services.

Research Design

This study looked at two groups. The control group that received treatment using the START plan (the treatment plan used by START clinicians) and the treatment group that received treatment using the new tool, the STP. Each group had 20 individuals who were being served in the START program. A randomized controlled between-subject research design was used to compare goal attainment over time of participants receiving treatment using the STP, compared to those who received treatment using the START plan (Kurland et al., 2018).

Sample

Participants were selected from a population of individuals with IDD and comorbid psychopathology who were enrolled in the START program before being randomly assigned to a treatment or control group. Demographic data for the sample indicated the following: age (7-12 years, 10%; 13-17 years, 20%; 18-24 years, 37.5%; 25-34 years, 17.5%; 35-44 years, 15%), race/ethnicity (20% African American, 2.5% Asian, 10% Hispanic, 62.5% White and 2.5% more than one race), severity of IDD (60% mild, 5% severe, 20% moderate and 5% normal intelligence), psychiatric condition (45% autism spectrum disorder, 40% attention-deficit/hyperactivity disorder [ADHD], 22.5% bipolar disorder, 22.5% depression and 17.5% psychotic disorder) (Kurland et al., 2018). Additionally, the authors reported two main presenting problems for the sample: 85% aggression (physical, verbal, property destruction, or threats), and 55% family or caregivers needing additional assistance (Kurland et al., 2018).

Recruitment. The inclusion criteria for this sample was that participants: (a) have a diagnosis of IDD or autism, (b) have a diagnosed psychiatric mental health disorder, (c) be enrolled in the START program, and (d) have a system of care (treatment team) to include either a parent/guardian, provider representative (group home manager/direct support staff/case manager), service coordinator, board-certified behavior analyst (BCBA), occupational therapist (OT), speech therapist (SLP), therapist/mental health counselor (LPC/LMFT/LP), and or a psychiatrist.

Participants. There were 93 subjects in the Kurland et al. (2018) study. Forty (40) subjects were individuals diagnosed with IDD and co-morbid mental illness, and 53 were their caregivers.

Data Collection

Kurland and her colleagues (2018) identified their global research question as: *"What influence does systemic engagement have on the overall goal attainment for people diagnosed with IDD?"* and used the STP as the independent variable. The dependent variables included service outcomes data which include: 1) demographic data and data indicating the use of crisis response and other emergency services; 2) pre- and post- intervention scores from the subscales of the Aberrant Behavior Checklist (ABC); 3) pre- and post- intervention Recent Stressor Questionnaire (RSQ) scores; and 4) completion of a systemic satisfaction survey at the end of the experimental period by caregivers. Data were gathered within a three-month period. The three-month pre- and post- period was chosen by the researchers based on protocols for assessment of clients established by the START Center and all data were collected in-person, through an online portal or over the phone (Kurland et al., 2018).

Measures

Kurland et al. (2018) utilized five measuring instruments to collect their data: the STP (Appendix A), the PSQ (Appendix B), START plan (Appendix D), ABC (Appendix E) and the RSQ (Appendix F).

Aberrant Behavior Checklist (ABC). The ABC is a caregiver report checklist that contains 58-items that are ranked on a scale from 0 (*not a problem*) to 3 (*severe in degree*) (Lecavalier et al., 2017). The ABC is a heavily cited and psychometrically sound measure of psychiatric symptoms for both adults and youth with IDD (Aman & Singh, 1986). A very large number of studies worldwide involving people with intellectual disability use the ABC total scale or subscale scores as a treatment outcome measure, whereas many of the other instruments have been developed as screening tools (Charlot & Beasley, 2013). This tool rates challenging behavior on a numerical scale from 0 to 3 in which 0 indicates no problem and 3 indicates a severe problem.

The ABC has been noted to have five subscales that include: irritability, social withdrawal/lethargy, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech (Lecavalier et al., 2017). Behaviors are grouped into these five subscales and are then scored by summing the items in the subscale. In all subscales, the higher the number, the more problematic or challenging the behaviors. The maximum scores in each subscale are irritability (45); lethargy (48); stereotypic behavior (21); hyperactivity (48); and inappropriate speech (12) (Aman & Singh, 1986). This research used the five subscales of the ABC as indicators for challenging behaviors. Data regarding the instrument indicate that it has been in use since 1985 and has been extensively validated through the use of Cronbach alpha with scores ranging from 0.86 to 0.92 for the subscales and 0.86 to 0.94 for the total instrument (Hanratty et al., 2015). Average ratings for each subscale are provided with the instrument to demonstrate the presence (or absence) of psychopathology.

Of particular interest for this research is the use of the irritability and hyperactivity subscales of the ABC. Outcomes data were collected on 1,055 START service recipients in several locations in the United States between March 2012 and December 2013; and based on these data, service recipients scored the highest on both the irritability and hyperactivity subscales at intake and re-assessment (Beasley et al., 2016). These results show that irritability and hyperactivity represent measures of externalizing challenging behaviors with symptoms such as aggression and affective lability. In addition, Charlot (2005) indicated that behaviors such as aggression are a surface manifestation of irritability in people with limited behavioral skill repertoires. Scholars utilizing these scales in research argue that scores of 18 and 20 on these tools is clinically significant (Navarro et al., 2014). Efforts to validate the use of the ABC in practice have demonstrated that while there is a moderate correlation between items located on the irritability and hyperactivity subscales, there are important differences in these measures that warrant the use of two different classifications for assessing behavior (Kaat, Lecavalier, & Aman, 2014). More specifically, research indicates that the irritability subscale of the ABC focuses on 15 items that are directly related to “disruptive, aggressive, and self-injurious behaviors” while the hyperactivity subscale focuses on 16 items related to impulsive and noncompliant behavior (Hustyi, Hall, Jo, Lightbody, & Reiss, 2014, p. 2695). What this study indicates is that apart from social withdrawal, stereotypic behavior and inappropriate speech, the irritability and hyperactivity subscales from the ABC do indeed evaluate different characteristics and behaviors for the individual. The principal investigator explored all subscales from the ABC and to reduce collinearity in the model due to high correlations among the subscales, the study’s focal point were the irritability and hyperactivity subscales.

Recent Stressors Questionnaire (RSQ). The RSQ is a tool that was developed by START researchers at the University of Massachusetts Medical Center and it is meant to help START clinicians gather a broad range of information about factors that are known to contribute to alterations in mood, behavior and mental status (Charlot et al., 2011). The RSQ includes 30 yes/no response items that can be grouped into five subdomains: care changes, environmental changes, medical issues, support system concerns, and psychiatric hospitalizations (Charlot et al., 2011). This tool was developed to assess alternations in mood and behavior; and much like the ABC, it is commonly used at intake to assess the client and every four to six weeks to evaluate progress (Charlot et al., 2011). Although reliability and validity data for the tool are limited, the RSQ has been noted to provide a starting point for identifying the most common stressors that can and do lead to the need for emergency psychiatric services (Charlot et al., 2011).

Systemic Treatment Plan (STP). As mentioned earlier, this tool was developed by Kurland and her colleagues. The tool incorporates short term goals where the clinician is to incorporate strategies and objectives on how to navigate the presenting problem from a systemic point of view. The goals from the STP were broken down into three levels, primary level, secondary level and tertiary level. These levels were adapted from the World Health

Organization’s public health tertiary care model which is a framework that drives the START program. The model comprehensively addresses health and social problems by utilizing a population approach to health promotion and prevention. It considers human factors such as characteristics of the source of harm and the environment. It also identifies causes and suggests possible interventions. The interventions are broken down into three different levels. The primary level where interventions target the entire population provides support and education before problems occur; and the secondary level where interventions are targeted at families or systems involved in a client’s life to alleviate identified problems and prevent escalation. Lastly, the tertiary level is where interventions are client-specific and an example of this intervention is sending an individual to an inpatient psychiatric hospital to receive treatment or the involvement of law enforcement in a crisis.

START Plan. This tool/intervention is the official treatment plan used by the START program. START researchers developed it and it has been used for years to project the level of involvement necessary for each case as determined by the START Coordinator. In addition, the START plan is used to rank the order in which services will be provided to include intake assessments, outreach visits, respite services, consultations, and so forth. The goals are generalized and not grouped using the tertiary care model. The START coordinator narrates the presenting problem and outlines steps that will be taken to help alleviate the problem. The START plan does not identify members of the treatment team. The START plan has not been validated but tracking these trends provides concrete data to the stakeholders regarding services rendered as well as indicating a need for additional funding in some cases. The reliability of the instrument has also not been acquired.

Participant Survey Questionnaire (PSQ). Positive outcomes in the study conducted by Kurland and colleagues were defined as the perceptions of treatment by caregivers (*n*=53). These perceptions were captured through a combination of questions from the satisfaction survey (see Appendix B) which was completed at the end of the study. The standard mean difference of these questions was statistically significant as outlined previously. Information regarding this survey is limited in terms of reliability and validity. The instrument was developed internally by the Kurland and colleagues as a means to evaluate how clients and caregivers perceive the services that they have received. This instrument used scores based on a scale of 1. Totally disagree, 2. Somewhat disagree, 3. Unsure, 4. Somewhat agree, and 5. Totally agree. Although extensive quantitative assessment of reliability for the instrument has not been acquired, the survey was reviewed by three experts in the START program. The use of content validity to assess new instruments has been consistently supported in the literature as a useful starting point for assessing the utility of new instruments (Heale & Twycross, 2015). For the purposes of this study, the researcher focused on positive outcomes based on the mean responses from questionnaire items 13, 15, and 21. The questions are:

Question 13: *I feel as though the goals identified were successful.*

Question 15: *The START client's immediate psychiatric needs were met.*

Question 21: *I feel as though the START client's well-being has improved over the course of the last 3 months.*

These questions captured outcomes in treatment for the individual with intellectual and developmental disabilities based on improved well-being in comparison to his or her presentation at intake.

Current Study

This study sought to address the gap in literature by exploring whether individual-level variables are impacted/change when utilizing two different treatment strategies (the STP and the START plan) in treatment. The individual-level factors that were examined in this study were challenging behavior scores and psychiatric diagnoses (autism, depressive disorders, psychotic disorders, anxiety disorders, [ADHD], and bipolar disorder).

Research Design

As mentioned at the beginning of this chapter, the research design that was used in this investigation was a quantitative retrospective case-control approach (Gelman & Carlin, 2014). The decision to utilize a retrospective case-controlled design was based on the novelty of the STP and the lack of significant evidence to validate its utility in practice despite the results from the original study by Kurland and her colleagues. The use of a retrospective case-controlled design was viewed as a viable alternative to assessing the efficacy of this approach especially since the principal investigator was curious to know whether the rate of challenging behaviors identified at intake affects outcomes in treatment for this population.

Sample

Convenience sampling was the method utilized to obtain data for this study. Recruitment of participants for the study was not necessary because the design utilized a retrospective approach and data was already gathered from the sample by Kurland and colleagues. Harm to human participants as a result of this research was minimal to none. The inclusion criteria for this sample – as was for the Kurland study - was that they: (a) have a diagnosis of IDD or autism, (b) have a diagnosed psychiatric mental health disorder, (c) be enrolled in the START program, and (d) have a system of care (treatment team) to include either a parent/guardian, provider representative (group home manager/direct support staff/case manager), service coordinator, board-certified behavior analyst (BCBA), occupational therapist (OT), speech therapist (SLP), therapist/mental health counselor (LPC/LMFT/LP), and or a psychiatrist. All data collected were de-identified to maintain the confidentiality and privacy of all client data evaluated. This effort to protect participants' confidentiality ensured that ethical concerns related to the study were adequately addressed and to conform to all requirements established by the institutional review board (see Appendix C).

There were 93 subjects in the Kurland et al. (2018) study. Forty (40) subjects were individuals diagnosed with IDD and co-morbid mental illness, and 53 were their caregivers. The sample size of this study was based on the available data and it was not necessary to conduct a power analysis to determine if the size was large enough to produce statistically significant results. The method of statistical analysis that was utilized in this study was linear regression. The objective of regression analysis is to help predict a single dependent variable from the collected data of one or more independent variables (Singh, 2007). When using this method of analysis, a rule of thumb that has been used for years by researchers is that one should have at least 10 observations for every predictor (Howell, 2010). Another suggestion is to increase the sample size by a minimum of 15 subjects for each variable included in the regression analysis (Gall, Gall & Borg, 2006). There is no empirical evidence supporting these rules, but it is clear that a reasonable amount of power requires fairly large samples; hence, more is better. There are 20 observations in the control group and 20 observations in the treatment group, both surpassing the threshold to produce statistically significant results.

Measures

This study did not utilize any instruments since there was no experimental manipulation. See the Original Study section for details on the measures.

Materials

The materials required for the completion of this research included computer equipment and data analysis software using the IBM Statistical Package for the Social Sciences (SPSS) Grad Pack version 25.0 Premium (IBM Corp., Released 2017). Computer equipment and data analysis software was necessary for organizing and analyzing the client data provided by Kurland and colleagues. This information provided the basis for examining the statistical outcomes reported through the satisfaction survey, the ABC and the RSQ. Data was analyzed from baseline (intake) to 12 weeks of treatment.

Procedure

Contact was established with Kurland and her colleagues (Appendix G) and the researchers provided consent to use data collected from their research for this study which included all pertinent client background information and assessment scores for comparison. Following the acquisition of these data, the information was entered into an analytical software program (SPSS) to conduct data analysis through the procedures described in the following section. These data were analyzed, and the results were compared to assess outcomes within and between groups. Data analysis provided information regarding the changes that occurred for clients in both groups over the 12-week period as well as other notable differences at baseline and follow-up scores for the two groups. Because the research employed a retrospective design, no additional training for the two START coordinators was required.

Study Variable Operationalization

Psychiatric conditions and challenging behavior scores rated by the ABC tool under the five subscales were the independent or predictor variables and the dependent or criterion variable was the positive outcomes in treatment. Each study variable is operationally defined in Table 1 and summarized below:

Challenging Behaviors. Challenging behaviors was operationalized using the mean scores for each of the following ABC sub-dimensions: irritability, lethargy, stereotypic behavior, hyperactivity, and inappropriate speech (Lecavalier et al., 2017).

Psychiatric Disorder. Based on the availability of data, psychiatric disorder was operationalized as a categorical variable using the following: autism, attention-deficit/hyperactivity disorder (ADHD), anxiety disorders, bipolar and related disorders, depressive disorders, and psychotic disorders.

Recent Stressors. These are factors that are known to contribute to alterations in mood and behavior. Recent stressors were operationalized using the mean RSQ scores (Charlot et al., 2011).

Treatment Outcomes. Caregiver's assessment of treatment outcomes. These outcomes were operationalized using the mean responses for START Participant's Survey Questionnaire Items 13, 15, and 21.

Systemic Treatment Plan. The STP is a tool that guided the treatment of individuals in the treatment group. It was developed by Kurland et al. (2018) to clearly organize, articulate, and measure systemic goals for individuals served.

START Plan. The START plan was the official treatment plan used by the START program. This tool guided the treatment of individuals in the control group. It was developed by

START researchers and its purpose was to project the level of involvement necessary for each case as determined by the START coordinator.

Table 1

Variables, Scales of Measurement, Variable Type, and Operationalization

Variable	Data	Variable Type	Source
Challenging behaviors	Interval	Independent Variable	ABC sub-dimension mean scores
Recent stressors	Interval	Independent Variable	RSQ mean scores
Treatment outcomes	Interval	Dependent Variable	PSQ Items 13, 15, and 21
Psychiatric diagnosis	Categorical	Covariate	Demographic survey

Analyses

Following the acquisition of these data, the type of analysis used to answer the research questions was based on a predictive design. Predictive designs are a form of correlation research that uses calculated information about the relationships between variables to forecast future outcomes (Sheperis, Young, & Daniels, 2010). In predictive studies, researchers estimate the likelihood of a particular outcome by using a certain set of variables. These variables end up being grouped and result in a more accurate prediction than any one variable. The purpose of this research was to investigate whether challenging behaviors and psychiatric conditions are predictor variables that lead to positive outcomes in the treatment of individuals diagnosed with IDD and comorbid mental health conditions. Here, the research design used simple linear regression as a statistical analysis technique to determine the predictive relationship of the given variables.

Regression is one of the most frequently used techniques in social science research. The most common form of regression is linear regression, where the dependent variable is related to the independent variable in a linear way (Singh, 2007). The goal of linear regression is to have a plane of best fit, where the values of the independent variable and the dependent variable that share a linear relationship, are as close to the observed dependent variable as possible. The linear regression equation takes the following form:

$$y = a + bx$$

In this equation, y represents the dependent variable, x represents the independent variable, a is defined as the intercept and b is defined as the regression coefficient. The value of b indicates the change in the dependent variable for every unit change in the independent variable (Singh, 2007). In other words, it provides a measure of the contribution of the independent variable toward explaining the dependent variable.

Information regarding this approach to data analysis indicates that there are two primary benefits to employing this approach in practice. First, it provides a method for assessing the relative influence of one or more predictor variables on the criterion variable (Al-Noor & Mohammad, 2013). In this study, an effort was made to assess the relative influence of challenging behaviors and psychiatric conditions on treatment outcomes. The use of linear regression facilitated the ability of the researcher to demonstrate whether there was a relative influence on these measures. By demonstrating this influence, it should be possible to establish the salience of the approach and to make recommendations for the integration of the STP as part of evidence-based care for individuals diagnosed with IDD and co-occurring mental health issues.

The second advantage of linear regression analysis is that it provides a useful tool for identifying anomalies or outliers within a data set (Schnieder, Hommel & Blettner, 2010; Al-Noor & Mohammad, 2013). Comparing different predictor variables provided an opportunity to discover not only how the STP influences outcomes, but also identifying if all the predictor variables are relevant to the model. In other words, regression provides insight into whether or not the STP simultaneously reduces lethargy, stereotypy, inappropriate speech, irritability and hyperactivity for individuals with IDD and co-occurring mental health issues. Another possibility is identifying individuals within the group that may have psychiatric conditions that cannot effectively be treated using the STP. Schneider et al. (2010), conducted a meta-analysis of regression and found that this analytical technique is useful in identifying risk factors that influence outcomes in medical treatment and that it leads to determining individual prognoses. Using the linear regression model to analyze these data was beneficial such that recommendations made for the use of the STP in practice will lead to effectively addressing the needs of clients and fostering success in the therapeutic process.

The researcher attempted to answer the global research question, *"How do challenging behaviors and psychiatric disorders impact treatment outcomes among individuals diagnosed with IDD who have received treatment using the STP and the START plan over a 12-week period?"*

The following research sub-questions guided the analysis using linear regression:

1a: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the STP over a 12-week period?*

1b: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the START plan over a 12-week period?*

2: *Do stressors improve through time for individuals receiving treatment using the STP over a 12-week period?*

3a: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the STP?*

3b: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the START plan?*

The research questions in this study have been related to linear regression analysis as shown in Table 2:

Table 2

Research Question with Associated Statistical Analysis

Research Question	Statistical Analysis
1a: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the STP over a 12-week period?* 1b: *Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the START plan over a 12-week period?*	*Linear regression was attempted using the equation: $y = a + bx$ • Response (y): Positive outcomes • Potential predictor (x1): Hyperactivity • Potential predictor (x2): Irritability • Potential predictor (x3): Lethargy • Potential predictor (x4): Inappropriate speech • Potential predictor (x5): Stereotypy • Parameters (a, b1, b2, b3, b4, b5): Regression coefficient
2: *Do stressors improve through time for individuals receiving treatment using the STP over a 12-week period?*	Pre-and post-RSQ mean scores with the use of a paired sample t-test.
3a: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the STP?* 3b: *Which psychiatric disorders are predictive of positive treatment outcomes after a 12-week use of the START plan?*	**Linear regression was attempted using the equation: $y = a + bx$ • Response (y): Positive outcomes • Potential predictor (x1): Autism Spectrum Disorder • Potential predictor (x2): ADHD

Research Question	Statistical Analysis
	- Potential predictor (x3): Anxiety Disorders - Potential predictor (x4): Bipolar and Related Disorders - Potential predictor (x5): Depressive Disorders - Potential predictor (x6): Psychotic Disorders - Parameters (a, b1, b2, b3, b4, b5, b6): Regression coefficient

*This equation was used for both groups (individuals being treated under the START plan and individuals being treated under the STP). The total number of scores per subscale for each individual was used for the potential predictor. These are (45) irritability, (48) lethargy, (21) stereotypic behavior, (48) hyperactivity, (12) inappropriate speech, (5) positive outcomes.

**The contingency table for the variables was generated as follows based on the number of categories in each variable group. These are (18) autism, (16) ADHD, (7) anxiety disorders, (9) bipolar disorders, (9) depressive disorders, (7) psychotic disorders, and (5) positive outcomes.

Once the linear regression model is applied and properly estimated, the higher the value of R^2 the greater the explanatory power of the regression equation and therefore, the better the prediction of the criterion variable (Pedhazur, 1982). On the final step, the significance of the predictor variables is examined. The individual regression coefficients is tested for statistical significance. The higher the correlation between the predictor and the criterion variables, the more accurate the predictions made by the regression equation. The line of best fit on the scatterplot should show a linear relationship. The closer the plots to this line, the more accurate the regression.

Chapter IV

Results

The purpose of this research was to evaluate the use of a new treatment protocol, the systemic treatment plan (STP) by identifying the predictors of positive treatment outcomes for individuals diagnosed with intellectual and developmental disabilities (IDD) and comorbid mental health conditions. The results obtained from the STP group were compared with those from a control group that received standard care under the START plan. Using a retrospective research design, data captured by Kurland et al. (2018) were utilized as the starting point for determining: 1) which challenging behaviors predicted positive outcomes for individuals receiving treatment using either the STP or the START plan; 2) how the STP impacted client scores on the RSQ; and 3) which psychiatric disorders were predictive of positive treatment outcomes after a 12-week course of treatment using either the START treatment plan or the STP. The results obtained from this study are presented in this chapter.

Demographic Data

As noted, the data captured by Kurland et al. (2018) were utilized as the starting point for initiating this research. A total of *N*=93 participants were included in the original study by Kurland et al. (2018): START plan (*n*=20), STP (*n*=20) and PSQ (*n*=53). To provide a comprehensive overview of the participants' demographics, Table 3 summarizes their data.

The data obtained were categorical in nature which made it impossible to compute means or medians. Nonetheless, an assessment for modes was conducted throughout the demographic profile. For both the control and treatment groups, the sample totals were 20 cases. The most frequently occurring age group was individuals between 18-24 years of age which accounted for 37.5% (*n*=15) of the sample. The predominant race/ethnicity for both groups was Whites with an average of 62.5% (*n*=25) of the total sample. The comparison group had 5% more Whites than the treatment group (*n*=13). African Americans were the second largest demographic group at 20% (*n*=8) followed by Hispanics at 10% (*n*=4).

There were variations in the levels of intellectual disability within the sample and the most common level of IDD was mild at 60% (*n*=24). Individuals in the treatment group had higher levels of mild IDD at 75% (*n*=15) than their comparison group counterparts at 45% (*n*=9). The second most common level of IDD was moderate at 20% (*n*=8) for both groups and in this case, individuals in the treatment team had higher levels of moderate IDD at 25% (*n*=5) than their comparison group counterparts at 15% (*n*=3). None of the individuals in the treatment group had a diagnosis of severe, borderline or normal intelligence. Only 10% (*n*=2) of individuals in the comparison group were recorded to have normal intelligence. Autism was seen to be the most common psychiatric diagnosis at 45% (*n*=18) followed by ADHD at 40% (*n*=16). The least common psychiatric diagnoses were for individuals diagnosed with adjustment disorder, antisocial personality disorder and tic disorders all at 2.5% (*n*=1) respectively. Finally, there were two main presenting problems for the sample upon admission. The most frequent presenting problem was individuals presenting with aggression (physical, verbal, property destruction, or threats) upon admission at 85% (*n*=34). The second most common reason for admission was that families and or caregivers were in need of additional assistance in the care of their loved ones at 55% (*n*=22).

Table 3

Full Demographic Profile for Participants

Demographics	Comparison (*n*=20)	Comparison Percent (%)	Treatment (*n*=20)	Treatment Percent (%)	Total (*N*=40)	Total Percent (%)
Age Range						
7-12	3	15.0	1	5.0	4	10.0
13-17	3	15.0	5	25.0	8	20.0
18-24	7	35.0	8	40.0	15	37.5
25-34	5	25.0	2	10.0	7	17.5
35-44	2	10.0	4	20.0	6	15.0
Race/Ethnicity						
African American	3	15.0	5	25.0	8	20.0
Asian	0	0.0	1	5.0	1	2.5
Hispanic	3	15.0	1	5.0	4	10.0
White	13	65.0	12	60.0	25	62.5
More than one race	0	0.0	1	5.0	1	2.5
Unknown	1	5.0	0	0.0	1	2.5
Severity of IDD by Group						
Severe	2	10.0	0	0.0	2	5.0
Moderate	3	15.0	5	25.0	8	20.0
Mild	9	45.0	15	75.0	24	60.0
Borderline	1	5.0	0	0.0	1	2.5
None noted	3	15.0	0	0.0	3	7.5
Normal intelligence	2	10.0	0	0.0	2	5.0
Psychiatric Diagnosis						
Autism	9	45.0	9	45.0	18	45.0
ADHD	7	35.0	9	45.0	16	40.0
Disruptive Disorders	4	20.0	11	55.0	15	37.5
Anxiety Disorders	7	35.0	6	30.0	13	32.5
Bipolar and Related Disorders	3	15.0	6	30.0	9	22.5

Demographics	Comparison (*n*=20)	Comparison Percent (%)	Treatment (*n*=20)	Treatment Percent (%)	Total (*N*=40)	Total Percent (%)
Depressive Disorders	5	25.0	4	20.0	9	22.5
Psychotic Disorders	5	25.0	2	10.0	7	17.5
Borderline Personality Disorder	0	0.0	3	15.0	3	7.5
Adjustment Disorder	0	0.0	1	5.0	1	2.5
Antisocial Personality Disorder	1	5.0	0	0.0	1	2.5
Tic Disorders	1	5.0	0	0.0	1	2.5
Other	0	0.0	1	5.0	1	2.5
Presenting Problem						
Aggression (physical, verbal, property destruction, or threats)	16	80.0	18	90.0	34	85.0
Diagnosis and treatment planning	1	5.0	1	5.0	2	5.0
Family needs assistance	12	60.0	10	50.0	22	55.0
Mental health symptoms	5	25.0	3	15.0	8	20.0
Self-injurious	2	10.0	5	25.0	7	17.5
Leaving unexpectedly	4	20.0	3	15.0	7	17.5
Suicidal ideation	1	5.0	5	25.0	6	15.0
Sexualized behavior	2	10.0	4	20.0	6	15.0
Transition from hospital	1	5.0	1	5.0	2	5.0
Other	1	5.0	1	5.0	2	5.0

Descriptive Analyses

The information contained in Table 3 provides an overview of the demographic data of the sample in this study. Additional analyses had to be conducted in order to assess the relationships between and within the variables in this study as well as assess any differences between the treatment and control groups. The first analysis looked at the relationships between the five continuous variables of challenging behaviors (ABC) using the Pearson correlation analysis method. The correlation coefficient produced in the Pearson correlation analysis indexed the strength and direction of the relationships among the subscales of irritability, lethargy, stereotypic behavior, hyperactivity, and inappropriate speech before treatment (pre-test) as outlined in Table 4. In the correlation test, a two-tailed test and a level of significance of 0.05 was used.

Table 4

Results of Pearson Correlation Analysis of Pre-test Scores of Five Sub-Scales of Challenging Behavior

		Pre-Lethargy	Pre-Irritability	Pre-Stereotypy	Pre-Inappropriate Speech	Pre-Hyperactivity
Pre-Lethargy	Pearson Correlation		0.36^{*}	0.36^{*}	0.08	0.31^{*}
	Sig. (2-tailed)		0.02	0.02	0.63	0.05
	N		40.0	40.0	40.0	40.0
Pre-Irritability	Pearson Correlation			0.49^{*}	0.73^{*}	0.67^{*}
	Sig. (2-tailed)			0.001	0.000	0.000
	N			40.0	40.0	40.0
Pre-Stereotypy	Pearson Correlation				0.31^{*}	0.44^{*}
	Sig. (2-tailed)				0.05	0.01
	N				40.0	40.0

		Pre-Lethargy	Pre-Irritability	Pre-Stereotypy	Pre-Inappropriate Speech	Pre-Hyperactivity
Pre-Inappropriate Speech	Pearson Correlation					0.48^{*}
	Sig. (2-tailed)					0.002
	N					40.0
Pre-Hyperactivity	Pearson Correlation					
	Sig. (2-tailed) N					

*. Correlation is significant at the 0.05 level (2-tailed).

Results from the Pearson correlation analysis as outlined in Table 4 showed that the pre-test scores of lethargy were significantly positively correlated with the pre-test scores of irritability ($r(38) = 0.36, p = 0.02$), stereotypic behavior ($r(38) = 0.36, p = 0.02$), and hyperactivity ($r(38) = 0.31, p = 0.05$). The significant positive correlation means that the higher the pre-test scores of lethargy, the higher the pre-test scores in irritability, stereotypic behavior, and hyperactivity. This indicates that the more an individual struggled with lethargy at the beginning of the study, the more they struggled with irritability, stereotypic behavior, and hyperactivity.

The pre-test scores of irritability were significantly positively correlated with the pre-test scores of stereotypic behavior ($r(38) = 0.49, p = 0.001$), hyperactivity ($r(38) = 0.73, p < 0.001$), and inappropriate speech ($r(38) = 0.67, p < 0.001$). The significant positive correlation between the pre-test scores of irritability and the pre-test scores of stereotypic behavior means that the higher the pre-test scores of irritability, the higher the pre-test scores in stereotypic behavior, inappropriate speech, and hyperactivity. This indicates that the more individuals struggled with irritability at the beginning of the study, their challenges with stereotypic behavior, inappropriate speech, and hyperactivity also increased. Pre-test scores of stereotypic behavior were significantly positively correlated with the pre-test scores of inappropriate speech (*r*(38) = 0.31, *p* = 0.05) and hyperactivity (*r*(38) = 0.44, *p* = 0.01). The significant positive correlation means that the higher the pre-test score of an individual's of stereotypic behavior, the higher their pre-test scores in inappropriate speech and hyperactivity. Pre-test scores of inappropriate speech was significantly positively correlated with the pre-test scores of hyperactivity (*r*(38) = 0.48, *p* = 0.002).The significant positive correlation means that the higher the pre-test scores of inappropriate speech, the higher their pre-test scores of hyperactivity.

Table 5 summarizes the results of the Pearson correlation analysis of the challenging behavior subscale scores of irritability, lethargy, stereotypic behavior, hyperactivity, and inappropriate speech after treatment (post-test) of the five different sub-dimensions of the ABC.

Table 5

Results of Pearson Correlation Analysis of Post-test Scores of Five Sub-Dimensions of Challenging Behavior

		Post-Lethargy	Post-Irritability	Post-Stereotypy	Post-Inappropriate Speech	Post Hyperactivity
Post-Lethargy	Pearson Correlation		0.30	0.48^{*}	0.12	0.38^{*}
	Sig. (2-tailed)		0.07	0.002	0.45	0.02
	N		39.0	39.0	39.0	39.0
Post-Irritability	Pearson Correlation			0.49^{*}	0.54^{*}	0.73^{*}
	Sig. (2-tailed)			0.001	0.000	0.000
	N			39.0	39.0	39.0
Post-Stereotypy	Pearson Correlation				0.43^{*}	0.51^{*}
	Sig. (2-tailed)				0.01	0.001
	N				39.0	39.0
Post-Inappropriate Speech	Pearson Correlation					0.44^{*}
	Sig. (2-tailed)					0.01

		Post-Lethargy	Post-Irritability	Post-Stereotypy	Post-Inappropriate Speech	Post Hyperactivity
	N					39.0
Post-Hyperactivity	Person Correlation					
	Sig. 2-tailed					
	N)					

*. Correlation is significant at the 0.05 level (2-tailed).

Results of the Pearson correlation analysis as outlined in Table 5 showed that the post-test scores of lethargy was significantly positively correlated with the post-test scores of stereotypic behavior ($r(37) = 0.48$, $p = 0.002$) and hyperactivity ($r(37) = 0.38$, $p = 0.02$). The significant positive correlation means that the higher an individual's posttest score of lethargy, the higher their post-test scores in stereotypic behavior and hyperactivity. Post-test scores of irritability was significantly positively correlated with the post-test scores of stereotypic behavior ($r(37) = 0.49$, $p = 0.001$), hyperactivity ($r(37) = 0.73$, $p < 0.001$), and inappropriate speech ($r(37) = 0.54$, $p < 0.001$). The significant positive correlation means that the higher the post-test score of irritability (indicating there is more problematic or challenging behavior of irritability among individuals diagnosed with IDD and comorbid mental health conditions after treatment), the higher their scores in stereotypic behavior, inappropriate speech, and hyperactivity after receiving treatment using the STP and START plan.

Post-test scores of stereotypic behavior were significantly positively correlated with the post-test scores of inappropriate speech ($r(37) = 0.43$, $p = 0.01$) and hyperactivity ($r(37) = 0.51$, $p = 0.001$). The significant positive correlation means that the higher an individual scores in stereotypic behavior after treatment so will be their scores in inappropriate speech and hyperactivity. Finally, the post-test scores of inappropriate speech were significantly positively correlated with the post-test scores of hyperactivity ($r(37) = 0.44$, $p = 0.01$). The significant positive correlation means that the higher an individual scores on inappropriate speech after treatment, the higher they will score on their symptoms of hyperactivity.

After completing the Pearson correlation analyses, the next step in examining the relationships between the variables was to conduct several Pearson's chi-square tests in order to determine if there are significant relationships between the variables of age, gender, race, ethnicity, disability level, and psychiatric diagnosis. The purpose of a Pearson's chi-square test or the chi-square test of association is to determine if there is a significant relationship between two categorical variables (Singh et al., 2013). It should be noted that for this study, the variables of gender, race, ethnicity, disability level, and psychiatric diagnosis are considered as categorical variables. In the chi-square test, a two-tailed test and level of significance of 0.05 was used. A significant relationship between variables exists when the *p*-value of the X^2 statistic of the chi-square test is less than or equal to the level of significance set at 0.05 (Singh et al., 2013). Table 6 summarizes the results of the first Chi-square test of the significance of the relationships of age with the variables of gender, race, ethnicity, disability level, and psychiatric diagnosis. Results of the Chi-square test showed that age is not significantly related with gender ($X^2(21) = 17.85$, $p = 0.66$), race ($X^2(84) = 68.36$, $p = 0.89$), ethnicity ($X^2(42) = 38.74$, $p = 0.62$), disability level ($X^2(105) = 103.19$, $p = 0.53$), and psychiatric diagnosis ($X^2(693) = 675.67$, $p = 0.67$).

Table 6

Results of Chi-Square Test of Significance of Relationships of Age with Gender, Race, Ethnicity, Disability Level, and Psychiatric Diagnoses

Variable 1	Variable 2	Pearson Chi-Square Value	df	p-value (2-sided)
Age	Gender	17.85	21	0.66
	Race	68.36	84	0.89
	Ethnicity	38.74	42	0.62
	Disability level	103.19	105	0.53

	Psychiatric diagnoses	675.67	693	0.67

The second Pearson Chi-square test was conducted on the significance of the relationships of gender with the variables of race, ethnicity, disability level, and psychiatric diagnosis as shown in Table 7. Cross tabulation to further show the degree of the significance of the relationship between gender and race can be seen in Table 8. Results of the Chi-square test showed that gender is only significantly related to race ($X^2(4) = 9.37$, $p = 0.05$). On the other hand, gender is not significantly related with ethnicity ($X^2(2) = 0.07$, $p = 0.97$), disability level ($X^2(5) = 3.22$, $p = 0.67$), and psychiatric diagnosis ($X^2(33) = 33.98$, $p = 0.42$).

Table 7

Results of Chi-Square Test of Significance of Relationships of Gender with Race, Ethnicity, Disability Level, and Psychiatric Diagnoses

Variable 1	Variable 2	Pearson Chi-Square Value	df	p-value (2-sided)
Gender	Race	9.37	4	0.05*
	Ethnicity	0.07	2	0.97
	Disability level	3.22	5	0.67
	Psychiatric diagnoses	33.98	33	0.42

*Significant relationship at the level of significance of 0.05

Table 8

Cross Tabulation Between Gender and Race

			Gender					
			Asian	Black or African American	White	Other	Unknown	Total
Race	Female	n	1	3	5	1	1	11
	Male	n	0	6	23	0	0	29
	Total	n	1	9	28	1	1	40

The third Pearson Chi-square test was conducted on the significance of the relationships of race with the variables of ethnicity, disability level, and psychiatric diagnosis as shown in Table 9. Results of the Chi-square test showed that race is not significantly related with ethnicity ($X^2(8) = 11.79$, $p = 0.16$), disability level ($X^2(20) = 24.00$, $p = 0.24$), and psychiatric diagnosis ($X^2(132) = 120.95$, $p = 0.75$).

Table 9

Results of Chi-Square Test of Significance of Relationships of Race with Ethnicity, Disability Level, and Psychiatric Diagnoses

Variable 1	Variable 2	Pearson Chi-Square Value	df	p-value (2-sided)
Race	Ethnicity	11.79	8	0.16
	Disability level	24.00	20	0.24
	Psychiatric diagnoses	120.95	132	0.75

The fourth Pearson Chi-square test was conducted on the significance of the relationships of ethnicity with the variables of disability level, and psychiatric diagnosis as shown in Table 10. Results of the Chi-square test showed that ethnicity is not significantly related with disability level ($X^2(10) = 8.25$, $p = 0.61$) and psychiatric diagnosis ($X^2(66) = 65.42$, $p = 0.50$).

Table 10

Results of Chi-Square Test of Significance of Relationships of Ethnicity with Disability Level and Psychiatric Diagnoses

Variable 1	Variable 2	Pearson Chi-Square Value	df	p-value (2-sided)
Ethnicity	Disability level	8.25	10	0.61
	Psychiatric diagnoses	65.42	66	0.50

Lastly, Table 11 summarizes the results of the Pearson Chi-square test of the significance of the relationship between disability level and psychiatric diagnosis. Results of the Chi-square test showed that disability level is not significantly related to psychiatric diagnosis ($X^2(165) = 172.00, p = 0.34$).

Table 11

Results of Chi-Square Test of Significance of Relationship between Disability Level and Psychiatric Diagnoses

Variable 1	Variable 2	Pearson Chi-Square Value	df	p-value (2-sided)
Disability level	Psychiatric diagnoses	172.00	165	0.34

After completing both the Pearson correlation analyses and the Pearson Chi-square tests, the next step in the data analysis process was to conduct a test of normality with the dependent and independent variables. A test of normality was conducted in order to calculate the probability that the sample was drawn from a normal population using two methods; 1) visual inspection of the distribution from a scatterplot and a histogram and 2) conducting analysis using the Kolmogorov-Smirnov and the Shapiro-Wilk tests using the SPSS statistical analysis software. In order for the visual inspection to take place, positive treatment outcomes were inputted into SPSS as the dependent variable and it was plotted against challenging behaviors as the independent variable. Both positive treatment outcomes and challenging behaviors are classified as continuous data. Psychiatric disorders were not considered for the test of normality due to the nature of the data being categorical. Once computed, an output of the independent variable was generated as shown in Figure 3 and Figure 4. The visual inspection was conducted by looking at the frequency distribution on the histogram and the Q-Q plot (quantile-quantile plot) right below it. The histogram and the Q-Q plots show that challenging behaviors data follow a normal distribution. This is evidenced by the bell-shaped curve of the frequencies in the histogram and the straight diagonal line in the scatterplot.

Figure 3

Histogram for Challenging Behavior Scores

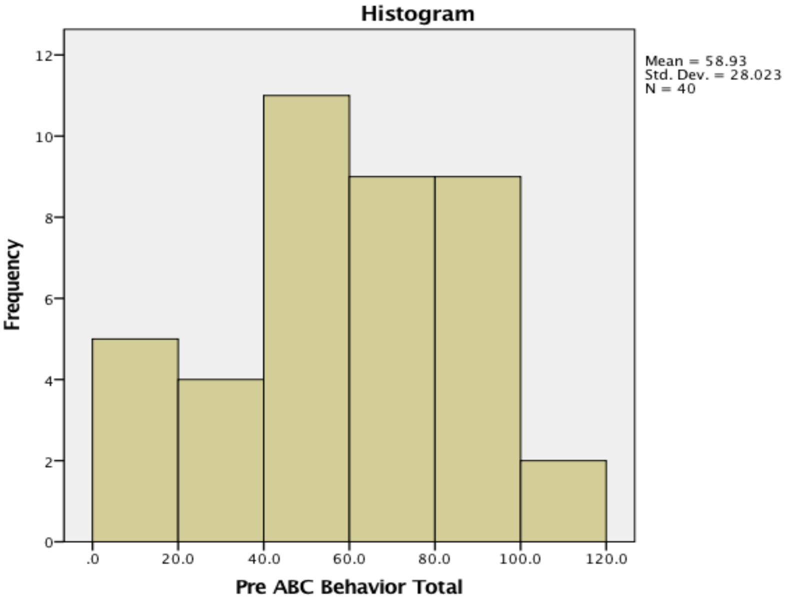
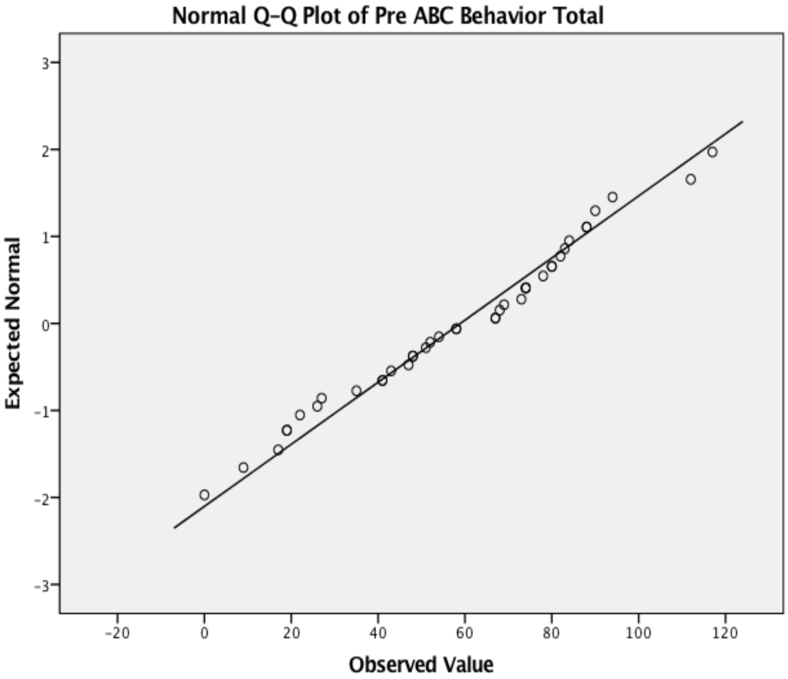


Figure 4

Q-Q Plots for Challenging Behavior Scores



An output of the dependent variable was generated as shown in Figure 5 and Figure 6. The visual inspection was conducted by looking at the frequency distribution on the histogram and the Q-Q plot (quantile-quantile plot). The histogram in Figure 5 shows that positive treatment outcome data does not follow a normal distribution due to the lack of a bell curve on the frequencies. The Q-Q plot, however, does indicate normal distribution as evidenced by the straight diagonal line in the scatterplot.

Figure 5

Histogram for Positive Treatment Outcome Scores

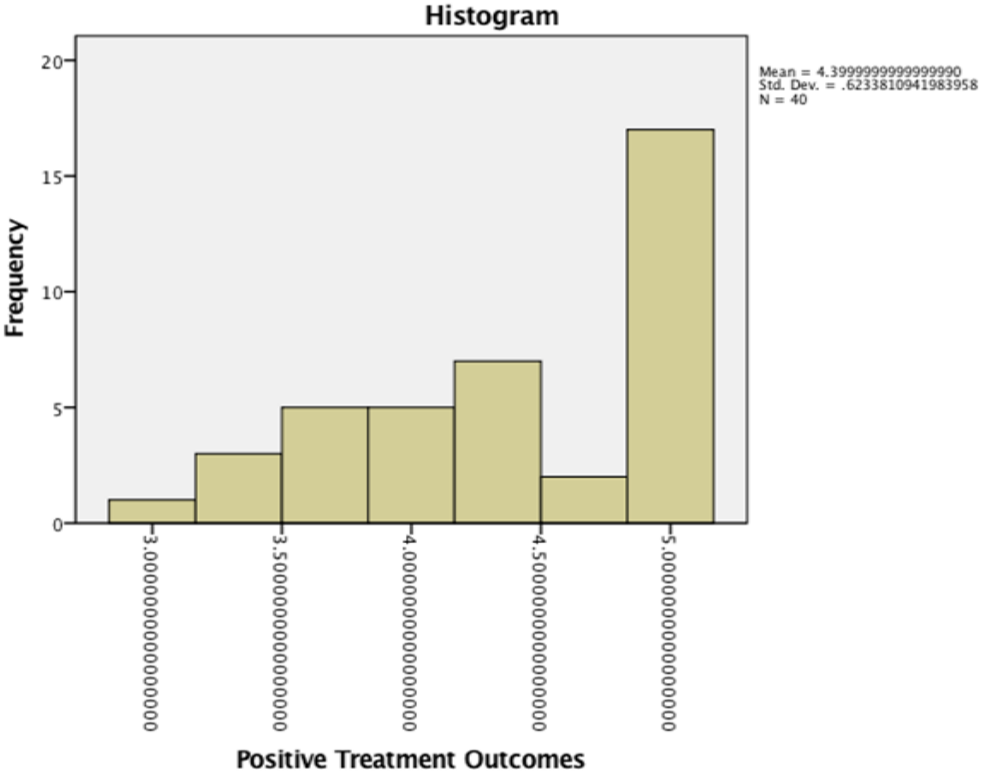
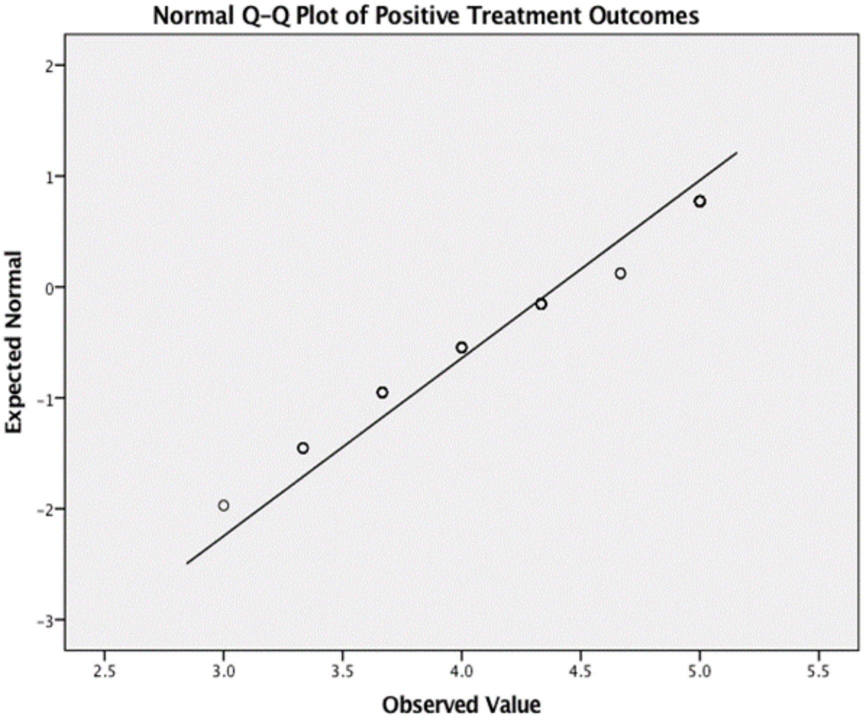


Figure 6

Q-Q Plots for Positive Treatment Outcome Scores



The second method of conducting a test of normality was to run the Kolmogorov-Smirnov and the Shapiro-Wilk tests using SPSS and these two tests function by comparing the sample scores to a normally distributed set of scores with the same mean and standard deviation (Ghasemi & Zahediasl, 2012). These tests are supplementary to the graphical assessment of normality conducted above. Results of the Kolmogorov-Smirnov and Shapiro-Wilk normality tests are shown in Table 12. The results indicate that for positive treatment outcomes, both tests have a p-value of less than 0.05, which indicates that data are not normally distributed while for challenging behaviours, data are normally distributed since both p values are greater than 0.05. In other words, the assumption here is that the population from which the sample is derived is normally distributed and the analysis of the parametric tests would lead to reliable results.

Table 12

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Positive Treatment Outcomes	.257	40	.000	.845	40	.000
Pre ABC Behavior Total	.113	40	.200*	.978	40	.617

*. This is a lower bound of the true significance.
a. Lilliefors Significance Correction

A combination of the visual inspections and the two normality tests provide a basis of judgment that the data is normally distributed. Even though the normality test results indicate a p-value of less than 0.05 for positive treatment outcomes, the Q-Q plot however, does indicate normal distribution as evidenced by the straight diagonal line in the scatterplot. Researchers such as Pallant, 2007; Elliott & Woodward, 2007; Ghasemi & Zahediasl, 2012, indicate that parametric procedures can be undertaken with sample sizes such as this (>30 or 40) even when the data are not normally distributed after conducting the Kolmogorov-Smirnov and the Shapiro-Wilk tests. This gives grounds to continue with the assessment of the research questions posed in this study.

Research Question

The results in this section are based on the individual research questions that guided the study. Inferential analyses began with linear regression and then a paired samples t-test. To answer research question 1, each challenging behavior before and after treatment were entered as predictors of positive treatment outcomes for individuals receiving treatment using the START plan (control group) and for those receiving care using the STP (treatment group) in order to assess which challenging behaviors acted as predictor variables to positive treatment outcomes. The objective of regression analysis is to help predict a single dependent variable from the collected data of one or more independent variables (Singh et al., 2013). To answer research question 2, a paired samples t-test was used to determine whether RSQ scores improved over time for individuals receiving treatment using the STP. The objective of paired sample t-tests is to test the difference between raw scores, and it is based on the assumption that data are measured on an interval/ratio scale (Singh et al., 2013). To answer research question 3, different psychiatric diagnoses were entered into separate linear regression models as the sole predictor of positive treatment outcomes for individuals receiving treatment using the START plan and for those receiving care using the STP in order to assess which psychiatric conditions predict positive treatment outcomes.

Research question 1. The first research question was divided into two parts. The first part asks, *"Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the STP over 12 weeks?"* The second part of the question asks, *"Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the START plan over 12 weeks?"*

This research question focused on identifying which challenging behaviors predicted positive treatment outcomes for individuals who received treatment using the STP over 12 weeks (1a) and for individuals who received treatment using the START plan over 12 weeks (1b). Challenging behaviors were classified as the independent variable and scores were based on ratings from the ABC tool. The five subscales in the ABC are irritability, lethargy, stereotypy, inappropriate speech, and hyperactivity. Positive outcomes in treatment as conceptualized by the average mean scores of three questions from the caregiver responses were classified as the dependent variable. Five different linear regression models were run based on the ABC subscales and data for each of these five measures are reviewed in Tables 13 through 17. Each of the five challenging behavior subscales before (pre-) and after (post-) treatment were inputted as predictors of positive treatment outcomes for individuals receiving treatment under the START plan (control group) and for those receiving treatment under the STP (treatment group).

Of note when reviewing these data is Table 13 which solely focuses on lethargy. The results of linear regression analysis for this challenging behavior indicated that in the comparison (START plan) group, lethargy was negatively correlated with positive treatment outcomes, B= -.05, t =-2.04, p =.06 before (pre) receiving the intervention (See Table 13). This result shows that there was a six percent chance that the relationship between lethargy and positive outcomes doesn't exist for individuals receiving treatment using the START plan.

After receiving treatment, lethargy was positively associated with positive treatment outcomes: B = .03, t = 1.77, p =.10. However, the results indicate that the behaviors were only a marginally statistically significant predictor of positive treatment outcomes. This result suggests that there was a 10% chance that more lethargy was related to positive outcomes in treatment for individuals receiving care under the START plan. Data provided in Tables 14 through 17 includes the remaining four variables measured from the ABC: irritability, stereotypy, hyperactivity, and inappropriate speech, respectively.

Table 13

Lethargy as a Predictor of Positive Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.40	.32		13.76	0.00

		Post-Lethargy	.03	.02	.42	1.77	0.10
		Pre-Lethargy	-.05	.03	-.48	-2.04	0.06
Systemic Treatment Plan	1	(Constant)	4.53	.20		22.29	0.00
		Post-Lethargy	-.03	.02	-.67	-1.60	0.13
		Pre-Lethargy	.03	.03	.56	1.34	0.20

Table 14

Irritability as a Predictor of Positive Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.65	.46		10.138	0.00
		Post-Irritability	-.01	.02	-.09	-.327	0.75
		Pre-Irritability	-.01	.02	-.13	-.472	0.64
Systemic Treatment Plan	1	(Constant)	4.74	.28		16.685	0.00
		Post-Irritability	.00	.02	.08	.179	0.86
		Pre-Irritability	-.02	.02	-.31	-.685	0.50

Table 15

Stereotypy as a Predictor of Positive Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.36	.27		16.02	0.00
		Post-Stereotypy	-.02	.05	-.10	-0.33	0.74
		Pre-Stereotypy	.01	.03	.11	0.36	0.73
Systemic Treatment Plan	1	(Constant)	4.46	.19		23.93	0.00
		Post-Stereotypy	.00	.04	-.02	-0.06	0.95
		Pre-Stereotypy	.01	.05	.06	0.15	0.88

Table 16

Hyperactivity as a Predictor of Positive Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	5.13	.41		12.45	0.00
		Post-Hyperactivity	.00	.01	-.06	-0.24	0.81
		Pre-Hyperactivity	-.03	.02	-.43	-1.67	0.12
Systemic Treatment Plan	1	(Constant)	4.38	.33		13.47	0.00
		Post-Hyperactivity	.00	.01	.03	0.12	0.91
		Pre-Hyperactivity	.00	.02	.06	0.21	0.84

Table 17

Inappropriate Speech as a Predictor of Positive Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.45	.27		16.71	0.00
		Post-Inappropriate Speech	-.03	.06	-.14	-0.46	0.65
		Pre-Inappropriate Speech	.00	.04	-.02	-0.05	0.96
Systemic Treatment Plan	1	(Constant)	4.59	.26		17.47	0.00
		Post-Inappropriate Speech	.01	.05	.05	0.20	0.84
		Pre-Inappropriate Speech	-.04	.04	-.22	-0.88	0.39

Using the STP in treatment was not correlated with any changes in positive treatment outcomes. Tables 14 through 17 show the actual coefficients for each of the other challenging behaviors across the two groups. None of the other challenging behaviors evaluated were statistically significant with positive treatment outcomes for individuals receiving either the control or intervention treatment.

In reference to the first part of this research question, *"Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the STP over 12 weeks?",* the results indicate that there were no challenging behaviors that met the statistically significant threshold to predict positive treatment outcomes for individuals receiving treatment using the STP in treatment over a 12-week period despite the theoretical support for using the STP to enhance positive behavioral outcomes.

In reference to the second part of this research question, *"Which challenging behaviors predict positive treatment outcomes for individuals who received treatment under the START plan over 12 weeks?",* the results indicate that one challenging behavior, lethargy, as measured by the ABC survey was the only behavior that was a marginally statistically significant predictor of positive treatment outcomes for individuals receiving the control treatment (START plan) over a 12-week period. As shown in Table 13, evidence of lethargy before receiving the control treatment was negatively correlated with positive treatment outcomes, B= -.05, t =-2.04, p =.06, whereas evidence of lethargy after receiving the control treatment was positively associated with positive treatment outcomes, B= .03, t = 1.77, p =.10.

Research question 2. The second research question posed for this study asked, "*Do stressors improve through time for individuals receiving treatment using the STP over a 12-week period?"* This research question focused on an assessment of whether RSQ scores improved over time when individuals received treatment using the STP from baseline (before treatment) to post-treatment (after 12 weeks of treatment). A paired-samples t-test was used to assess whether the RSQ scores improved over time by comparing the means of RSQ scores before and after treatment. Since the RSQ survey includes 30 yes/no response items, the scores that were included in the analyses were the sum of all yes responses which created an RSQ total score that ranged from 0 to 18. By summing the yes responses, an interval/ratio level composite was created and therefore, running a t-test for this analysis was appropriate. The results from this analysis can be found in Tables 18 and 19. The results demonstrate that while individuals receiving treatment under the STP reported fewer stressors on average from the pre- (M_{pre} = 7.20) to post-treatment (M_{post} = 6.80), the results were not statistically significant: *t* (19) = .35, *p* =.73.

Table 18

Mean Scores for RSQ in STP Group

	Mean	N	Std. Deviation	Std. Error Mean
Pre-RSQ Total Score	7.200	20	4.5722	1.0224
Post-RSQ Total Score	6.800	20	4.1116	.9194

Table 19

Paired Samples T-Test for STP Group

Paired Differences							
Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
			Lower	Upper	t	df	Sig. (2-tailed)
.4000	5.0513	1.1295	-1.9641	2.7641	.354	19	.727

In reference to the second research question, *"Do stressors improve through time for individuals receiving treatment using the STP over a 12-week period?",* the results indicate that individuals receiving treatment under the STP reported slightly improved scores on average following 12-weeks of treatment but the slight improvement in stress scores did not meet the threshold to be considered as significant improvement *t* (19) = .35, *p* =.73.

Research question 3. The first part of the third research question asked, "*Which psychiatric disorders are predictive of positive treatment outcomes after 12 weeks of using the STP in treatment?"* The second part asked, "*Which psychiatric disorders are predictive of positive treatment outcomes after 12 weeks of using the START plan in treatment?"* These research questions focused on an evaluation of psychiatric disorders and their predictive ability for positive treatment effect following12 weeks of receiving care using either the STP (3a) or the START plan (3b). Six different psychiatric disorders were evaluated in the context of positive treatment outcomes: autism, anxiety, bipolar disorder, ADHD, psychotic disorder, and depressive disorder. The six psychiatric disorders were inputted into separate linear regression models as predictors of positive treatment outcomes for individuals receiving treatment under the START plan (control group) and for those receiving treatment under the STP (treatment group). The results from the linear regression analysis can be found concurrently in Tables 20 through 25. The results indicate that of the six psychiatric diagnoses reviewed, only one, autism (see Table 20), was noted to be a marginally statistically significant predictor of positive treatment outcomes for individuals receiving treatment using the STP after 12 weeks: *B*= .47, *t* = 1.98, *p* =.06. None of the other psychiatric diagnoses were statistically significant predictors of positive treatment outcomes for individuals receiving either the intervention or control treatment.

Table 20

Autism as a Predictor of Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.33	.204		21.25	0.00
		Autism	-0.04	.322	-0.03	-0.13	0.90

Systemic Treatment Plan	1	(Constant)	4.23	.164		25.86	0.00
		Autism	0.47	.238	0.43	1.98	0.06

Table 21

Anxiety as a Predictor of Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.33	.177		24.55	0.00
		Anxiety	-0.08	.395	-0.05	-0.21	0.84
Systemic Treatment Plan	1	(Constant)	4.43	.138		32.11	0.00
		Anxiety	0.24	.425	0.13	0.55	0.59

Table 22

Bipolar Disorder as a Predictor of Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.29	.171		25.13	0.00
		Bipolar Disorder	0.15	.441	0.08	0.34	0.74
Systemic Treatment Plan	1	(Constant)	4.55	.150		30.26	0.00
		Bipolar Disorder	-0.21	.274	-0.18	-0.78	0.44

Table 23

ADHD as a Predictor of Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.38	.194		22.58	0.00

		ADHD	-0.19	.328	-0.14	-0.59	0.56
Systemic Treatment Plan	1	(Constant)	4.43	.181		24.45	0.00
		ADHD	0.05	.264	0.04	0.18	0.86

Table 24

Psychotic Disorder as a Predictor of Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.21	.167		25.16	0.00
		Psychotic Disorder	0.54	.374	0.32	1.45	0.16
Systemic Treatment Plan	1	(Constant)	4.45	.139		31.98	0.00
		Psychotic Disorder	0.05	.429	0.03	0.11	0.91

Table 25

Depressive Disorder as a Predictor of Treatment Outcomes

Treatment Group			Unstandardized Coefficients		Standardized Coefficients	t	Sig.
			B	Std. Error	Beta		
START Plan	1	(Constant)	4.27	.181		23.57	0.00
		Depressive Disorder	0.20	.362	0.13	0.55	0.59
Systemic Treatment Plan	1	(Constant)	4.49	.147		30.49	0.00
		Depressive Disorder	-0.16	.321	-0.12	-0.48	0.63

In reference to the first part of the third research question, *"Which psychiatric disorders are predictive of positive treatment outcomes after 12 weeks of using the STP in treatment?",* the results indicate that only individuals with an autism diagnosis are the ones who experienced marginally statistically significant differences in outcomes after 12-weeks of treatment ($B = .47$, $t = 1.98$, $p =.06$). The results suggest that autistic clients work well using the STP in treatment in comparison to other psychiatric disorders. It may be possible to argue that the structure of the STP is geared toward significantly changing the behavior of the autistic client through the use of systemic engagement. In reference to the second part of the third research question, *"Which psychiatric disorders are predictive of positive treatment outcomes after 12 weeks of using of the START plan in treatment?"* the results indicate that there are no psychiatric conditions that act as a predictor of positive treatment outcomes when the START plan is used after 12 weeks of treatment.

Discussion

A critical review of the results included in this chapter suggests that individuals receiving treatment under the STP reported fewer stressors on average following 12-weeks of treatment in comparison to their START plan counterparts. In reference to the global research question, *"How do challenging behaviors and psychiatric disorders impact treatment outcomes among individuals diagnosed with intellectual and developmental disabilities who have received treatment using the STP and the START plan over a 12-week period?",* the results indicate that there were no challenging behaviors that impacted positive treatment outcomes after 12-weeks of treatment despite the theoretical support for using the STP to enhance positive behavioral outcomes. Further, only clients with autism experienced marginal differences in outcomes after 12-weeks of treatment, suggesting that autistic clients experience positive outcomes when using the STP in treatment in comparison to other psychiatric disorders.

The marginal statistical significance of autism means that the p-value is just over the arbitrary threshold for significance and is interpreted as such. The p-value here (p=0.06) comprises the probability of the observed results to be marginally true (Fisher, 1936). Perezgonzalez (2015) highlighted an important property of Fisher's levels of significance, which is that levels of significance do not need to be rigid around a convenient level of significance of five percent. This line of thought leads to support the conclusion that autism is a marginal predictor of positive treatment outcomes for individuals who receive treatment using the STP.

There are a few factors that may have contributed to this level of significance. First, the sample size (*n*=40) might be considered marginally small. The small sample size could have played a role in the probability of autism being marginal in predicting positive outcomes. The general consensus in the scientific community is that having a large sample size increases the robustness of the statistical analyses (Fischer, 1960; Biau, Kernéis, & Porcher, 2008). Nevertheless, there are particular cases when trials conducted on a small sample are justified, such as early-phase trials with the aim of guiding the conduct of subsequent research (or formulating hypotheses) or, more rarely, for rare diseases with the aim of prospectively conducting meta-analyses (Biau et al.,2008).

Second, according to Kurland et al. (2018), 45% of the sample in this study were diagnosed with autism, which is nearly half the sample size. Christensen, Braun, Baio, Bilder, Charles, Constantino, & Lee (2018) highlight that the prevalence of autism continues to rise and there is a plethora of challenges that individuals diagnosed with autism and their family members face, especially during childhood. Based on the demographic data collected in this research, 55% of families presented at intake needing assistance in caring for their loved ones. Hundreds of papers have highlighted the stresses and strains experienced by parents of children with autism

(Helps, 2016). For instance, some studies have shown that there is a growing rate of divorce among parents of children diagnosed with autism (Karst & Van Hecke, 2012; Higgins, Bailey, & Pearce, 2005). Low state of well-being, low marital satisfaction, low parental self-efficacy, high levels of stress, fatigue, depressive and anxious symptomatology are just some of the many factors that contribute to these increasing rates (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, & Bolt, 2010). With these challenges in mind, caregivers and family members in distress might have been motivated to seek help and have an increased level of investment in their dependent's treatment within the 12-week period in order to obtain a sense of relief from stressors. Half of the sample size having an autism diagnosis as well as more than half of caregivers wanting to alleviate stressors might be factors that contributed to the results of this study being marginally statistically significant.

Furthermore, 85% of the sample had a presenting problem of aggression (physical, verbal, property destruction, or threats). Several researchers, including Bodfish, Symons, Parker, and Lewis (2000) have found that individuals with autism exhibit aggression and more severe self-injurious behavior than matched controls with those with intellectual and developmental disabilities but without autism. Percentage rates such as these lead to support the idea of the drive to invest in alleviating distressing symptoms for not only the client being served but the caregivers as well. This factor might have played a role in the results of this study being marginally statistically significant. Picardi, Gigantesco, Tarolla, Stoppioni, Cerbo, Cremonte, and Nardocci (2018) support this idea and mention that caregivers of individuals diagnosed with autism have greater necessity for vigilant parenting, the need to provide support and accommodations for their child's education, greater investment in healthcare, constant self- and child-advocacy.

Third, over the last several years, significant attention and focus has been placed on autism treatment and research. This increased attention has led to an influx of resources that are geared towards autism treatment. According to Payakachat, Tilford, Kovacs, and Kuhlthau (2012), the increase in the prevalence of autism has led to a demand for improved understanding of the comparative effectiveness of different pharmacologic, behavioral, medical, and alternative treatments for children as well as systems for providing services. Such treatments and resources includes applied behavior therapy (ABA), occupational therapy, speech therapy, sensory integration therapy, the picture exchange communication system (PECS), as well as complementary and alternative treatments (CAM), which include aspects such as chelation (removing heavy metals like lead from the body), biologicals (secretin), body-based systems (deep pressure), and special diets (Levy, 2003). These resources are holistic, systems-based, and cater to multiple avenues of the individual’s life in comparison to the other psychiatric conditions where psychotherapy and psychotropic medication are the most typical intervention provided (Fleming et al., 1996; Harper & Wadsworth, 1993; Kennedy & Meyer, 1998). The diversity in treatment options and resources might have been advantageous and contributed to the secondary level goals in the STP to be achieved for individuals in the autism cohort. According to Kurland et al. (2018), individuals who received treatment using the STP had more services at referral in comparison to individuals receiving care under the START plan. In particular, individuals who had an autism diagnosis received, overall, the highest number of services as compared to other psychiatric conditions.

Finally, the reliability of the caregiver responses obtained from the PSQ to operationalize positive treatment outcomes might be in question. Health outcome measurement in populations of disabled individuals/children is often accomplished by asking the parent/caregiver to report on their perceptions, owing to concerns that the individual/child may not be able to respond reliably. A growing body of literature provides evidence for obtaining health outcome responses, or patient-reported outcomes, directly from the child and such an approach in autism is complicated as children (and adults) may lack a theory of mind that allows them to communicate health outcomes as measured by different instruments (Payakachat et al., 2012). In other words, it is important to recall that these data reflect caregiver responses of their perceptions, not a direct measurement of outcomes. The measurement instrument might not have captured adequately the outcomes of the individual served, perhaps corrupted by the emotional connection of the parent/caregiver which would lead the results to be marginally statistically significant.

Notwithstanding the assertions above, the results from this analysis demonstrate that individuals receiving treatment using the STP reported fewer stressors on average than their START plan counterparts. This decrease in stressors supports the indication of systemic engagement through the use of the STP for addressing specific needs of clients seeking services for managing IDD and co-occurring psychiatric disorders. Empirical evidence elucidating the efficaciousness of the STP is further limited. The pilot study by Kurland et al. (2018), upon which this study is based on, was initially developed to enhance START coordinators' systemic engagement in order to have rapid systems change and decrease emergency service use. The results of Kurland's study did demonstrate promising outcomes in treatment effectiveness even though the validity and reliability of the STP and PSQ were not acquired. In addition, consequently, the results of both represent novel insight into not only the START program, but services rendered to individuals diagnosed with IDD and co-occurring conditions. The results from this study provides additional insight in reference to systemic engagement that should be helpful for program evaluation.

Study Limitations

Research Design

This study was exploratory in nature and it involved the use of historical data from a relatively small sample of clients with IDD and co-occurring mental health issues (*n*=40). Kurland and her colleagues used two different groups that were sampled using the convenient sampling method. These two groups received two different treatment approaches which make it impractical to conduct a correlation analysis. Limitations from convenient sampling make it difficult to state with certainty that the sample is truly representative of all clients diagnosed with IDD and co-occurring mental health issues.

Linear Regression Analysis

The primary limitation of using a linear regression model for data analysis is that when the approach is used in practice, researchers frequently equate correlation coefficients obtained from analysis with causation (Al-Noor & Mohammad, 2013). Correlation coefficients may demonstrate that two variables have a relationship with one another. However, the relationship does not indicate that one variable caused the other. This issue is one of concern when making recommendations for evidence-based practice. In this study, the inability to state causation with certainty may impact the ability of practitioners to use the STP in practice.

Another important limitation of using linear regression is that running separate analyses yields multiple and often differing sets of results. Also, running separate analyses provide no formal statistical means of evaluating how similar or different the results are (Goldwasser & Fitzmaurice, 2006). The final limitation of using linear regression analysis is that it provides no formal means of summarizing effects in a single set of results in cases where the separate analyses yield results that are sufficiently similar (Goldwasser, & Fitzmaurice, 2006).

Chapter V

Summary, Implications, and Recommendations

The purpose of this research was to investigate whether challenging behaviors and psychiatric conditions were predictor variables that led to positive outcomes in the treatment of individuals diagnosed with intellectual and developmental disabilities (IDD) and comorbid mental health conditions when the new treatment protocol, the systemic treatment plan (STP) was in use. The results obtained from this study suggest that autism is the best predictor of positive treatment outcomes when the STP is being used. In addition, even though there is no statistical significance, the results from this study demonstrate that using the STP in treatment led to a decrease in stressors compared to counterparts receiving treatment using only the START plan. An assessment of the results from this study suggests that these outcome measures may not be appropriate for fully evaluating STP or its parent START (systemic, therapeutic, assessment, resources, and treatment) program. In light of the findings, this chapter provides a summary of the entire research along with a consideration of the implications of the results, and recommendations for future research and clinical practice.

Summary

Individuals diagnosed with IDD and comorbid psychiatric disorders represent a uniquely vulnerable population. In addition to facing both physical and mental health challenges associated with IDD, individuals in this population also face a myriad of challenges accessing healthcare services (Singh et al., 2013; Wong et al., 2015). Structural barriers including a lack of well-trained personnel to meet the specific needs of this group coupled with the absence of evidence-based supports to provide treatment represent two significant barriers that can impede the ability of clients with these disorders to acquire effective support services (Singh et al., 2013;

Wong et al., 2015). These issues systemically impact the functioning of the client and further have a profound impact on the client's quality of life (Horovitz et al., 2014; Turygin et al., 2013).

Despite the current challenges that providers face when delivering care for clients with IDD and co-occurring psychiatric disorders, some efforts have been made to ameliorate the gap between theory and practice. In particular, the START program initiated by the University of New Hampshire Institute on Disability has been identified as a comprehensive foundation for delivering structured care for this population (Beasley et al., 2018). While the START program has been nationally recognized, it is currently only implemented in a handful of states across the nation (Center for START Services, Institute on Disability, 2019). Further, empirical evidence validating this model of care is limited. While existing studies do suggest that START may have some important benefits for reducing emergency room use or hospitalization rates for clients by incorporating systemic engagement (Beasley, 2002; Kalb et al., 2016), a comprehensive understanding of how this program works to address the needs of the target population has to be extensively illuminated both in practice and in literature.

The STP was developed and incorporated into the START program to enhance support for clients with IDD and co-occurring psychiatric disorders (Kurland et al., 2018). The theoretical foundations of the STP is rooted in strategic family therapy (SFT) to augment the communication and relational environments that encompass the client seeking care (Kurland et al., 2018; Murray, 2014). Through the application of the STP to the treatment of clients with IDD and comorbid mental/behavioral health issues, it should theoretically be possible to improve communication and relations between the client, caregivers and the provider, leading to a reduction in behavioral symptoms along with concomitant reductions in hospitalization and emergency room utilization rates. Only one study, conducted by Kurland et al. (2018) has been undertaken to assess the implications of the STP. In that study, the authors sought to evaluate the role of systemic engagement on overall goal attainment in individuals with IDD. The results of the research conducted by Kurland et al. (2018) demonstrated promising outcomes with the researchers reporting that clients with IDD receiving treatment using the STP had fewer crisis events, fewer resource center visits/need for respite care, higher levels of goal attainment, and better outcomes when compared with clients that received services using the START plan only.

Unfortunately, the study conducted by Kurland et al. (2018) represented the only evaluation of the STP to date. Given the need to build an evidence-based practice to support treatment for clients with IDD and co-occurring psychiatric disorders, the decision was made to retrospectively review the data collected by Kurland et al. (2018) to determine if there were additional areas in which positive outcomes for clients receiving treatment could be identified. Using the research conducted by Kurland and her colleagues as a foundation for the current study, the decision was made to evaluate Kurland and coworker's data to determine if the STP had a more significant impact on five traits measured through the Aberrant Behavior Checklist (ABC): lethargy, irritability, stereotypy, hyperactivity and inappropriate speech. Data from the ABC were collected by Kurland et al. (2018) at baseline before the initiation of the study and after 12-weeks of treatment. The same information was collected for clients receiving treatment using the START plan. Additionally, evaluations of data collected by Kurland et al. (2018) were made based on pre- and post-assessment scores recorded on the Recent Stressors Questionnaire (RSQ) and with regard to current mental health diagnoses of the individuals sampled.

Based on the linear regression analyses, the results of this study indicated that there were no challenging behaviors that acted as predictors of positive treatment outcomes despite the theoretical support for using the STP to enhance positive behavioral outcomes. However, the results did demonstrate that individuals receiving treatment under the STP reported fewer stressors on average following 12-weeks of implementation. Further, when evaluating positive treatment outcomes, only clients with autism experienced marginally statistically significant differences in outcomes after 12-weeks of treatment ($B = .47$, $t = 1.98$, $p = .06$, Table 20). The results suggest that autistic clients work well using the STP in treatment in comparison to other psychiatric disorders. It may be possible to argue that the structure of both the STP and the START program are geared toward significantly changing the behavior of the client through the use of systemic engagement. Research concerning these interventions seems to suggest that both START and the STP change service dynamics to enhance the coordination of care as well as the engagement of providers in the treatment of the client (Kurland et al., 2018; Beasley et al., 2016; Beasley et al., 2018; Kalb et al., 2016). What is important to note when reviewing these findings is that the true mechanisms by which START and the STP work to improve the lives of clients with intellectual and developmental disabilities and co-occurring mental health issues through systemic engagement have not been fully delineated. Thus, while the findings do not indicate significant changes in positive treatment outcomes for either approach, systemic engagement may be the mechanism of action by which START and the STP work to improve broader service utilization outcomes for the client: i.e., reduced hospitalization and emergency room utilization rates.

Implications

The purpose of this study was to investigate the key predictors of treatment outcomes among individuals diagnosed with IDD and co-occurring mental/behavioral health conditions. The researcher sought to explore whether challenging behaviors and psychiatric conditions were predictive variables that led to positive outcomes in the treatment of this population in order to further assist clinicians and programs catering to this population to identify which individual factors yield positive outcomes in treatment. In addition, other aims were to help decrease inappropriate inpatient hospitalization and emergency room visits, to help clinicians have a better understanding of individual, clinical and treatment needs to improve service outcomes for the IDD population, to help other stakeholders who are involved directly or indirectly in the care of individuals diagnosed with IDD to understand issues that affect this population, and finally to understand the systems linkage approach as an effective strategy to treat individuals in this population.

Although the findings from this study do not definitively demonstrate that the STP significantly influences positive treatment outcomes for the target population, the findings do provide additional insight into the abilities of the START program and the STP to foster further exploration of how these programs work. As previously noted, existing research on START and the STP have demonstrated some positive benefits for using these approaches in practice. The positive outcomes obtained from START and the STP may be the result of better coordination of care and more proactive efforts to identify and address problems before they require escalation to the emergency room or to inpatient care. When looking at these data from this perspective, it is possible to see a broad range of implications for building practice with the use of systemic engagement.

Implications for IDD Programs

The juxtaposition of the results from this study into the existing empirical literature on START and the STP demonstrate the need to reconceptualize how interventions function to meet the needs of clients with IDD and co-occurring mental health issues. Reconceptualization of how the program supports influence outcomes for individuals in this population needs to occur and a way to look at it is to shift the focus of program evaluation from individual client outcomes only, to a combination of the individual client and engagement of stakeholders within their system of care. START and the STP both provide a framework for providers in the system of care to change how service is conceptualized and operationalized in practice. These changes represent the most important components of systemic approaches, leading to better macro-outcomes without necessarily focusing on individual changes in client behavior. The implications of making this change in practice are significant and can be integrated into other programs designed to provide care for the target population to enhance treatment outcomes.

A critical review of the literature on the START program from the Center for START Services, Institute on Disability (2019) indicates that the model has been in use for over 30 years and at present, there are only 10 states in which START services are located: New Hampshire, New York, Maryland, North Carolina, Arkansas, Iowa, Oklahoma, Texas, Colorado, and Washington. The program utilizes systemic engagement through person-centered practices, continuous training, and skill-building of practitioners within the community, active participation of stakeholders, collection and analysis of data, and ongoing modification of services in response to individual and trend-related outcomes, along with the changing needs of the system (Beasley et al., 2016). This systems linkage approach enables vulnerable groups to overcome disparities in access to mental health care (Charlot & Beasley, 2013). Through this approach, clients have more extensive access to preventative supports that will improve service outcomes and reduce the need for emergency services and hospitalization (Beasley et al., 2016). Beasley et al. (2016) argue that the primary benefit of START is that it works to fill gaps in the current continuum of care, leading to higher levels of engagement for medical, mental health, and other service providers. The program therefore increases the capacity of the community to serve individuals with IDD and co-occurring mental health disorders (Beasley et al., 2016).

Similar arguments can be made regarding the STP. A closer examination of the theoretical foundations for this tool indicates that systemic treatment addresses the larger context in which problematic behaviors occur (Kurland et al., 2018; Beasley et al., 2018). The STP, which was shown to lead to a reduction in problematic behavior is predicated on aspects of the strategic family therapy model in which relational and communicative environments are identified as having a direct impact on the development of problematic behavior (Kurland et al., 2018; Murray, 2014). When reviewing data examining the application of the STP and the START plan in practice, the START coordinator is credited to playing a crucial role with regard to systemic engagement in team communication and coordination as well as outreach (Kurland et al., 2018; Beasley et al., 2016).

There is a growing body of evidence demonstrating favorable outcomes of systemic engagement in decreasing challenging behaviors with people diagnosed with IDD. These strategies are both preventative and integrative and acts as a functional alternative to the practices that are commonly used with this population. Currently, there is a lack of coordinated mental health supports that are meant to meet the needs of individuals with IDD (Whittle et al., 2018). Service delivery systems continue to operate in silos where the medical, mental health, psychological, and social supports provided to individuals with IDD are not integrated (Beasley et al., 2016), significantly limiting the ability of clients and families to access needed care. In addition, psychotropic medication is the most typical intervention provided for challenging behaviors (Fleming et al., 1996; Harper & Wadsworth, 1993; Kennedy & Meyer, 1998). What is evident is that when it comes to providing effective, evidence-based support for individuals with

IDD and comorbid mental health diagnoses, there are unmet systemic needs that must be addressed to augment outcomes for those requiring these services. Some programs that have utilized systemic engagement through integrated service delivery in the United Kingdom and Australia (Grindle et al., 2008; Koritsas et al., 2008). These programs have been effective in using systemic engagement based on the specific needs of their programs to decrease challenging behaviors with people diagnosed with IDD. The common factors between START and other programs incorporating systemic engagement in practice is that there is a focus on improvement of quality of life of the individual, improvement of access to services, identification of gaps in the system, and improving competencies for all including self-advocates, families, direct support staff, and clinically trained professionals. Programs catering to this population can incorporate practices used by START and the STP to enhance treatment outcomes by:

I. Identifying a clinician/clinicians within the program who will have a role similar to the START coordinator.

II. Identifying systemic goals similar to ones that were outlined in the STP and have all stakeholders participate or be involved in working through the objectives.

III. Utilization of the systemic engagement concepts that were used/adapted by the START coordinator in the study conducted by Kurland et al. (2018).

IV. Engage with clients, caregivers and first responders during crisis episodes to prevent unnecessary visits to the emergency room or inpatient hospitalization.

Reframing how programs catering to this population traditionally provide care will provide a useful foundation upon which individual or macro-level changes will occur in treatment outcomes, particularly with individuals diagnosed with autism.

The prevalence of autism is on the rise (Christensen et al., 2018). In this study, almost half of the sample had a diagnosis of autism. Research has shown that caregivers of individuals diagnosed with autism have a greater necessity for vigilant parenting, the need to provide support and accommodations for their child's education, greater investment in healthcare, as well as constant self- and child-advocacy (Picardi et al., 2018). What this shows is that there is already an investment by stakeholders to obtain positive outcomes and programs need to adjust to the need by utilizing approaches such as systemic engagement in care. The results obtained from this study suggest that autism is the best predictor of positive treatment outcomes when the STP is being used. Clearly, successful interventions for autism have the potential to greatly affect health outcomes and can have extensive economic benefits (Payakachat et al., 2012).

Implications for Marriage and Family Therapists

Tackling autism is not just a challenge that is left for social service agencies that cater to individuals diagnosed with IDD, but for systemic therapists as well (Stoika, 2019). Marriage and family therapy clinicians, as systemic therapists, do have a unique contribution to make to this vulnerable population. Unfortunately, some family therapists may feel daunted by, or somehow not authorized to work with this population since historically, individuals diagnosed with autism have been receiving care in the developmental disability community (Solomon, & Chung, 2012). This discouragement is also due in part to Freud (1904), who ascertained that individuals with cognitive deficits do not benefit from psychotherapy. This idea is troubling, if not downright antiquated, in light of research which does suggest that mental health counseling can be useful for improving the function and quality of life for individuals in this population (Brown et al., 2013; Holwerda et al., 2013).

Nonetheless, there is a large group of family therapists who work with people of all ages who have autism (Helps, 2016). While the concept of systemic engagement in counseling has been operationalized through the development of approaches such as the SFT, the common practice that has been employed by marriage and family therapists to treat families with these challenges are models such as solution-focused brief therapy, narrative therapy and structural family therapy (Brockman, Hussain, Sanchez, & Turns, 2016; Cashin, Browne, Bradbury, & Mulder, 2013; Goepfert, Mulé, von Hahn, Visco, & Siegel, 2015; Tilsen, Russell, & Nylund, 2005; Simon, 2004; Stoddart, 1999; Olinger, 2010). The defining characteristics are that there is a focus on family communication patterns that serve to maintain the problem, treatment goals that derive from the problem/symptoms are presented, a belief that change can be rapid and does not require insight into the causes of the problem, and finally, the use of resistance to promote change by applying strategic interventions (Piercy et al., 1996). Family therapists are usually curious about the psychiatric diagnostic labels that families bring with them to therapy and they typically work to deconstruct the meaning of *this* label to *this* person in *this* family and at *this* point in the family life cycle (Helps, 2016).

Marriage and family therapists are encouraged to employ systemic treatment plans that are multifaceted just like the STP to enhance treatment outcomes not only for the individual diagnosed with autism, but for the family system at large. According to Solomon and Chung (2012), families of individuals diagnosed with autism face problems in multiple domains, including accessing supportive/therapeutic/educational services, balancing work and family, and dealing with powerful feelings. An integrative approach allows family therapists to flexibly address interrelated problems or constraints (Solomon & Chung, 2012). The implication is that family therapists would need to place an emphasis on engagement with stakeholders and become aware of other facets of the client's system of care.

In order to put this concept into practical perspective, the non-profit organization Talking About Curing Autism (TACA) based in California, utilizes the metaphor of a three-legged stool to represent the multiple domains that parents need to address (Solomon & Chung, 2012). The first leg represents traditional therapies like applied behavior analysis (ABA), relationship development intervention (RDI), the developmental, individual difference, relationship-based model (DIR/Floor time), speech therapy, occupation therapy, and educational supports. The second leg represents biomedical interventions like the Autism Research Institute (ARI) approach (Solomon & Chung, 2012). The third leg represents emotional support for the family and without attention to any one of these three "legs," the family system and/or the child with autism becomes, or remains, out of balance (Solomon & Chung, 2012). Clearly, the leg which is most relevant to family therapists is emotional support for the family, but family therapists should have some understanding of the other two legs.

When marriage and family therapists create comprehensive treatment plans, the family being treated moves from the vicious cycle of experiencing crisis episodes towards coping and hence, improved well-being. Neely, Amatea, Echevarria-Doan, and Tannen (2012) highlight the role of the marriage and family therapist as essential, noting that the therapist acts as a mediator and advocate for the family as they navigate the different systems of care with which the client with autism may be associated. Mediation and advocacy are similar roles carried by coordinators within the START program. Other researchers such as Ramisch (2012), highlight the use of the ABCX model as a treatment technique to be used with families of children diagnosed with autism. Ramisch (2012) states that marriage and family therapists working with couples who have children with autism need to asses and develop treatment plans that address family stressors and needed resources as well as incorporating functional coping strategies into treatment. In addition, Bradford (2010) suggests that family therapists should provide education about the condition to parents, guiding families towards additional educational resources, providing therapy to family members regarding any grief or confusion regarding the diagnosis, and the potential stressors of living with a family member with a life-long disability. For over 30 years now, marriage and family therapists have advocated for systemic treatment planning when working with families of children with autism (Harris, 1983). Family therapists are well-suited to help caregivers and individuals diagnosed with not only autism, but with intellectual and developmental disabilities and other co-occurring psychiatric conditions.

The results from this study, especially when reviewed in combination with existing research, have marked implications for changing the way that programs are structured in addition to changing the way in which providers approach client care. Altering these dimensions of service provision provides a pathway to obtaining positive outcomes in treatment as well as highlighting the unique perspective of the role of not only the marriage and family therapist, but the different programs in the community that cater to this population.

Recommendations

The findings from this study provide a broad foundation for identifying recommendations for future research and clinical practice. First, the sample size for this study was relatively small (*n*=40). There is an impetus to expand the sample size with the potential to include clients from more than one START site. Preliminary evidence on the use of the STP provided by Kurland et al. (2018), does suggest that this intervention can provide important supports for augmenting outcomes for clients with IDD and comorbid psychiatric disorders. Consequently, expanding the sample to validate further the findings reported by Kurland et al. (2018) will be imperative to expanding the evidence-base for this tool in practice. Methodologically rigorous studies including randomized controlled trials, would be recommended to help ensure that the findings represent a reliable assessment of the program. Such studies might lead to a shift of the results from being marginally statistically significant to being statistically significant.

Second, while further validating the STP as an important tool, qualitative research including program reviews to track differences in the START plan and the STP, and other tools designed to meet the needs of this population may be warranted. This type of research should essentially provide a step-by-step guide to understanding how the START plan and the STP work in comparison. This information may be instrumental in changing the way that providers view their roles in coordinating care for the client. Through this type of research, it may be possible to markedly shift the role or actions of service providers such that the supports and level of care provided to the client are augmented, leading to reductions in the need for emergency care or inpatient hospitalization use.

Third, additional research needs to be conducted on therapeutic frameworks that work best with individuals diagnosed with IDD and co-occurring psychiatric disorders. Exploration of contemporary systemic practices such as the use of social-constructionism and dialogical approaches for individuals and families would be illuminating to assist marriage and family therapists successfully cater to this population. Exploring these recommendations might lead future researchers to identify new/additional predictor variables of positive treatment outcomes.

References

Abbott, K. V., Barton, F. B., Terhorst, L., & Shembel, A. (2016). Retrospective studies: A fresh look. *American Journal of Speech-Language Pathology, 25*(2), 1-7. https://dx.doi.org/10.1044/2016_AJSLP-16-0025

Allen, D., Langthorne, P., Tonge, B., Emerson, E., McGill, P., Fletcher, R., & Kennedy, C. (2013). Towards the prevention of behavioral and psychiatric disorders in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *26*(6), 501-514.

Al-Noor, N. H., & Mohammad, A. A. (2013). Model of robust regression with parametric and nonparametric methods. *Mathematical Theory and Modeling, 3*(5), 27-39.

Altoè, G., Bertoldo, G., Callegher, C. Z., Toffalini, E., Calcagnì, A., Finos, L., & Pastore, M. (2020). Enhancing Statistical Inference in Psychological Research via Prospective and Retrospective Design Analysis. *Frontiers in Psychology*, *10*. https://doi.org/10.3389/fpsyg.2019.02893

Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities, 51*(5), 360-375. https://dx.doi.org/10.1352/1934-9556-51.5.360

Aman, M. G., & Singh, N. N. (1986). *Aberrant behavior checklist manual.* Slosson Educational Publishing.

Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisarak, J., & Larson, S. (2013). The state of science and wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 51*(5), 385-398.

https://dx.doi.org/10.1352/1934-9556-51.5.385

Anderson, L. T., & Ernst, M. (1994). Self-injury in Lesch-Nyhan disease. *Journal of Autism and Developmental Disorders, 24*, 67–81.

Barnighausen, T., Rottingen, J., Rockers, P., Shemilt, I., & Tugwell, P. (2017). Quasi-experimental study designs series—paper 1: Introduction. *Journal of Clinical Epidemiology, 89*(1), 4-11. https://dx.doi.org/10.1016/j.jclinepi.2017.02.020

Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-centered active support-increasing choice, promoting independence and reducing challenging behavior. *Journal of Applied Research in Intellectual Disabilities, 25*, 291–307.

Beasley, J. B. (2002). Trends in coordinated and planned mental health service use by people with dual diagnosis. In J. Jacobson & R. Fletcher (Eds.), *Contemporary dual diagnosis: MH/MR service models, volume II: Partial and supportive services* (pp. 35-51). NADD.

Beasley, J. B., Klein, A., & Weigle, K. (2016). Diagnostic, treatment, and service considerations to address challenging behavior: A model program for integrated service delivery. In: I. L. Rubin, J. Merrick, D. E., Greydanus, & D. R. Patel (Eds.), *Health care for people with intellectual and developmental disabilities across the lifespan*, (pp. 1629-1644). Springer Publishing.

Beasley, J. B., Kalb, L., & Klein, A. (2018). Improving mental health outcomes for individuals with intellectual disability through the Iowa START (I-START) program. *Journal of Mental Health Research in Intellectual Disabilities, 11*(4), 287-300. https://dx.doi.org/10.1080/19315864.2018.1504362

Bertalanffy, L. V. (1949). *Zu einer allgemeinen systemlehre. Biologia generalis, 19*(1), 114–129.

Bertalanffy, L. V. (1968). *General system theory: Foundations, development, applications.*

George Braziller.

Biau, D. J., Kernéis, S., & Porcher, R. (2008). Statistics in brief: The importance of sample size in the planning and interpretation of medical research. *Clinical Orthopaedics and Related Research*, *466*(9), 2282–2288. https://dx.doi.org/10..1007/s11999-008-0346-9

Bodfish J. W., Symons F. J., Parker D. E., & Lewis M. H. (2000). Varieties of repetitive behavior in autism: Comparisons to mental retardation. *Journal of Autism and Developmental Disorders 30***,** 237–43.

Boer, H., Holland, A., Whittingtom, J., Butler, J., Webb, T., & Clarke, D. (2002). Psychotic illness in people with Prader Willi syndrome due to chromosome 15 maternal uniparental disomy. *The Lancet, 359*, 135–136.

Bradford, K. (2010). Brief education about autism spectrum disorders for family therapists. *Journal of Family Psychotherapy*, *21*(3), 161-179.

Brockman M., Hussain K., Sanchez B., Turns B. (2016). Managing child behavior problems in children with autism spectrum disorders: Utilizing structural and solution focused therapy with primary caregivers. *The American Journal of Family Therapy, 44*(1), 1-10.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Harvard University Press.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development. *Developmental Psychology, 22,* 723–742.

Brown, J. F., Brown, M. Z., & Dibiasio, P. (2013). Treating individuals with intellectual disabilities and challenging behaviors with adapted dialectical behavior therapy. *Journal of Mental Health Research in Intellectual Disabilities, 6*(4), 280-303. https://dx.doi.org/10.1080/19315864.2012.700684

Cashin, A., Browne, G., Bradbury, J., & Mulder, A. (2013). The effectiveness of narrative therapy with young people with autism. *Journal of Child and Adolescent Psychiatric Nursing*, *26*(1), 32-41.

Center for START Services, Institute on Disability. (2019). *START locations*. https://www.centerforstartservices.org/locations

Chadwick, O., Kusel, Y., & Cuddy, M. (2008). Factors associated with the risk of behavior problems in adolescents with severe intellectual disabilities. *Journal of Intellectual Disability Research, 52*, 864–876.

Charlot, L. (2005). Use of behavioral equivalents for symptoms of mood disorder. In P. Sturmey (Ed.), *Mood disorders in people with mental retardation* (pp. 17–45). NADD.

Charlot, L., Abend, S., Ravin, P., Mastis, R. K., Hunt, A., & Deutsch, C. (2011). Non-psychiatric health problems among psychiatric inpatients with intellectual disabilities. *Journal of Intellectual Disabilities Research, 55*(2), 199-209. https://dx.doi.org/10.1111/j.1365-2788.2010.01294.x

Charlot, L., & Beasley, J. B. (2013). Intellectual disabilities and mental health: United States-based research. *Journal of Mental Health Research in Intellectual Disabilities, 6*, 74-105.

Christensen D. L., Braun K. V. N., Baio J., Bilder D., Charles J., Constantino J. N., Lee L. C. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years: Autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summaries, 65*(13), 1.

Collins, M. S. R., & Cornish, K. (2002). A survey of the prevalence of stereotypy, self-injury, and aggression in children and young adults with Cri du Chat syndrome. *Journal of Intellectual Disability Research, 46*, 133–140.

Cooper, S. A., Melville, C. A., & Einfeld, S. L. (2003). Psychiatric diagnosis, intellectual disabilities and diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation (DC-LD). *Journal of Intellectual Disability Research, 47*, 3–15.

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Sage.

Dimitriadou, I., & Kartasidou, L. (2017). The role of support systems for independence of individuals with intellectual disabilities. *International Journal of Pedagogy and Curriculum, 24*(3), 39-48. https://dx.doi.org/10.18848/2327-7963/cgp/v24i03/39-48

Doyle, C., & Mitchell, D. (2003). PTSD and people with learning disabilities: A literature-based discussion. *Journal of Learning Disabilities, 7*(1), 23–33.

Durbin, A., Sirotich, F., Lunsky, Y., & Durbin, J. (2017). Unmet needs of adults in community mental health care with and without intellectual and developmental disabilities: A cross-sectional study. *Community Mental Health Journal, 53*, 15-26. https://dx.doi.org/10.1007/s10597-015-9961-6

Dykacz, J.M. (2005). Prospective and Retrospective Studies. *Encyclopedia of Statistics in Behavioral Science* (eds B.S. Everitt and D.C. Howell). https://dx.doi.org/10.1002/0470013192.bsa509

Elliott, A. C., & Woodward, W. A. (2007). Statistical analysis quick reference guidebook: With SPSS examples. Sage Publications.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196,* 129–136

Fahs, J., Weigle, K. L., Smith, K., & Benson, M. A. (2007). *The effects of interdisciplinary crisis* *prevention and intervention services on persons with dual diagnoses: Cost effectiveness and clinical outcomes.* Symposium presented at the 24th Annual Convention of the NADD, Atlanta, GA.

Fisher, R. A. (1936). Design of experiments. *British Medical Journal*, *1*(3923), 554-554.

Fleming, I., Caine, A., Ahmed, S., & Smith, S. (1996). Aspects of the use of psychoactive medication among people with intellectual disabilities who have been resettled from long-stay hospitals into dispersed housing. *Journal of Applied Research in Intellectual Disabilities, 9* (3), 194–205.

Freud, S. (1904). *On Psychotherapy*, Vol. XVI. Hogarth Publications.

Gall, M. D., Gall, J. P., & Borg, W. R. (2006). *Educational research: An introduction* (8th ed.). Allyn and Bacon Publications.

Gelman, A. and Carlin, J. (2014). Beyond power calculations: Assessing type s (sign) and type m (magnitude) errors. *Perspectives on Psychological Science*, 9(6):641–651.

Ghasemi, A., & Zahediasl, S. (2012). Normality tests for statistical analysis: a guide for non-statisticians. *International journal of endocrinology and metabolism*, *10*(2), 486–489. https://doi.org/10.5812/ijem.3505

Goepfert, E., Mulé, C., von Hahn, E., Visco, Z., & Siegel, M. (2015). Family system interventions for families of children with autism spectrum disorder. *Child and Adolescent Psychiatric Clinics*, *24*(3), 571-583.

Goldwasser, M. A., & Fitzmaurice, G. M. (2006). Multivariate linear regression analysis of childhood psychopathology using multiple informant data. *International Journal of Methods in Psychiatric Research, 10*(1):1-10.

Grindle, C., Kovshoff, H., Hastings, R., & Remington, B. (2008). Parents' experiences of home-based applied behavior analysis programs for young people with autism. *Journal of Autism and Developmental Disorders, 39*, 42-56. https://dx.doi.org/10.1007/s10803-008-0597-z

Hanratty, J., Livingstone, N., Robalino, S., Terwee, C. B., Gold, M., Oono, I. P., & McConachie, H. (2015). Systematic review of the measurement properties of tools used to measure behavior problems in young children with autism. *PLoS ONE, 10*(12), 1-22. https://dx.doi.org/10.1371/journal.pone.0144649

Harper, D. C., & Wadsworth, J. S. (1993). Behavioral problems and medication utilization. *Mental Retardation, 31*(2), 97–105.

Harris, S. L. (1983). A family systems approach to behavioral training with parents of autistic children. *Child & Family Behavior Therapy*, *4*(1), 21-35.

Hartley S. L., Barker E. T., Seltzer M. M., Floyd F., Greenberg J., Orsmond G., & Bolt D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24*(4), 449.

Harvey, S. T., Boer, D., Meyer, L. H., & Evans, I. M. (2009). Updating a meta-analysis of intervention research with challenging behavior: Treatment validity and standards of practice. *Journal of Intellectual & Developmental Disability, 34*, 67–80.

Hatton, C., & Emerson, E. (2004). The relationship between life events and psychopathology amongst children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 109–17.

Heale, R., & Twycross, A. (2015). Validity and reliability in quantitative studies. *Evidence-Based Nursing, 18*(3), 66-67. https://dx.doi.org/10.1136/eb-2015-102129

Heller, T., Fischer, D., Marks, B., & Hsieh, K. (2014). Interventions to promote health: Crossing networks of intellectual and developmental disabilities and aging. *Disability and Health Journal, 7*(Suppl 1), S24-32. https://dx.doi.org/10.1016/j.dhjo.2013.06.001

Helps, S. (2016). Systemic psychotherapy with families where someone has an autism spectrum condition. *NeuroRehabilitation*, *38*(3), 223–230. https://dx.doi.org/10.3233/NRE-161314

Hemmings, C. P., Gravestock, S., Pickard, M., & Bouras, N. (2006). Psychiatric symptoms and problem behavior in people with intellectual disabilities, *Journal of Intellectual Disability Research, 50*: 269–76.

Hewitt, A., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental Disabilities, 51*(5), 349-359. https://dx.doi.org/10.1352/1934-9556-51.5.349

Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism, 9*(2), 125–137. https://dx.doi.org/10.1177/1362361305051403

Holland, A. J. (1999). Psychiatry and mental retardation. *International Review of Psychiatry 11*, 76–82.

Holwerda, A., van der Klink, J. J. L., de Boer, M. R., Groothoff, J. W., & Brouwer, S. (2013). Predictors of work participation of young adults with mild intellectual disabilities. *Research in Developmental Disabilities, 34*(6), 1982-1990. https://dx.doi.org/10.1016/j.ridd.2013.03.018

Horner, R. H., Vaughn, B. J., Day, H. M., & William, A. (1996). The relationship between setting events and problem behavior: Expanding our understanding of behavioral support. In L. K.Koegel, R. L.Koegel, & G. Dunlap (Eds.), *Positive behavioral support: Including* *people with difficult behavior in the community* (pp. 476-491). Brookes Publishing.

Horovitz, M., Shear, S., Mancini, L. M., & Pellerito, V. M. (2014). The relationship between axis I psychopathology and quality of life in adults with mild to moderate intellectual disability. *Research in Developmental Disabilities, 35*(1), 137-143. https://dx.doi.org/10.1016/j.ridd.2013.10.014

Howell, D. C. (2010). *Statistical methods for psychology*. Thomson Wadsworth Publishing.

Hustyi, K. M., Hall, S. S., Jo, B., Lightbody, A. A., & Reiss, A. L. (2014). Longitudinal trajectories of aberrant behavior in Fragile X syndrome. *Research in Developmental Disabilities, 35*(11), 2691-2701. https://dx.doi.org/10.1016/j.ridd.2014.07.003

IBM Corp. (Released 2017). IBM SPSS Statistics for Macintosh, Version 25.0. IBM Corp.

Jones, M., Edwards, I., & Gifford, L. (2002). Conceptual models for implementing biopsychosocial theory in clinical practice. *Manual Therapy*. (7) 2–9.

Kaat, A. J., Lecavalier, L., & Aman, M. G. (2014). Validity of the aberrant behavior checklist in children with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 44*, 1103-1116. https://dx.doi.org/10.1007/s10803-013-1970-0

Kalb, L. G., Beasley, J., Caoili, A., & Klein, A. (2019). Improvement in mental health outcomes and caregiver service experiences associated with the START program. *American Journal on Intellectual and Developmental Disabilities*, *124*(1), 25-34. https://dx.doi.org/10.1352/1944-7558-124.1.25

Kalb, L. G., Beasley, J., Klein, A., Hinton, J., & Charlot, L. (2016). Psychiatric hospitalization among individuals with intellectual disability referred to the START crisis intervention and prevention program. *Journal of Intellectual Disability Research, 60*(12), 1153-1164. https://dx.doi.org/10.1111/jir.12330

Kalb, L. G., Stuart, E. A., Mandell, D. S., Olfson, M., & Vasa, R. A. (2017). Management of mental health crises among youths without ASD: A national survey of child psychiatrists. *Psychiatric Services, 68*, 1039-1045. https://dx.doi.org/10.1176/appi.ps.201600332

Karst J. S., Van Hecke A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review, 15*(3), 247-277.

Kennedy, C. H., & Meyer, K. A. (1998). The use of psychotropic medication for people with severe disabilities and challenging behavior: Current status and future directions. *Journal of the Association for Persons with Severe Handicaps, 23*, 83–97.

Koritsas, S., Iacono, T., Hamilton, D., & Leighton, D. (2008). The effect of active support training on engagement, opportunities for choice, challenging behavior and support needs. *Journal of Intellectual and Developmental Disability, 33,* 247–256.

Koslowski, N., Klein, K., Arnold, K., Kosters, M., Schutzwohl, M., Salize, H. J., & Puschner, B. (2016). Effectiveness of interventions for adults with mild to moderate intellectual disabilities and mental health problems: Systematic review and meta-analysis. *British Journal of Psychiatry, 209*(2), 469-474. https://dx.doi.org/10.1192/bjp.bp.114.162313

Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*(1), 70–82.

Kurland, L., Wasonga, J., Bednar, H., Broome, K., Patterson, C., & Wilcox, M. (2018, May). *Enhancing outcomes and systemic engagement through goal-setting.* Poster presented at the START National Training Institute, Boston, MA. https://www.centerforstartservices.org/2018-snti-research-posters

Kurtz, P. F., Chin, M. D., Huete, J. M., Tarbox, R. S. F., O'Connor, J. T., Paclawskyj, T. R., & Rush, K. S. (2003). Functional analysis and treatment of self-injurious behavior in young children: A summary of 30 cases. *Journal of Applied Behavior Analysis, 36*, 205–219.

Lecavalier, L., Smith, T., Johnson, C., Bearss, K., Swiezy, N., Aman, M. G., & Scahill, L. (2017). Moderators of parent training for disruptive behaviors in young children with autism spectrum disorders. *Journal of Abnormal Child Psychology, 45*, 1235-1245. https://dx.doi.org/10.1007/s10802-016-0233-x

Levy, S. (2003). Complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental and Behavioral Pediatrics, 24,* 418-423.

Lowe, K., Jones, E., Allen, D., Davies, D., James, W., Doyle, T., & Moore, K. (2007). Staff training in positive behavior support: Impact on attitudes and knowledge. *Journal of Applied Research in Intellectual Disabilities, 20*, 30–40.

Lunsky, Y., & Benson, B. A. (2001). Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability. *Journal of Intellectual Disability Research, 45*, 106–114.

Man, J., Kangas, M., Trollor, J., & Sweller, N. (2017). Clinical competencies and training needs of psychologists working with adults with intellectual disability and comorbid mental ill health. *Clinical Psychologist, 21*(3), 206-214. https://dx.doi.org/10.1111/cp.12092

Matson, J. L., & Williams, L. W. (2014). The making of a field: The development of comorbid psychopathology research for persons with intellectual disabilities and autism. *Research in Developmental Disabilities, 35*, 234-238. https://dx.doi.org/10.1016/j.ridd.2013.09.043

McClintock, K., & Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviors in people with intellectual disabilities: A meta-analytic study. *Journal of Intellectual Disability Research*, *47*, 405-16. https://dx.doi.org/10.1046/j.1365-2788.2003.00517.x.

McDermott, S., Royer, J., Cope, T., Lindgren, S., Momany, E., Lee, J. C., Armour, B. S. (2018). Using medicaid data to characterize persons with intellectual and developmental disabilities in five U.S. states. *American Journal of Intellectual and Developmental Disabilities, 123*(4), 371-381. https://dx.doi.org/10.1352/1944-7558-123.4.371

McGillivray, J. A., & McCabe, M. P. (2007). Early detection of depression and associated risk factors in adults with mild ⁄ moderate intellectual disability. *Research in Developmental Disabilities 28*, 59–70.

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation* (4th ed.). Jossey-Bass Publications.

Mevissen, L., Lievegoed, R., & De Jongh, A. (2011). EMDR treatment in people with mild ID and PTSD: 4 cases. *Psychiatric Quarterly*, *82*(1), 43-57.

Morisse, F., Vandemaele, E., Claes, C., Claes, L., & Vandevelde, S. (2013). Quality of life in persons with intellectual disabilities and mental health problems: An explorative study. *Scientific World Journal, 1*, 1-8. https://dx.doi.org/10.1155/2013/491918

Murray, S. B. (2014). A case of strategic couples therapy in adult anorexia nervosa: The importance of symptoms in context. *Contemporary Family Therapy, 36*, 392-397. https://dx.doi.org/10.1007/s10591-014-9301-y

National Association of State Directors of Developmental Disability Services. (2013). *Data on the estimated number of people with IDD by state*. http://www.nasddds.org/uploads/documents/University_of_Minnesota_Data_on_the_Esti mated_Number_of_People_with_IDD_by_State.pdf

Navarro, F., Pearson, D. A., Fatheree, N., Mansour, R., Hasjmi, S. S., & Rhoads, J. M. (2014). Are ‘leaky gut’ and behavior associated with gluten and dairy containing diet in children with autism spectrum disorders? *Nutritional Neuroscience, 18*(4), 177-185. https://dx.doi.org/10.1179/1476830514Y.0000000110

Neely J., Amatea E. S., Echevarria-Doan S., Tannen T. (2012). Working with families living with autism: Potential contributions of marriage and family therapists. *Journal of Marital and Family Therapy, 38*, 211-226.

Nichols, M. P., & Schwartz, R. C. (1998). *Family therapy: Concepts and methods* (4th ed.). Allyn & Bacon Publications.

Olinger, C. (2010). Privileging insider-knowledges in the world of autism. *International Journal of Narrative Therapy & Community Work*, *2010*(2), 37.

Pallant, J. (2007). SPSS survival manual: A step by step guide to data analysis using SPSS for windows. (3rd ed.). McGraw Hill Publications.

Parke, R. D. (2017). Family psychology: Past and future reflections on the field. *Journal of Family Psychology, 31*(3), 257-260. https://doi.org/10.1037/fam0000318

Payakachat, N., Tilford, J. M., Kovacs, E., & Kuhlthau, K. (2012). Autism spectrum disorders: a review of measures for clinical, health services and cost-effectiveness applications. *Expert Review of Pharmacoeconomics & Outcomes Research*, *12*(4), 485–503. https://dx.doi.org/10.1586/erp.12.29

Pedhazur, E. J. (1982). *Multiple regression in behavioral research.* Rinehart & Winston Publications.

Perezgonzalez J. D. (2015). Fisher, Neyman-Pearson or NHST? A tutorial for teaching data testing. *Frontiers in Psychology*, *6*, 223. https://dx.doi.org/10.3389/fpsyg.2015.00223

Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Nardocci, F. (2018). Parental burden and its correlates in families of children with autism spectrum disorder: A multicentre study with two comparison groups. *Clinical Practice and Epidemiology in Mental Health: CP & EMH*, *14*, 143–176. https://dx.doi.org/10.2174/1745017901814010143

Piercy, F. P., Sprenkle, D. H., & Wetchler, J. L. (1996). *Family therapy sourcebook.* Guilford Press.

Ramisch J. (2012). Marriage and family therapists working with couples who have children with autism. *Journal of Marital and Family Therapy, 38*(2), 305-316.

Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency*, *86*, 567–574.

Richman, D. M., Barnard-Brak, L., Bosch, A., Thompson, S., Grubb, L., & Abby, L. (2013). Predictors of self-injurious behavior exhibited by individuals with autism spectrum disorder. *Journal of Intellectual Disability Research, 57*(5), 429-439. https://dx.doi.org/10.1111/j.1365-2788.2012.01628.x

Rosen, W., & Burchard, N. (1990). Community activities and social support networks: A social comparison of adults with and adults without mental retardation. *Education & Training in Mental Retardation, 25*, 193-204.

Ross, J., Marcell, J., Williams, P., & Carlson, D. (2013). Postsecondary education employment and independent living outcomes of persons with autism and intellectual disability. *Journal of Postsecondary Education and Disability, 26*(4), 337-351.

Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and

Language Therapists (2007) *Challenging behaviour: A unified approach* (CR144). http://www.rcpsych.ac.uk/files/pdfversion/cr144.pdf

Salkind, N. J. (2010). Encyclopedia of research design. SAGE Publications, Inc. https://doi.org/10.4135/9781412961288

Sandhu, D., & Tomlins, R. (2017). Clinical needs and outcomes of adults with intellectual disabilities accessing an inpatient assessment and treatment services and the implication for development of community services. *Journal of Intellectual Disabilities, 21*(1), 5-19. https://dx.doi.org/10.1177/1744629515615267

Schalock, R. L., & Luckasson, R. (2013). What's at stake in the lives of people with intellectual disability? Part I: The power of naming, defining, diagnosing, classifying, and planning supports. *Intellectual and Developmental Disabilities, 51*(2), 86-93. https://dx.doi.org/10.1352/1934-9556-51.2.086

Schmidt, J. D., Rooker, G. W., Fodstad, J. C., Orchowitz, P., Goetzel, A., Kurtz, P. F., & Hagopian, L. P. (2016). On the relation between adaptive functioning and the reinforcement function of challenging behavior. *International Journal of Developmental Disabilities, 62*(3), 174-183. https://dx.doi.org/10.1080/20473869.2016.1177302

Schneider, A., Hommel, G., & Blettner, M. (2010). Linear regression analysis: Part 14 of a series on evaluation of scientific publications. *Deutsches Arzteblatt international*, *107*(44), 776–782. https://dx.doi.org/10.3238/arztebl.2010.0776

Sheperis, C., Young, J., & Daniels, M. (2010). *Counselling research: Quantitative, qualitative, and mixed methods*. Pearson Publications.

Simon, G. (2004). Systemic family therapy with families with a child who has a diagnosis of Asperger syndrome. *Human Systems: The Journal of Systemic Consultation and*

Management, *15*(4), 257-274.

Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities, 38*, 18-29. https://dx.doi.org/10.1016/j.ridd.2014.10.008

Singh, K. (2007). *Quantitative social research methods*. SAGE Publications India Pvt Ltd. https://dx.doi.org/10.4135/9789351507741

Singh, N. N., Lancioni, G. E., Karazsia, B. T., Winton, A. S. W., Myers, R. E., Singh, A. N. A., Singh, J. (2013). Mindfulness-based treatment of aggression in individuals with mild intellectual disabilities: A waitlist control study. *Mindfulness, 4*, 158-167. https://dx.doi.org/10.1007/s12671-012-0180-8

Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process, 51*, 250–264.

Spendelow, J. (2011). Assessment of mental health problems in people with Down Syndrome: Key considerations. *British Journal of Learning Disabilities, 39*. https://dx.doi.org/10.1111/j.1468-3156.2010.00670.x

Stephens, A. (2014). Systemic intervention practice at an Australian Aboriginal and Torres Strait Islander alcohol and other drugs treatment centre. *Systemic Practice and Action Research, 27*(4), 309-323. https://dx.doi.org/10.1007/s11213-013-9291-y

Stoddart, K. P. (1999). Adolescents with Asperger syndrome: Three case studies of individual and family therapy. *Autism*, *3*(3), 255-271.

Stoica, D. (2019). Families facing autism spectrum disorders. Landmarks for marriage and family therapists. *Agora Psycho-Pragmatica*, *1*(1), 70-76.

Thompson, T., & Caruso, M. (2002). Self-injury: Knowing what we're looking for. In S. Schroeder, M. Oster-Granite, & *T.* Thompson (Eds.), *Self-injurious behaviour. Gene-brain-behavior-relationships* (pp. 23–39). American Psychological Association.

Ticha, R., Hewitt, A., Nord, D., & Larson, S. (2013). System and individual outcomes and their predictors in services and support for people with IDD. *Intellectual and Developmental Disabilities, 51*(5), 298-315. https://dx.doi.org/10.1352/1934-9556-51.5.298

Tilsen, J., Russell, S., & Nylund, D. (2005). Nimble and courageous acts: How Michael became the boss of himself. *Journal of Systemic Therapies*, *24*(2), 29-42.

Toogood, S., Drury, G., Gilsenan, K., Parry, D., Roberts, K., & Sheriff, S. (2009). Establishing a context to reduce challenging behavior using procedures from active support. *Tizard Learning Disability Review, 14*, 29–36.

Turygin, N. C., Matson, J. L., MacMillan, K., & Konst, M. (2013). The relationship between challenging behavior and symptoms of depression in intellectually disabled adults with and without autism spectrum disorders. *Journal of Developmental and Physical Disabilities, 25*(4), 475-484. https://dx.doi.org/10.1007/s10882-012-9321-1

Turygin, N., Matson, J. L., & Adams, H. (2014). Prevalence of co-occurring disorders in a sample of adults with mild and moderate intellectual disabilities who reside in a residential treatment setting. *Research in Developmental Disabilities, 35*(1), 1802-1808. https://dx.doi.org/10.1016/j.ridd.2014.01.027

Tveter, A. L., Bakken, T. L., Rossberg, K. I., Bech-Pedersen, E., & Bramness, J. G. (2016). Short communication: Reliability and validity of the UKU side effect rating scale for adults with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities, 10*(3), 166-171. https://dx.doi.org/10.1108/amhid-10-2015-0051

Vereenooghe, L., & Langdon, P. E. (2013). Psychological therapies for people with intellectual disabilities: A systematic review and meta-analysis. *Research in Developmental Disabilities, 34*(11), 4085-4102. https://dx.doi.org/10.1016/j.ridd.2013.08.030

Wacker, D. P., Berg, W. K., Harding, J. W., Derby, K. M., Asmus, J. M., & Healy, A. (1998). Evaluation and long-term treatment of aberrant behavior displayed by young children with developmental disabilities. *Developmental and Behavioral Pediatrics, 19*, 260–266.

Weakland, J., Fisch, R., Watzlawick, P., & Bodin, A. (1974). Brief therapy: Focused problem resolution. *Family Process, 13*(2), 141-167.

Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2018). Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review. *Journal of Mental Health Research in Intellectual Disabilities, 11*(1), 69-102. https://dx.doi.org/10.1080/19315864.2017.1408724

Wigham, S., Hatton, C., & Taylor, J. (2011). The effects of traumatizing life events on people with intellectual disabilities: A systematic review. *Journal of Mental Health Research in Intellectual Disabilities, 4*:1, 19-39. https://dx.doi.org/10.1080/19315864.2010.534576

Wilkinson, R. G., & Marmot, M. (1998). *Social determinants of health: The solid facts.* Copenhagen: World Health Organization Centre for Urban Health (Europe) & International Centre for Health and Society.

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, *45*(7), 1951-1966. https://dx.doi.org/10.1007/s10803-014-2351-z

World Health Organization (2004). *Prevention of mental disorders. Effective interventions and* *policy options.* Summary Report. WHO, Geneva.

Zeig, J. K. (2007). A Tribute to Jay Haley, *American Journal of Clinical Hypnosis, 50*(1), 5-9.

Appendix A:

Systemic Treatment Plan (STP)

SYSTEMIC TREATMENT PLAN

Name: Scarlett Johansson Date: 08/19/2017

DOB: 08/18/1981_____ Client #:

_3236858___

Presenting Problem:

Client is a 36-year-old, Caucasian female with a diagnosis of Autism Disorder, Bipolar Disorder and sexual trauma who was referred to the START program due to challenging behaviors soon after she moved to a new group home after residing with her mother since birth. Scarlett has been showing signs of irritability and aggression prior to going to bed. She has been engaged in verbal altercations with group home staff and has also been showing signs of hyperactivity and insomnia. She sleeps on average 4 hours a night and has poor appetite. Staff at the group home attributes her challenging behaviors to current lifestyle and social circle (mother). Staff reports symptoms occur 4 to 5 times weekly, rates subjectively at a severity level of 7 on a linear scale from 0-10 (0 being absence of symptoms) and have been present for approximately 3 weeks; thus, creating significant impairment in her social, affective, and adaptive functioning.

Client Resources/ Team (system) Members:

Team includes Martha who is the mother and Guardian, the provider agency (Day Break) represented by Ashton, her Counselor Tom, Psychiatrist Daniel and Service Coordinator, Seth.

Team (Systemic) Challenges:

It is apparent that majority of the team members are new to this case and do not know Scarlett well enough. There was a high level of disconnect during the initial team meeting mainly due to the fact that it was the first interaction. The provider expressed anger outbursts to the mother stating that she was not showing support when needed. The non-clinical team appeared to lack psychoeducation on Scarlett's diagnoses. The guardian appears withdrawn and admits to struggling with caregiver fatigue.

Appendix A (Continued)

Short-Term Goals with Measurable Objectives (Biopsychosocially defined)	***Person Responsible***	***Frequency***	***Projected Duration***	***Goal Completion date /staff initial***	***Revision Date***
Primary Level					
Clinical Impression/Systemic Hypothesis: Caregiver's lack of education on the diagnosis and symptoms of Trauma, Autism and Bipolar Disorder. **Goal:** Staff from the provider agency as well as Scarlett's mother will receive training on Trauma informed care principles as well as Autism and Bipolar Disorder symptoms. **Objectives:** (a) START Coordinator will educate team members on ways to navigate Scarlett's symptoms using the provisional CSCPIP as well as provide information on trauma, Autism and Bipolar Disorder. **Measure goal completion via:** Completion of objectives outlined above and evidence that the team members and group home staff are able to utilize the CSCPIP.	START Coordinator	Minimum of 1 X a quarter for 60 minutes	Minimum of 12 weeks		
Secondary Level					

Appendix A (Continued)

Clinical Impression/Systemic Hypothesis: The team is disconnected (rigid boundaries) and there is a need for improved supports. **Goal:** Have Scarlett's mother become more engaged and diffuse the boundaries between team members. Additionally, assist group home staff with Scarlett's challenging behaviors in the evening. **Objectives:** Continue the Joining process with all members of the team. Have a separate meeting with Martha and Ashton in order to settle differences in a constructive manner. Submit a referral for In-home therapeutic supports. Provide Martha resources for caregiver support groups. Crisis intervention through the 24-7 crisis hotline. **Measure goal completion via:** Verbal reporting of increase in social functioning and communication from team members and reports from the Resource Center Counselors that Scarlett's challenging behaviors are less frequent.	START Coordinator	Minimum of 1 X a month for 60 mins (Team meetings). Minimum of 3 X a week for 60 mins (In-home supports).	Minimum of 12 weeks		

Appendix A (Continued)

Tertiary Level					
Clinical Impression/Systemic Hypothesis: Scarlet appears to be struggling with manic symptoms and struggles with acclimating to her new environment. **Goal:** Have Daniel assess symptoms for medical intervention. Have mother use systemic desensitization by having Scarlett go back home on the weekends. Help Scarlett manage her become more engaged and assist the provider to channel frustrations in a healthy way. **Objectives:** Schedule a follow-up appointment with psychiatrist. Scarlett will learn coping skills, emotional regulation (stress management), learn to identify maladaptive negative thoughts and how to replace them with more positive, adaptive thoughts. (b) Continue attending counseling sessions and refer to Behaviorist. **Measure goal completion via:** Verbal reporting of functioning, symptoms decrease and completion of objectives.	Service Coordinator Counselor Psychiatrist	Minimum of 1 X a week for 50 mins (counseling and Behavioral Analyst) Minimum of 1 X month for 30 mins (Psychiatrist)	Minimum of 12 weeks		

START Coordinator Signature: ____ **Date:** _____

Appendix B:

Participant's Survey Questionnaire (PSQ)

I have read the information provided above and I voluntarily agree to participate in this research study as shown by my continuation of this survey.

Agree Disagree

1. Please select the title that you feel best describes your current occupation in relation to the client currently being served by START.
   a. Client
   b. Parent/Guardian
   c. Provider Representative (Group Home Manager/Direct Support Staff/Case Manager)
   d. Service Coordinator
   e. Board Certified Behavior Analyst
   f. Occupational Therapist
   g. Speech Therapist
   h. Therapist/Counselor
   i. Psychiatrist
   j. Other (please explain) ___________________________

2. What is the frequency of contact that you have with the client currently being served by START? (Circle one)
   a. Daily contact
   b. More than once a week contact
   c. Weekly contact
   d. Monthly contact
   e. Quarterly contact (every three months)

The following questions are about your engagements with START over the last 3 months. For each question, please mark a number at the end of each question from the options below:

1. Totally Disagree.
2. Somewhat Disagree.
3. Unsure.
4. Somewhat Agree.
5. Totally Agree.

Appendix B (Continued)

3. Based on my experience, having goals identified by the treatment team is important for the START client. ___
4. Based on my experience, the goals that were identified by the treatment team had positive outcomes for the START client. ___
5. The treatment team was engaged and invested in the START client's overall wellbeing. ___
6. I was engaged and invested in the START client's treatment team. ___
7. The goals identified were reasonable/achievable. ___
8. The goals that the team identified were challenging. ___
9. There was more than one goal identified and the team knew which ones were the most important (short term) and which ones were the least important (long term). ___
10. The training that I have received based on the identified goal made an overall difference in the START client's wellbeing. ___
11. Different strategies (objectives) were used to help achieve the identified goals. ___
12. Biological, psychological and social aspects about the START client's life were considered while generating goals. ___
13. I feel as though the goals identified were successful. ___
14. I feel as though the goals identified were specific to the START client. ___
15. The START client's immediate psychiatric needs were met. ___
16. Additional resources that were needed to help the START client were obtained. ___
17. Communication in the treatment team was open and honest. ___
18. Everyone participated and was heard in team discussions. ___
19. I understood the goals and objectives clearly, and I was committed to them. ___
20. Team members understood goals and objective clearly, and we all committed to them. ___
21. I feel as though the START client's well-being has improved over the course of the last 3 months. ___
22. Overall, I was satisfied with this service. ___

The following questions are specifically directed towards the treatment group that received systemic engagement. For each question, please mark a number at the end of each question from the options below:

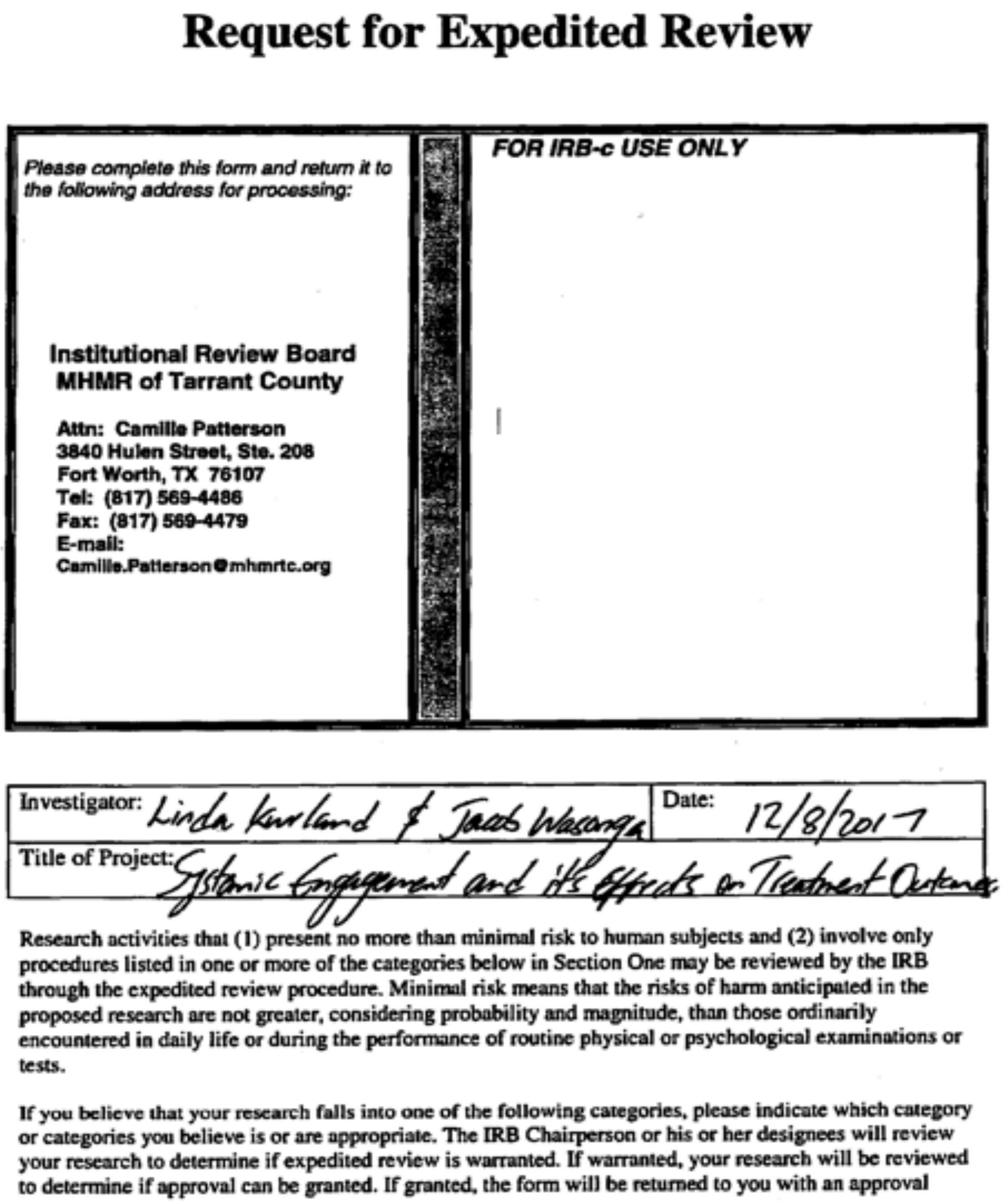
1. Totally Disagree.
2. Somewhat Disagree.
3. Unsure.
4. Somewhat Agree.
5. Totally Agree.

Appendix B (Continued)

23. The START Coordinator showed leadership in the team meetings. ___
24. The START Coordinator was neutral and unbiased. ___
25. The START Coordinator was invested in the case and was a team player. ___
26. The START Coordinator provided support, motivation, guidance, and hope during this process. __
27. The START Coordinator strategized different ways (objectives) of achieving the identified goals. __
28. The START Coordinator encouraged critical analysis as well as differentiation (separation of thoughts and feelings) when discussing crucial matters. ___
29. The START Coordinator expressed his/her reasoning as to what kept the START client in recurrent crisis episodes. ___
30. The START Coordinator expressed his/her reasoning as to what made the treatment team (system) become "stuck" in recurrent ways of functioning. ___
31. The START Coordinator challenged unproductive assumptions during the team meetings. ___
32. Based on my experience, having goals identified by the treatment team was important for the START client. ___

Appendix C:

MHMR Tarrant County IRB Committee Approval Form



Request for Expedited Review

Please complete this form and return it to the following address for processing:

Institutional Review Board
MHMR of Tarrant County

Attn: Camille Patterson
3840 Hulen Street, Ste. 208
Fort Worth, TX 76107
Tel: (817) 569-4486
Fax: (817) 569-4479
E-mail:
Camille.Patterson@mhmrtc.org

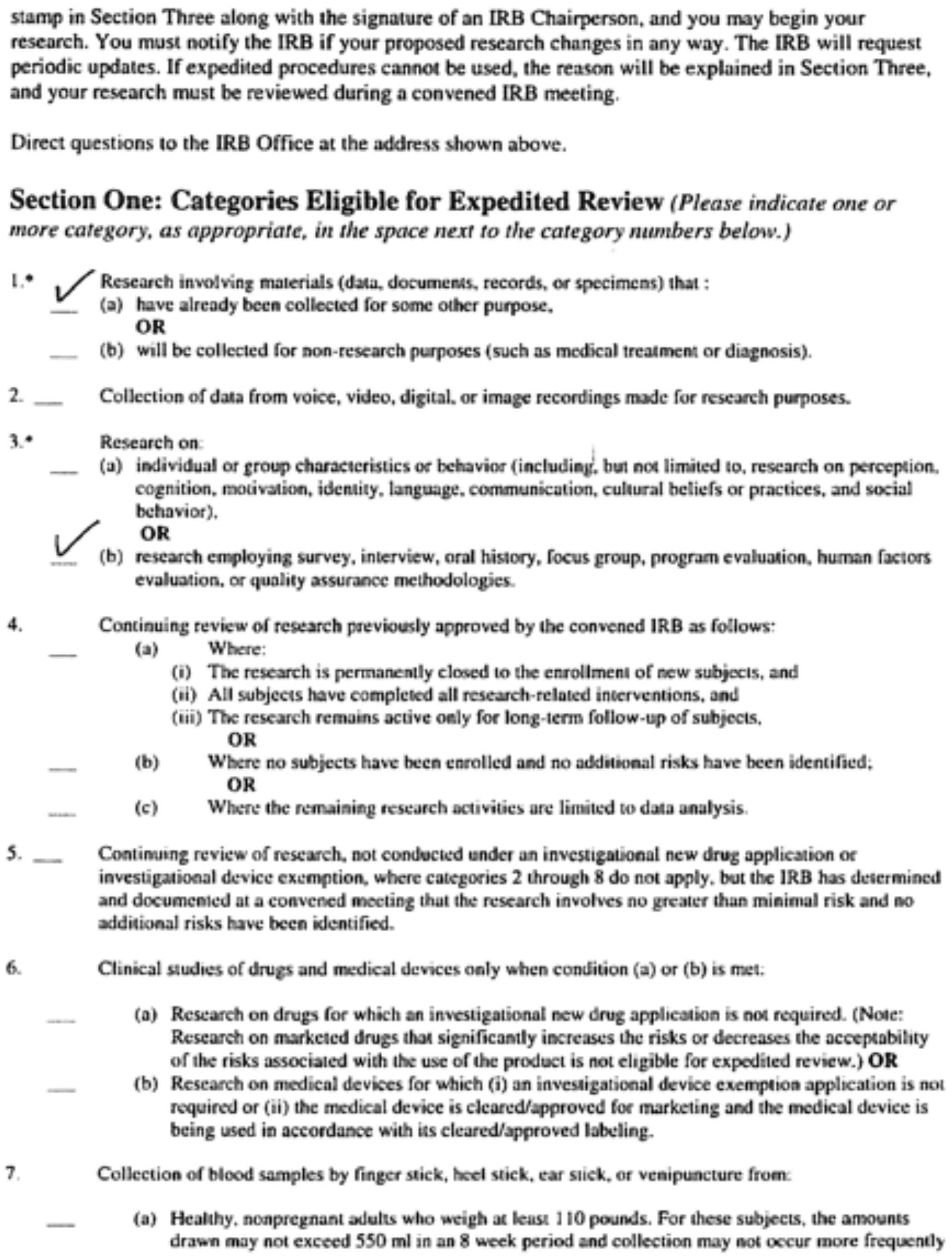
FOR IRB-c USE ONLY

Investigator: Linda Kurland & Jacob Wasonga	Date: 12/8/2017
Title of Project: Systemic Engagement and it's Effects on Treatment Outcomes	

Research activities that (1) present no more than minimal risk to human subjects and (2) involve only procedures listed in one or more of the categories below in Section One may be reviewed by the IRB through the expedited review procedure. Minimal risk means that the risks of harm anticipated in the proposed research are not greater, considering probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

If you believe that your research falls into one of the following categories, please indicate which category or categories you believe is or are appropriate. The IRB Chairperson or his or her designees will review your research to determine if expedited review is warranted. If warranted, your research will be reviewed to determine if approval can be granted. If granted, the form will be returned to you with an approval

Appendix C (Continued)



stamp in Section Three along with the signature of an IRB Chairperson, and you may begin your research. You must notify the IRB if your proposed research changes in any way. The IRB will request periodic updates. If expedited procedures cannot be used, the reason will be explained in Section Three, and your research must be reviewed during a convened IRB meeting.

Direct questions to the IRB Office at the address shown above.

Section One: Categories Eligible for Expedited Review *(Please indicate one or more category, as appropriate, in the space next to the category numbers below.)*

1.* Research involving materials (data, documents, records, or specimens) that :
- ✓ (a) have already been collected for some other purpose,
  OR
- ___ (b) will be collected for non-research purposes (such as medical treatment or diagnosis).

2\. ___ Collection of data from voice, video, digital, or image recordings made for research purposes.

3.* Research on:
- ___ (a) individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior),
  OR
- ✓ (b) research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

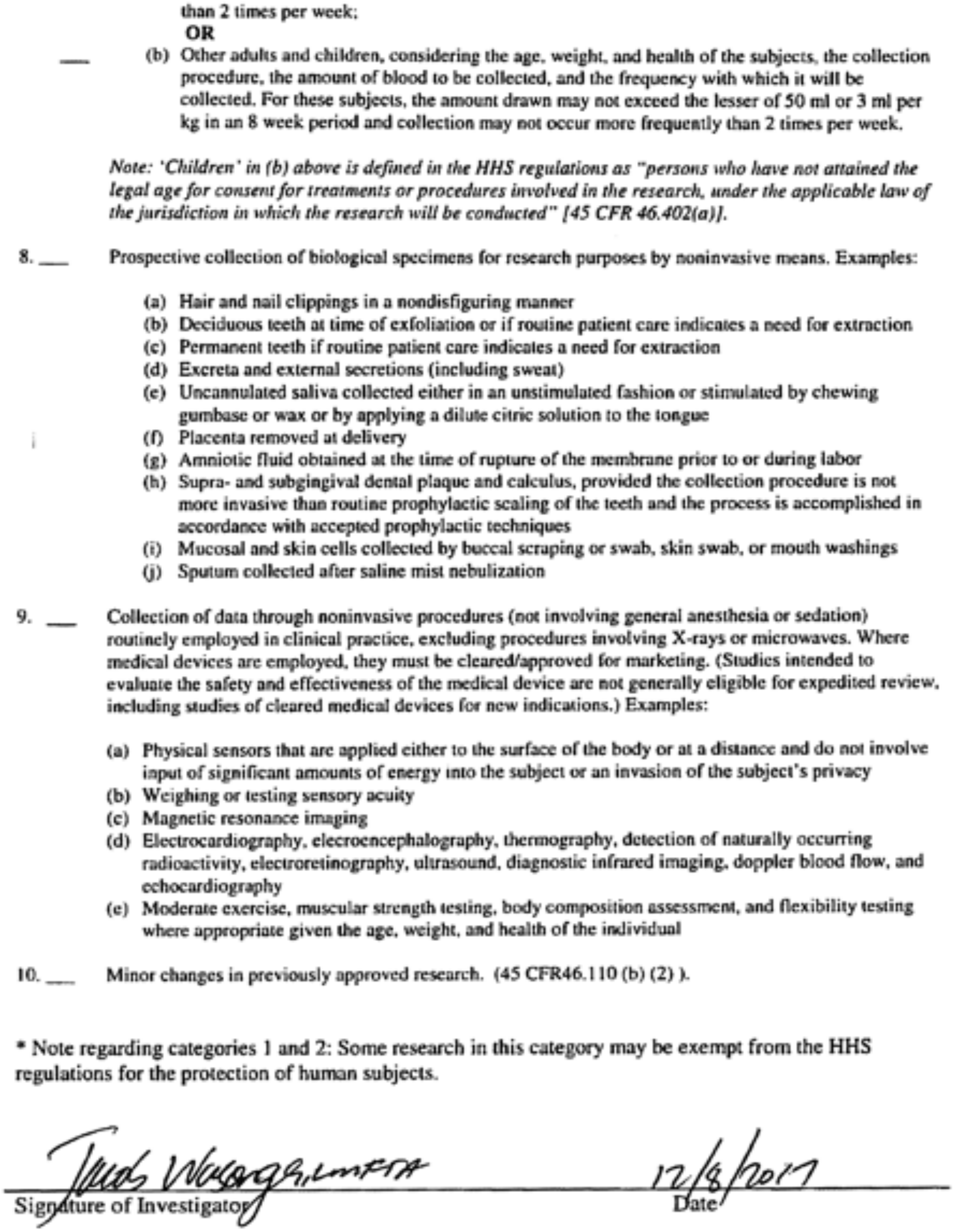
4\. Continuing review of research previously approved by the convened IRB as follows:
- ___ (a) Where:
  - (i) The research is permanently closed to the enrollment of new subjects, and
  - (ii) All subjects have completed all research-related interventions, and
  - (iii) The research remains active only for long-term follow-up of subjects,
  OR
- ___ (b) Where no subjects have been enrolled and no additional risks have been identified;
  OR
- ___ (c) Where the remaining research activities are limited to data analysis.

5\. ___ Continuing review of research, not conducted under an investigational new drug application or investigational device exemption, where categories 2 through 8 do not apply, but the IRB has determined and documented at a convened meeting that the research involves no greater than minimal risk and no additional risks have been identified.

6\. Clinical studies of drugs and medical devices only when condition (a) or (b) is met:
- ___ (a) Research on drugs for which an investigational new drug application is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.) **OR**
- ___ (b) Research on medical devices for which (i) an investigational device exemption application is not required or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

7\. Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture from:
- ___ (a) Healthy, nonpregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently

Appendix C (Continued)



than 2 times per week;
OR

___ (b) Other adults and children, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

Note: 'Children' in (b) above is defined in the HHS regulations as "persons who have not attained the legal age for consent for treatments or procedures involved in the research, under the applicable law of the jurisdiction in which the research will be conducted" [45 CFR 46.402(a)].

8. ___ Prospective collection of biological specimens for research purposes by noninvasive means. Examples:

(a) Hair and nail clippings in a nondisfiguring manner
(b) Deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction
(c) Permanent teeth if routine patient care indicates a need for extraction
(d) Excreta and external secretions (including sweat)
(e) Uncannulated saliva collected either in an unstimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue
(f) Placenta removed at delivery
(g) Amniotic fluid obtained at the time of rupture of the membrane prior to or during labor
(h) Supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the process is accomplished in accordance with accepted prophylactic techniques
(i) Mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings
(j) Sputum collected after saline mist nebulization

9. ___ Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving X-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.) Examples:

(a) Physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy
(b) Weighing or testing sensory acuity
(c) Magnetic resonance imaging
(d) Electrocardiography, elecroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography
(e) Moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual

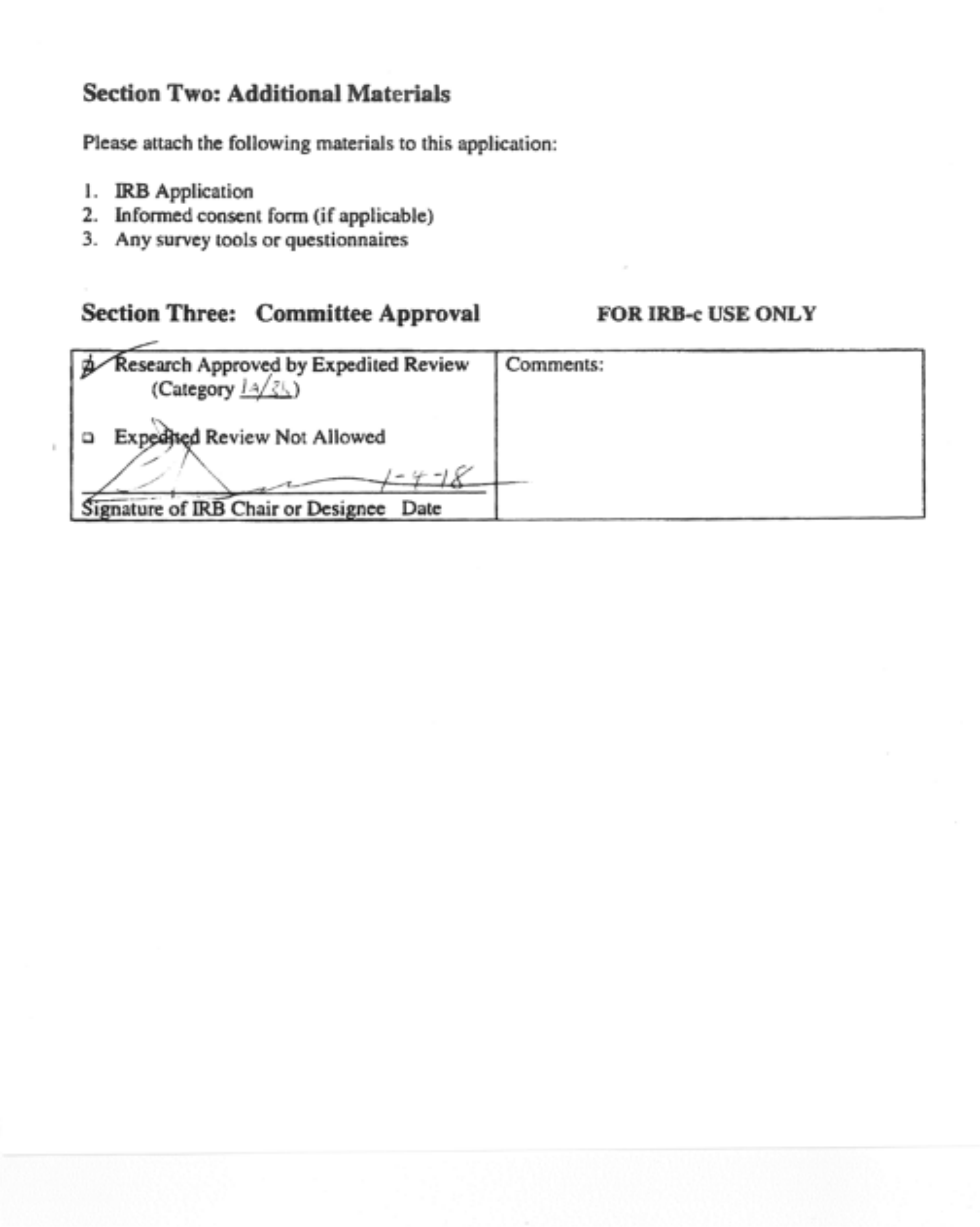
10. ___ Minor changes in previously approved research. (45 CFR46.110 (b) (2)).

* Note regarding categories 1 and 2: Some research in this category may be exempt from the HHS regulations for the protection of human subjects.

12/8/2017

Signature of Investigator　　　　Date

Appendix C (Continued)



Section Two: Additional Materials

Please attach the following materials to this application:

1. IRB Application
2. Informed consent form (if applicable)
3. Any survey tools or questionnaires

Section Three: Committee Approval

FOR IRB-c USE ONLY

☑ Research Approved by Expedited Review (Category 1A/3A) ☐ Expedited Review Not Allowed 1-4-18 Signature of IRB Chair or Designee Date	Comments:

Appendix D:

START Plan

****Below is a sample START Action Plan. It is one that has been updated quarterly. The previous quarters can be found on the START website in the START Action Plan section. The key has been removed for the purposes of providing this sample.**

START PLAN

START PLAN **Complete every 3 months for first year of case activity.
****In second year of activity: Level of Involvement, Involvement Intensity rank 3-4: complete every 3 months**
Level of Involvement, Level of Intensity 1-2: complete every 6 months

---

DEMOGRAPHIC INFORMATION

Client Name: Jim Smith
Date of Referral: 06/13/2014
Referral Source: Lets Help Case Management Agency
Funding: Medicaid Waiver
START Coordinator: Megan **Date Assigned: 6/13/2014**
START Coordinator: **Date Assigned:**

REASON FOR REFERRAL (1-4): 4, 2

(please list all that apply)
4- Externalized Behavioral Dyscontrol (may include physical and/ or verbal aggression, Impulse control, self-Injury, property destruction)
3- Complicated Medical/Neuro
2 - Clinical Consult
1-0ther

CASE INVOLVEME NT/ INTENSITY	**Date of Initial Plan:** *07/2014*	**Date of Update:** *10/2014*	**Date of Update:** *1/2015*	**Date of Update:** *4/2015*
Projected Level of Involvement(1-4)*	3	3	2	4
Involvement Intensity (1-4)**	4	4	2	4
Level of Person's Current Stability (1-4)***	2	2	2	3
Frequency of CET/ Crisis Plan Follow Up Contacts (1-4)****	3	3	2	4

Appendix D (Continued)

Frequency of Systems Linkage Contacts (1-4)****	3	3	3	3
Anticipated Primary Mode of Contact (1-4)	3	3	3	3

PROJECTED/CURRENT SERVICES (Approved by clinical director)

Projected/ Current Services to be Provided (updated every time START plans completed)	Order in which Services will be provided (rank 1-16)	**Frequency of Contacts** 1-quarterly 2-monthly 3-bl-monthly 4-weekly 1st Q	2nd Q	3rd Q	4thQ	Date Completed
Triage Call/ Emergency Assessment	9				2	
Intake Meeting/Preliminary Assessment	1	4				7/2014
CSE	3	3				8/2015
Cross-Systems Crisis Plan	2	4			3	8/2014
CET						
CET Follow up						
Rx Consult	7		1			12/2014
Rx Follow up	8		1			12/2014
Team Case Consult	6	2	2	2	4	
Consultations/ Linkages	5		2		2	12/ 2014
Outreach visits	4		3	2	4	
Anticipated respite? ☐ Yes ☐ No (If no, end ranking at 12)						
Planned Respite	n/a					
Emergency Respite	n/a					
Sit e-based Respite	n/a					

Recent Stressors Questionnaire	Completed? Y/N	**Aberrant Behavior Checklist Cumulative Score**	Score	Date
Intake	☐ Y/N ☐	Intake	60	06/2014

Appendix D (Continued)

Every Crisis	☐ Y/N☐	**6 mo or Inactive**	34	12/2014

Use * to indicate different responder at time of follow up

Team's Current Concerns and Additional Notes: 7/2014--At the time of referral/Intake the coordinator is meeting with the team frequently as the CSCP and CSE are completed. Jim lives with his parents and his mother is Ill and would prefer an out of home placement for Jim. The family would benefit from outreach/linkage every two weeks as his case manager is working on Identifying placement. The coordinator will also be available for technical assistance for case manager regarding placement options.

10/2014- CSCP and CSE were completed this past quarter. It was determined that a new OT assessment would be beneficial along with a psychiatric consult from the START medical director. Coordinator will send medical records and medication history to MD and will meet with him during next consult time. Coordinator will also attend next psychiatry appointment. The team is still looking of placement for Jim and are considering apartment living for him.

1/2015 - Psychiatric consultation was completed with MD and follow-up action planning has occurred. See documentation/chart for action plan. At this time, additional respite services have been put in place In Jim's home. The family has possibly identified an apartment for Jim. Coordinator will be providing team consultation and outreach as the team begins planning for this transition.

4/2015 -Transition to new placement occurred in 2/2015. It went well for a brief period of time but unexpected In-home staff turnover has made the transition difficult. New staff is being trained on the CSCP, frequent/weekly outreach is being conducted by coordinator. The CSCP has been revised based on changes in current situation.

Appendix E:

Aberrant Behavior Checklist (ABC)

ABERRANT BEHAVIOR CHECKLIST- COMMUNITY

Clients Name: ______________________

Rater's Name: ______________________

Clients Gender (circle): Male/Female

Relationship to Client (check):
☐ Parent
☐ Teacher
☐ Trainer/Supervisor
☐ Other (please specify)
____

Date of Birth ______________________
Month Day Year

Today's Date ______________________
Month Day Year

Where Was the Client Observed?
☐ Home
☐ School
☐ Residential Unit
☐ Workshop
☐ Other (please specify)
____

If in School, Type of Class (check one):
☐ Developmentally Handicapped
☐ Severe Behavior Handicap
☐ Multi-handicapped
☐ Other______________

Ethnic Group (check):
☐ Caucasian
☐ African-American
☐ Hispanic
☐ Other (please specify) ______________________

CLIENTS MEDICAL STATUS (Please circle)

a. Deafness?	No	Yes	? (Don't Know)
b. Blindness?	No	Yes	?
c. Epilepsy?	No	Yes	?
d. Cerebral Palsy?	No	Yes	?

e. Other ______________________

CURRENT MEDICATIONS (Please list any medication and dosage schedule)

1. ______________________
2. ______________________
3. ______________________
4. ______________________
5. ______________________

Additional Copies Available From
SLOSSON EDUCATIONAL PUBLICATIONS, INC.
P.O. Box 280, East Aurora, New York 14052

Appendix E (Continued)

INSTRUCTIONS

The ABC-Community rating scale is designed to be used with clients living in the community. Please note that the term *client* is used throughout to refer to the person being rated. This may be a child of school age, an adolescent, or an adult.

Please rate this client's behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the appropriate number:

0 = not at all a problem
1= the behavior is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

When judging this client's behavior, please keep the following points in mind:

(a) Take relative *frequency* into account for each behavior specified. For example if the client averages more temper outbursts than most other clients you know or most others in his/her class, it is probably moderately, serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have *to* occur more frequently to merit an extreme rating.

(b) If you have access to this information, consider the experiences of other care providers with this client. If the client has problems with others but not with you, try to take the whole picture into account

(c) Try to consider whether a given behavior interferes with his/her *development, functioning,* or *relationships.* For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item - your first reaction is usually the right one.

1. Excessively active at home, school, work, or elsewhere	0	1	2	3
2. Injures self on purpose	0	1	2	3
3. Listless, sluggish, inactive	0	1	2	3
4. Aggressive to other children or adults (verbally or physically)	0	I	2	3
5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums/outbursts	0	1	2	3
11. Stereotyped behavior; abnormal, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable and whiny	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizarre in behavior	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3
20. Fixed facial expression; lacks emotional responsiveness	0	1	2	3

Appendix E (Continued)

21. Disturbs others	0	1	2	3
22. Repetitive speech	0	1	2	3
23. Does nothing but sit and watch others	0	1	2	3
24. Uncooperative	0	1	2	3
2.5. Depressed mood	0	1	2	3
26. Resists any form of physical contact	0	1	2	3
27. Moves or rolls head back and forth repetitively	0	1	2	3
28. Does not pay attention to instruction	0	1	2	3
29. Demands must be met immediately	0	1	2	3
30. Isolates himself/herself from other children or adults	0	1	2	3
31. Disrupts group activities	0	1	2	3
32. Sits or stands in one position for a long time	0	I	2	3
33. Talks to self loudly	0	1	2	3
34. Cries over minor annoyances and hurts	0	1	2	3
35. Repetitive hand, body, or head movements	0	1	2	3
36. Mood changes quickly	0	1	2	3
37. Unresponsive to structured activities (does not react)	0	1	2	3
38. Does not stay in seat (e.g., during lesson or training periods, meals, etc.)	0	1	2	3
39. Will not sit still for any length of time	0	I	2	3
40. Is difficult to reach, contact, or get through to	0	1	2	3
41. Cries and screams inappropriately	0	1	2	3
42. Prefers to be alone	0	1	2	3
43. Does not try to communicate by words or gestures	0	1	2	3
44. Easily distractible	0	1	2	3
45. Waves or shakes the extremities repeatedly	0	1	2	3
46. Repeats a word or phrase over and over	0	1	2	3
47. Stamps feet or bangs objects or slams doors	0	1	2	3
48. Constantly runs or jumps around the room	0	1	2	3
49. Rocks body back and forth repeatedly	0	1	2	3
50. Deliberately hurts himself/herself	0	1	2	3
51. Pay no attention when spoken to	0	1	2	3
52. Does physical violence to self	0	1	2	3
53. Inactive, never moves spontaneously	0	1	2	3
54. Tends to be excessively active	0	1	2	3
55. Responds negatively to affection	0	1	2	3
56. Deliberately ignores directions	0	1	2	3
57. Has temper outbursts or tantrums when he/she does not get own way	0	1	2	3
58. Shows few social reactions to others	0	1	2	3

Appendix E (Continued)

ABERRANT BEHAVIOR CHECKLIST

SCORE SHEET

Resident's Name: ____________________

Date: ____________________ Study Phase: ____________________

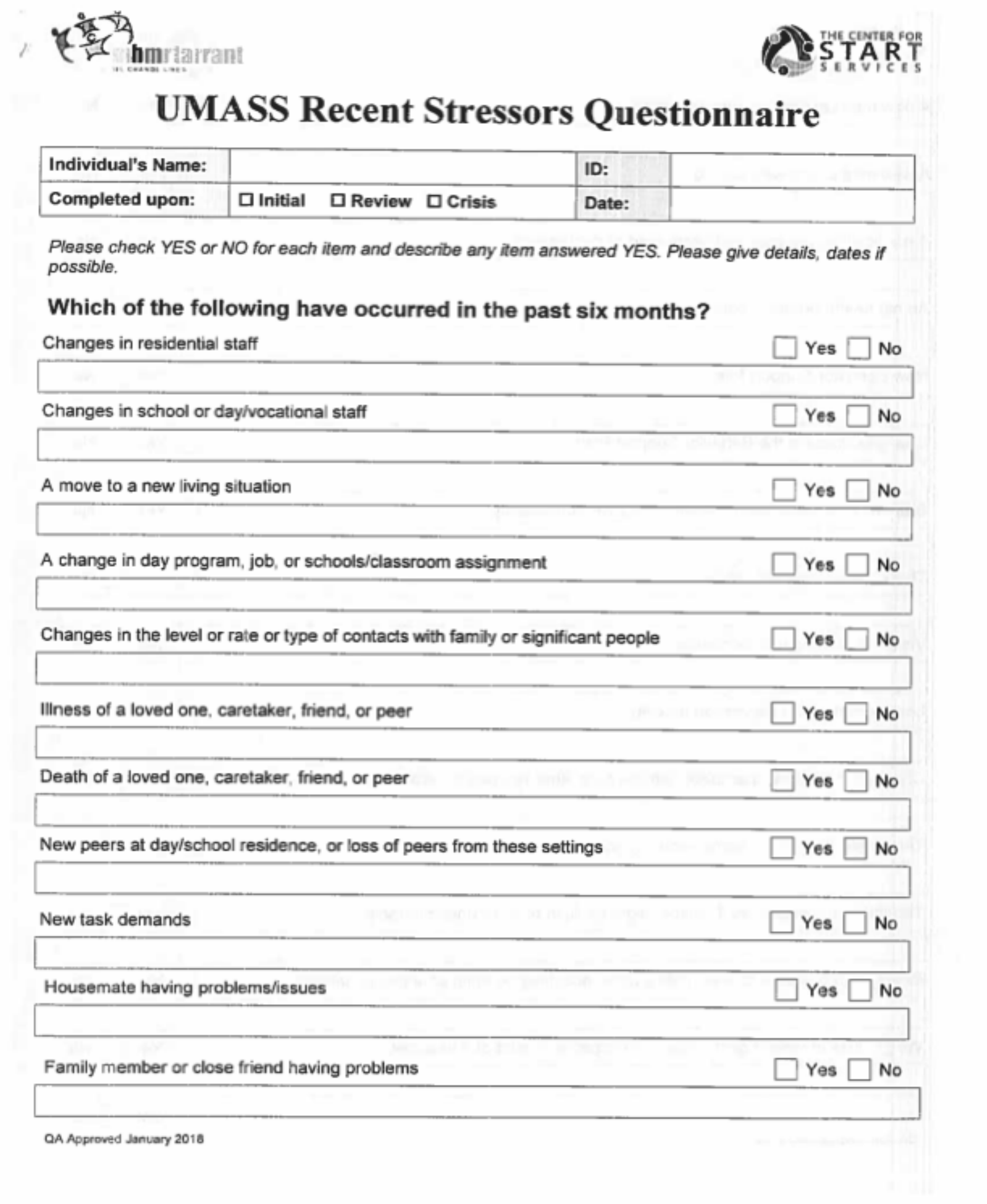
Rater: ____________________

Subscale I (Irritability)	Subscale II (Lethargy)	Subscale III (Stereotypy)	Subscale IV (Hyperactivity)	Subscale V (Inappropriate Speech)
2	3	6	1	9 ________
4	5	11	7	22 ________
8	12	17	13	33 ________
IO	16	27	15	46________
14	20	35	18	
19	23	45	21	
25	26	49	24	
29	30		28	
34	32		31	
36	37		38	
41	40		39	
47	42		44	
50	43		48	
52	53		51	
57	55		54	
	58		56	
Total________	Total________	Total________	Total________	Total________

Additional Copies Available From
SLOSSON EDUCATIONAL PUBLICATIONS, INC.
P.O. Box 280, East Aurora, New York 14052

Appendix F:

Recent Stressor Questionnaire (RSQ)



THE CENTER FOR START SERVICES

UMASS Recent Stressors Questionnaire

Individual's Name:		**ID:**	
Completed upon:	☐ **Initial** ☐ **Review** ☐ **Crisis**	**Date:**	

Please check YES or NO for each item and describe any item answered YES. Please give details, dates if possible.

Which of the following have occurred in the past six months?

Changes in residential staff ☐ Yes ☐ No

Changes in school or day/vocational staff ☐ Yes ☐ No

A move to a new living situation ☐ Yes ☐ No

A change in day program, job, or schools/classroom assignment ☐ Yes ☐ No

Changes in the level or rate or type of contacts with family or significant people ☐ Yes ☐ No

Illness of a loved one, caretaker, friend, or peer ☐ Yes ☐ No

Death of a loved one, caretaker, friend, or peer ☐ Yes ☐ No

New peers at day/school residence, or loss of peers from these settings ☐ Yes ☐ No

New task demands ☐ Yes ☐ No

Housemate having problems/issues ☐ Yes ☐ No

Family member or close friend having problems ☐ Yes ☐ No

QA Approved January 2018

Appendix F (Continued)

mhmr tarrant

THE CENTER FOR START SERVICES

A new medical problem was identified ☐ Yes ☐ No

A new medication was started ☐ Yes ☐ No

A medication was changed (increased or decreased) ☐ Yes ☐ No

An old health problem worsened recently ☐ Yes ☐ No

New Behavior Support Plan ☐ Yes ☐ No

Changes made in the Behavior Support Plan ☐ Yes ☐ No

Staff may not have been following the BSP consistently ☐ Yes ☐ No

There was suspected abuse ☐ Yes ☐ No

Vision or hearing loss or change ☐ Yes ☐ No

Loss of mobility or decreased mobility ☐ Yes ☐ No

Changes in doctors, therapists, teachers, or other key service providers ☐ Yes ☐ No

Things are different at home, work, or school ☐ Yes ☐ No

The Individual seems as if he/she might be ill, in pain, or uncomfortable ☐ Yes ☐ No

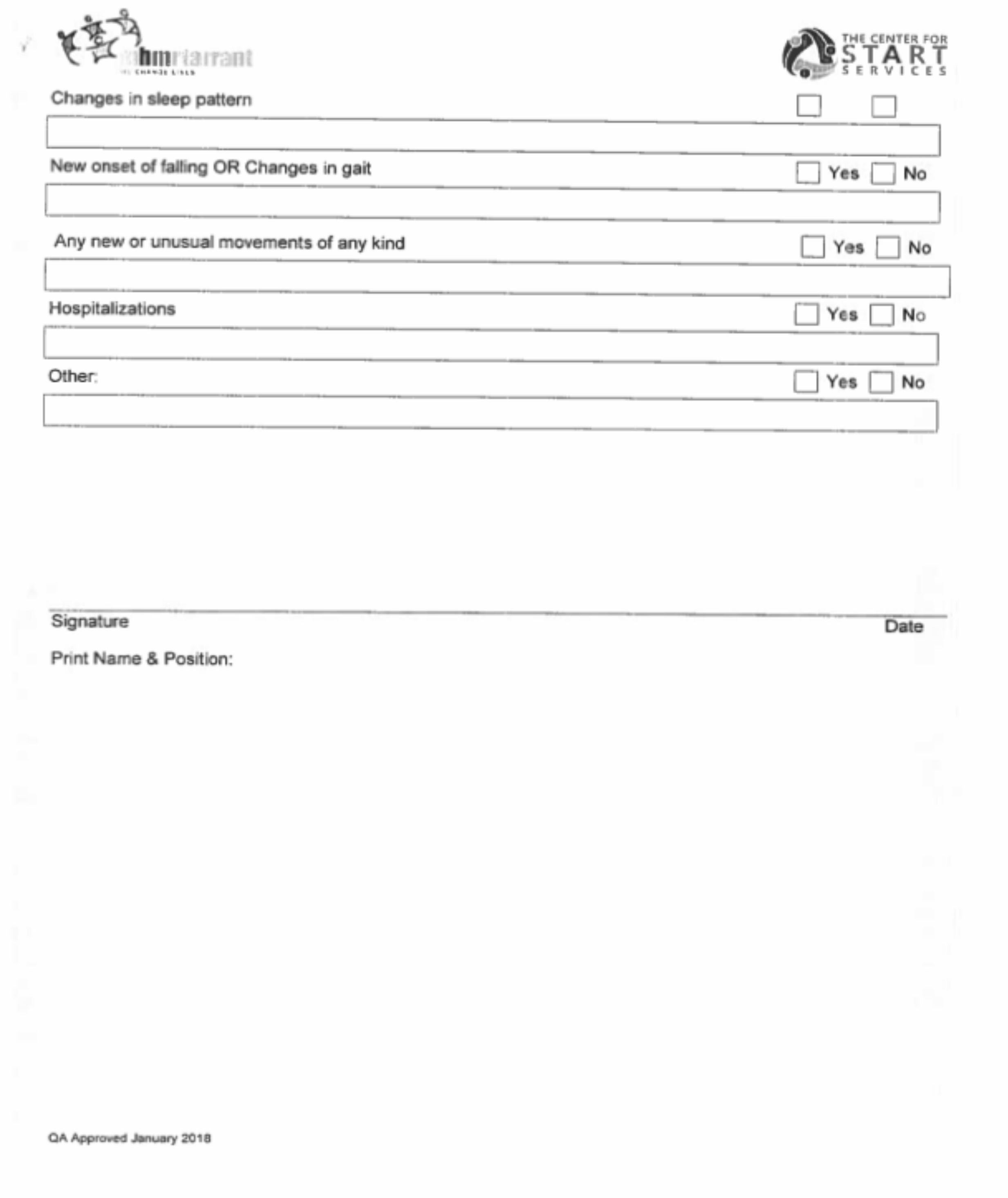
Changes in bowel or bladder habits (new incontinence other changes in habits) ☐ Yes ☐ No

Weight loss or weight gain. Change in appetite or start of a new diet ☐ Yes ☐ No

☐ Yes ☐ No

QA Approved January 2018

Appendix F (Continued)



THE CENTER FOR START SERVICES

Changes in sleep pattern ☐ ☐

New onset of falling OR Changes in gait ☐ Yes ☐ No

Any new or unusual movements of any kind ☐ Yes ☐ No

Hospitalizations ☐ Yes ☐ No

Other: ☐ Yes ☐ No

Signature Date

Print Name & Position:

QA Approved January 2018

Appendix G:

Consent to Use Data

mhmr tarrant
WE CHANGE LIVES

October 9, 2018

St. Mary's University
Institutional Review Board
San Antonio, Texas

Dear St. Mary's University IRB Committee,

We are familiar with Jacob Wasonga's research project entitled Systemic Engagement and its Effects on Treatment Outcomes. This project was approved by MHMR's IRB on December 8, 2017.

We understand research collected as part of this study will be utilized for Jacob Wasonga's dissertation. We understand that confidentiality of participants' research data is ensured, and that no identifying participant data will be shared with non-MHMR staff.

Sincerely,

Paul Duncan

Paul Duncan, JD, B.S.W., L.M.S.W., A.P.
Director of Rights
MHMR Tarrant County
Institutional Review Board Chairman
Cc: Camille Patterson., Ph.D.
IRB Coordinator