

PROGRAM EVALUATION OF A SOCIAL-EMOTIONAL GROUP PROGRAM FOR
CHILDREN WITH TOURETTE'S DISORDER AND TICS

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Abstract

Tourette syndrome (TS) and tic disorders have been associated with significant functional impairments in school, peer, and family domains. While there is an abundance of literature highlighting these challenges, limited programs are available that target improvement of quality of life factors for this population. The author of this dissertation conducted a program evaluation of a 10-week Cognitive Behavioral Therapy Social-Emotional Group Program for children with TS at a large university using Charles Maher's model of Program Planning and Evaluation (2012). The first research task of this study was to create a Program Design document outlined in Maher's guide. The second research task was to answer relevant program questions identified by the program's director related to the program's success in connecting children and families affected by TS, the program's provision of tangible skills to address problems related to TS, the program's task of increasing acceptance of tics, and the program's provision of quality training to graduate students. Data were collected through semi-structured interviews with the director, administrative director, group supervisor, and student clinicians, as well as review of relevant program documents. The Program Design document and the evaluation of the indicated questions provided information about program goals, procedures, strengths, and recommendations to the director and stakeholders involved in the program. Results suggested that the program's elements are in line with the program's goals to connect children and families affected by TS, provide tangible problem solving skills, increase acceptance of tics, and provide training to graduate students. Recommendations for further development were discussed. The intent of this evaluation and feedback was to facilitate sound decisions to be made about the program and to contribute to further program development and improvement.

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Chapter I

Introduction and Overview

Functional Impacts of Tic Disorders:

Tics—which are characterized as involuntary, rapid, sudden, recurrent, nonrhythmic movements or vocalizations—have been associated with significant distress and functional impairment in school, peer, and family domains. Additionally, tics have been associated with poorer quality of life for children and adolescents (Bawden, Stokes, Camfield, Camfield, & Salisbury, 1998; Carter, O'Donnell, Schultz, Scahill, Leckman, & Pauls, 2000; Conelea, Woods, Zinner, Budman, Murphy, Scahill, & ... Walkup, 2011).

While an abundance of research reveals the impact of tic disorders on these various domains of functioning, there is a dearth of programs geared toward addressing impairment within these domains. Pharmacological and behavioral treatments focus solely on reducing tic severity, due to the premise that severity is wholly responsible for the functional impairment and diminished quality of life in youth with TS. However, the interplay between severity, impairment, and quality of life remains unclear and it is thus important to provide interventions that address psychosocial factors (McGuire, Arnold, Park, Nadeau, Lewin, Murphy, & Storch 2015).

Little research is available on programs addressing these impairments, particularly in group settings. While research in this area is limited, qualitative feedback from case studies has been positive and has indicated that group approaches offer children and parents opportunities to meet one another in a supportive environment, suggesting a need for further investigation (Verdellen, Griendt, Hartmann, & Murphy, 2011). In addition to a need for increased

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interventions targeting psychosocial functioning in children with TS, evaluation of existing programs is crucial in order to further our knowledge and understanding of what is effective and what is not. Conducting a program evaluation of such programs will provide educators, clinicians, and researchers with information about resources that can be utilized in order to address these issues that are common for youth with tics.

Dissertation Task:

The purpose of this dissertation was to provide relevant, meaningful, and constructive feedback to stakeholders involved in the Tourette Syndrome (TS) Clinic's Social-Emotional Group Program at Rutgers University. The social-emotional group program is a 10-week group that is run annually at the TS clinic. It caters to children and adolescents that have various tic disorders and provides a CBT-based approach to target psychoeducation about tics, cognitive challenging to normalize tics and address negative beliefs, and problem solving difficult social situations. Data for the dissertation were collected through a review of program documents and semi-structured interviews with the program director, the administrative director of the Rutgers Psychological Services clinic, the group supervisor, and graduate student clinicians co-leading the group program.

The gathered information was utilized in completing two tasks. The first main task was to put the program into an evaluable form and create a Program Design Document using Charles Maher's resource guide for Planning and Evaluating Human Services Programs (2012). This document is helpful in providing relevant information to stakeholders in order to guide and further develop program goals, activities, and components. The second task was to utilize

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available data to determine whether the program has added value to the target population.

Specific questions were related to the program's goals and were identified by the director: (1) Is the program successful in connecting children and families affected by TS? (2) Is the program providing tangible skills to help children manage challenging situations? (3) Is the program successful in increasing acceptance of tics in its participants? (4) Is the program providing quality training to graduate students?

The Program Design Document and the findings of the evaluation provide relevant information and recommendations for stakeholders to make sound decisions about the program and to facilitate program development and improvement. The study also has implications for clinicians, professionals, and other stakeholders who work with the target population.

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Chapter II

Review of Relevant Literature

Definition of Tic Disorders:

Tics are characterized by the Diagnostic Statistical Manual-Fifth Edition (DSM-5) as “sudden, rapid, recurrent, but nonrhythmical motor movements and/or vocalizations, generally preceded by premonitory somatosensory urges.” Tourette’s Disorder (TD) is a neurodevelopmental disorder that typically has a childhood onset. In order to obtain a DSM-5 diagnosis of TD, an individual has to meet the following criteria: express multiple motor and at least one vocal tic at some point in their life, possibility of tics waxing and waning in frequency but having had persisted for more than one year since the first tic onset, onset before age 18, and the disturbance not being attributable to the physiological effects of a substance or another medical condition (DSM-5). Conditions that have lasted for less than one year and have consisted of single or multiple motor and/or vocal tics are diagnosed as Provisional Tic Disorder. Additionally, a diagnosis of Persistent (chronic) Motor or Vocal Tic Disorder is given when only motor tics or only vocal tics have been present for at least one year. Diagnoses of Other Specified Tic Disorder or Unspecified Tic Disorder are given when presenting symptoms are characteristic of a tic disorder and result in clinically significant impairment in social, occupational, or other important areas but do not meet full criteria for a tic disorder. While prevalence data differ significantly in the research, the DSM-5 indicates that the estimated prevalence of Tourette’s disorder ranges from 3 to 8 per 1,000 in school-age children. For the purposes of the following discussion and given that the group program under evaluation serves children with all of the tic disorders described in the DSM-5, the following discussion will not

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focus on distinguishing the different tic disorders but rather will use the terms “tics” or Tourette’s syndrome (TS) to refer to the various identified tic disorders.

Evidence-Based Treatments for Tic Disorders:

A majority of individuals affected by chronic tics that are mild in severity benefit from psychoeducation, support from those around them, and a “watch and wait” strategy, given that tic symptoms often subside in adolescence (Tagwerker & Walitza, 2015). However, if tics do not subside or if a reduction in symptoms is desired, behavioral interventions such as Habit Reversal Training (HRT) have been shown to be effective treatments for symptoms reduction.

HRT involves building awareness of warning signals, referred to as premonitory urges, and practicing a voluntary competing response as a substitute for the tics when the premonitory urge is identified. HRT consists of three parts: The first part is awareness training, in which a rationale for building awareness of tics is provided, tics are described in detail and reenacted until all of its constituent parts and movements are identified, antecedent sensations known as premonitory urges are described and identified, and acknowledgement of the tics and its premonitory urges are practiced. The second component is competing response training, which consists of identifying an alternate behavior or movement that is physically incompatible with the tic and practicing this movement each time a tic is about to occur. The third part of HRT is social support, which entails identifying a support person, training the person to appropriately praise the client whenever he or she uses their competing response correctly, and training the support person to remind the client to use the competing response. HRT is often the primary

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component of Comprehensive Behavioral Intervention for Tics (CBIT), which also includes psychoeducation, contingency management, reward systems, and relaxation training.

HRT has been shown to be a successful treatment for tic disorders. Dutta and Cavanna (2013) conducted a review of 8 randomized controlled studies, which consisted of studies exploring the effectiveness of HRT in the treatment of TS and other chronic tic disorders in children or adults. Only studies utilizing standardized methods of diagnosis (ie. DSM-IV-TR) and standardized outcome measures such as the Yale Global Tic Severity Scale (YGTSS) were included. A total of 353 clients were included in the review. Four of the studies compared HRT to supportive therapy and one compared it to Exposure Response Prevention (ERP). Dutta and Cavanna found that HRT was concluded to lead to significantly greater tic reduction than supportive therapy and ERP. Long term outcomes were less conclusive due to methodological limitations.

McGuire, Piacentini, Brennan, Lewin, Murphy, Small, and Storch, (2014) also conducted a meta-analysis of 8 randomized controlled trials and found medium to large treatment effects for TS using HRT. Further, they found that these effects were comparable to treatment effects of randomized controlled studies exploring the effects of antipsychotic medications. This suggested HRT as a more preferential treatment, given the absence of potential side effects associated with use of antipsychotic medications.

In summarizing the literature on HRT, Koch and Blacher (2007) concluded that HRT met APA Division 12 criteria as a well-established intervention for tics. HRT has also been identified as an Empirically Supported Treatment for chronic tic disorders by APA guidelines (Franklin & Himle, 2007).

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Pharmacological treatment has also been shown to be effective for symptom reduction and when tics have a severe, chronic course, causing pain, discomfort, emotional problems, and significant functional impairment (Tagwerker & Walitza). However, there is a dearth of evidence-based studies on the various medications and few double blind controlled studies examining the effects of medications for tic disorders, with rationale for widely used and promising medications being based almost entirely on case series and open label studies (Thomas & Cavanna, 2013).

The literature on pharmacological treatment for TS was thoroughly screened and discussed by a working group of the European Society for the Study of Tourette Syndrome (ESSTS). The authors agreed that there was a lack of randomized, double blind control trials directly comparing different pharmacological treatment options for TS (Roessner, Plessen, Rothenberger, Ludolph, Rizzo, Skov, Strand, Stern, Termine, & Hoekstra, 2011). In reviewing the existing literature, they concluded that the best evidence arising from randomized, double blind, placebo-controlled studies support typical antipsychotics haloperidol and pimozide, with some indication suggesting that pimozide is more effective and has a more favorable side effect profile than haloperidol. The authors acknowledged that these medications have been replaced by atypical antipsychotics in Europe's clinical practice, with the best evidence existing for the use of risperidone. Still, these medications also present with side effects similar to typical antipsychotics, including sedation, akathisia, weight gain, extrapyramidal symptoms (EPS), neuromalignant syndrome, and tardive dyskinesia (Roessner et al., 2011). Medications used to treat tics often have unwanted side effects, such as weight gain, drowsiness, sedation, and depression, with more severe side effect including dystonia, parkinsonism, akathisia, and tardive

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dyskinesia (Eddy, Rickards, & Cavanna, 2011). For these reasons, individuals are often encouraged to seek out behavioral treatment prior to turning to pharmacological options.

Tics and Comorbidities:

The severity of TS varies widely and is further complicated by a large number of comorbid conditions, which is estimated to be approximately 80-90% (Cavanna, Servo, Monaco, & Robertson, 2009). Given the high rate of comorbidity, it is likely that many difficulties found in individuals with TS also partly result from such comorbidities. Comorbid conditions consist of Attention Deficit Hyperactivity Disorder, Obsessive-Compulsive Disorder, anxiety, depression, bipolar affective disorder, learning disorder, oppositional defiant disorder, and conduct disorders (O'Hare, Helmes, Reece, Eapen, & McBain, 2016).

The presence of comorbid conditions such as OCD and ADHD has been shown to have an impact on psychosocial, educational, and neuropsychological consequences of TS (Mol Debes, 2013). Carter, O'Donnell, Schultz, Scahill, Leckman, and Pauls, (2000) found that children with TS and ADHD exhibited more externalizing and internalizing behavior problems and poorer social adaptation than children with TS only. Furthermore, they found that a diagnosis of ADHD and the severity of obsessional symptoms were significantly associated with social and emotional adjustment difficulties in kids with TS.

Studies have varied in their findings about the impact differences between TS without a comorbid condition versus TS with a comorbid condition. O'Hare et al. (2016) studied a sample of 86 primary caregivers of children and adolescents with TS and found that those with children experiencing TS plus comorbid conditions reported lower global quality of life than those with

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TS only. However, they found that this difference in functional impairment was restricted to the emotional and school domains only, and no significant differences were found in physical and social impairment. No differences were found in social functioning and peer relationships between the two groups and results indicated that the impairment in social and peer functioning was primarily attributable to the presence of TS (O'Hare et al., 2016). Another study of 83 individuals with TS found that participants with purely TS reported a significantly better health-related quality of life than participants that had TS and three or more comorbid conditions, while little differences were found between individuals with TS only versus TS plus two comorbid conditions (Eapen, Snedden, Črnčec, Pick, & Sachdev, 2016). Despite the varied literature about the impact of comorbid conditions, it is apparent that TS presentation is further complicated by the high rates of comorbidities and the combination of these conditions with TS result in further functional impairment.

Quality of Life in Individuals with Tic Disorders:

Quality of life (QOL) in psychological and health research broadly refers to the various aspects that contribute to overall health and include such subcategories as limitations in physical and social activities, psychological stress and well-being, limitations in usual role activities due to physical or emotional problems, and general health perceptions (Bagwell, 2014). Muldoon, Barger, Flory, and Manuck (1998) offer two primary pieces of information gathered when assessing quality of life: functional status of the individual and the individual's appraisal of how their health impacts his or her life. Another definition of quality of life is "a patient's perceptions

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of the impact of disease and treatment functioning in a variety of dimensions including physical mental and social domains” (Varni, Seid, & Rode, 1999).

There is an overall consensus in the literature that TS significantly impacts quality of life factors in youth. Quality of life is especially affected when comorbid conditions are present (Cavanna et al., 2009). Research indicates that the presence of tics is generally associated with impairment in family, peer, and school domains. Thus, it is important to understand the impact of TS on quality of life in this population as well as to identify ways clinicians can address these deficits in order to improve functioning.

In a study of quality of life factors in a sample of 59 clinically-referred children and adolescents with chronic tic disorders, Storch, Merlo, Geffken, Goodman, Murphy, Lack, and Milsom (2007) found that children with tics reportedly experienced a lower quality of life than healthy children in all areas assessed except for physical functioning, as measured by the Pediatric Quality of Life Inventory (PedsQL). The areas in which significant differences were found included emotional, social, and school functioning. They did not find a significant difference in QOL between the TS group and a comparison group consisting of children with other psychiatric disorders such as anxiety, depression, and externalizing disorders. However, the authors found that parents tended to rate their children’s psychosocial functioning as higher than parents of children with other psychiatric disorders. Interestingly, children with tics rated their quality of life similarly to children with other psychiatric disorders, suggesting that these children experienced functional impairment and psychological distress that their parents might not have been aware of.

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Conelea, Woods, Zinner, Budman, Murphy, Scahill, and Walkup (2011) found that tic severity correlated with decreased quality of life in a large sample of youth and parents responding to questions examining the functional impact of tics. Tic severity was also positively correlated with anxiety symptoms and impaired family functioning. Another study exploring quality of life in a sample of 57 children with TS found quality of life to be significantly lower in comparison to a control group, especially in areas of emotional well-being and school (Cutler, Murphy, T., Gilmour, J., & Heyman, 2009). Through focus group panels, Cutler et al. learned that children with TS revealed that close friends were mostly accepting of their TS but that they faced teasing from a wider circle of peers and experienced worries about how these peers viewed them. Eddy et al. (2011) confirmed such findings and found that TS was associated with significant differences in QOL aspects related to social and home activities involving peer and family interactions when compared to healthy controls and an epilepsy comparison group. They also found that comorbidities such as OCD and ADHD resulted in more widespread problems, which was consistent with findings mentioned earlier. However, in their exploration of the functional impact of TS and its comorbid conditions, Cavanna, Luoni, Selvini, Blangiardo, Eddy, Silvestri, and Termine (2013) found that there were no significant differences between the TS only and TS plus comorbidities groups on the overall quality of life scores. Still, they did find significant differences in school and home life impairment scores, with the comorbid groups indicating more impairment in these domains. Overall, comorbid conditions appear to negatively impact QOL in the TS population.

Bawden et al. (1998) found children with TS to have poorer peer relationships when compared to their classmates as well as a comparison group of children with diabetes. However,

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there were no reported social skills or self-esteem deficits in the TS group. Bawden et al. found that the psychosocial problems found in the TS sample did not appear to be a general result of having a chronic illness. Relatedly, Zinner, Conelea, Glew, Woods, and Budman (2012) studied 211 parent-child dyads affected by TS and found that 26% of participants reported experiencing peer victimization. Participants identified as victims were associated with greater tic frequency, complexity, and severity; explosive outbursts, internalizing problems, and lower quality of life. These results provided evidence of the negative social implications for children with TS and the need to address such factors.

Storch, Murphy, Chase, Keeley, Goodman, Murray, and Geffken, (2007) found that children with TS experienced higher levels of peer victimization than healthy controls and children with type-1 diabetes, suggesting that the presence of tics may invite peer attacks. The authors also confirmed a positive cross-sectional relationship between peer victimization and anxiety, loneliness, and general internalizing symptoms. Additionally, they found that peer victimization mediated the relationship between tic severity and loneliness. Storch et al. stated that while a primary focus of treatment may be tic reduction, it is important for treating clinicians to also address psychosocial variables to improve interpersonal functioning, with suggestions including social skills training, navigating negative peer relationships, and maintaining appropriate friendships.

Storch, Brassard, and Masia-Warner (2003) investigated the relationship between overt and relational peer victimization with social anxiety and loneliness in a sample of 383 adolescents. In boys, they found that overt victimization was significantly correlated with fear of negative evaluation and physiological symptoms, but not social avoidance, while boys' relational

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victimization was significantly associated with all three factors. In girls, the study found that both overt and relational victimization were significantly associated with fear of negative evaluation, physiological symptoms, and social avoidance. The study indicated that both boys and girls experiencing both types of victimization experience elevated levels of social anxiety and loneliness. Given the increased levels of loneliness, social anxiety, and avoidance, an important implication of this study was that youth are more likely to avoid educational and social activities, which may then impact their development in these domains (Storch, Brassard, & Masia-Warner, 2003). This suggests that targeting tics exclusively might not be enough to improve TS clients' quality of life and direct interventions focusing on social development might be necessary.

In addition to social implications for children with TS, many face educational difficulties within the school environment. Wadman, Glazebrook, Beer, and Jackson (2016) utilized a case study approach to explore effects of TS specifically within the school environment on thirty-five children in middle school from the perspectives of the students, their parents, and school staff. Major themes that emerged as problem areas for the students related to increased difficulties with completing schoolwork, negative responses to their TS from staff and students, and increased difficulty managing emotions in school. Wadman et al. also found that only a small number of difficulties were correlated with tic severity, suggesting that severity is not a good indicator of the school-related difficulties that students experience. This further suggests that targeting tic severity in the treatment of TS might not fully address some of the difficulties that these clients face.

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Studies on quality of life factors in the TS population highlight the importance of targeting problem solving, social skills, and coping skills within social settings in order to improve quality of life for children with TS. The ample research on tics and their association with lower quality of life in youth living with tics suggests a need for programs and interventions that have a goal of improving factors related to quality of life and not just focus on reducing tics. Unfortunately, there is a dearth of such programs.

Impact of TS and Comorbidities on Families:

TS and its comorbid conditions have been shown to have significant impairment on the family unit. Wilkinson, Marshall, and Curtwright (2008) explored the relationship between Tourette Disorder (TD) and parent reported stress in a sample of 84 parents. This study found that parents did not experience significant levels of stress if the children with TD did not present with any other comorbid conditions. Significant parental stress was related to the presence of comorbid conditions in addition to the TD. The authors did not find a change in stress levels when children were receiving support services in school, suggesting that family-based interventions are needed in order to impact level of family stress. Although TD without any comorbid conditions was not related to high stress levels, these findings are still relevant and important given the high rate of comorbidities in the TS population.

In a study by Lee, Chen, Wang, and Chen (2007), the researchers found significant levels of stress in parents of children with TS. Furthermore, the study found that lower levels of social support were related to higher levels of parent stress and recommended social support groups to help parents obtain helpful resources and alleviate stress.

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A study investigating the effects of perceived social support, caregiver characteristics, and characteristics of a child's disorder on caregiver strain found that caregiver strain was experienced in caregivers of children with TD. The authors found that social support was an important variable in lowering caregiver strain, even in the presence of greater tic severity. The authors provided suggestions to increase perceived caregiver support, which included increasing caregiver awareness of outside support systems and increasing their actual support.

Available Treatments Addressing Quality of Life Factors:

Although research continuously points to social, emotional, and behavioral difficulties in youth with TS, available treatments mostly focus on decreasing tic frequency and severity through behavioral and pharmacological interventions, rather than addressing these other psychosocial domains.

Some studies have found promising results for a cognitive behavioral approach that applies a psychosocial intervention to address impairment associated with tics. Storch, Morgan, Caporino, Brauer, Lewin, Piacentini, and Murphy (2012) introduced a preliminary study on a treatment protocol they developed called Living With Tics (LWT) and its effect on quality of life and psychosocial functioning in eight children with primary diagnoses of TS and chronic tic disorder. The LWT protocol consisted of eight modules delivered over ten weekly sessions. The modules included psychoeducation about tics, cognitive restructuring focusing on distorted beliefs about having tics, problem solving skills, distress tolerance to prevent explosive behavior, overcoming tic-related avoidance, coping in school, improving self-esteem, and abbreviated habit reversal training to directly target tics. Six of the eight participants were considered to be

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treatment responders and exhibited improvement in tic-related impairment, quality of life, and self-concept.

McGinty, De Nadai, Park, and Storch (2012) also explored the application of the LWT protocol through a case study of a 22-year-old male, who was experiencing tic symptoms and psychosocial difficulties resulting from his tics. The study revealed positive psychosocial effects as well as decreased tic symptoms for the subject. McGuire et al. (2015) applied the Living With Tics (LWT) protocol to youth ages 7 to 17 with chronic tic disorders. This curriculum was modified from its original to include parent training and emotion regulation. In addition to a significant decrease in tic severity, the results revealed a significant decrease in clinician rated tic-related impairment as well as child-rated quality of life in comparison to a waitlist control group.

Although LWT addresses quality of life factors, programs addressing such issues in a group setting are limited, despite the clear indication in the literature about difficulties in the social and peer domains. Providing such a psychosocial intervention in a group setting that would provide children with an opportunity to practice learned skills with other kids and to cultivate relationships would be a logical next step.

Available Group Treatments for Children with TS:

As mentioned previously, there is a scarcity of available programs addressing quality of life factors in children with TS within a group setting. One study was found that utilized a group approach to the treatment of tics: Yates, Edwards, King, Luzon, Evangeli, Stark, McFarlane Heyman, Murphy, Ince, and Kodric (2016) compared a Habit Reversal group and an Educational

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group and their effects on tic severity and quality of life. Results indicated that tic severity decreased significantly more in the HRT group, while quality of life tended to improve in both groups with generally no significant differences. This suggested that focusing on tic management in a group setting may indirectly result in quality of life improvement, but did not necessarily lead to improvement in coping and social skills.

Murphy and Heyman (2007) developed a group for children with TS that focused on helping children understand and deal with their tics. The groups covered topics such as understanding TS and tic management, self-esteem building, school and bullying, coping with anger, obsessive-compulsive difficulties, and general feedback and review. While they did not statistically evaluate the impact of the group, qualitative data suggested that participants found the group to be positive, useful, and helpful in allowing them to discuss issues that are unique to children with TS.

Evaluating the group program that is implemented annually at the TS clinic at Rutgers University will contribute to the current literature and potentially expand the use of existing psychosocial interventions. Providing stakeholders with essential information regarding the program's value, fidelity, and effectiveness will allow them to make informed decisions about the program and target potential areas in need of improvement.

Social-Emotional Group Program for Children with TS at Rutgers University:

The Tourette Syndrome Clinic at Rutgers University holds an annual group for children with tic disorders. The program is a Cognitive Behavioral program that is designed to help youth cope with Tourette syndrome and tics. It consists of 10 sessions and includes psychoeducation

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about tics, identification of thoughts and feelings relating to tics, coping with difficult thoughts and feelings, and problem solving. It is unique in that it aims to address quality of life impairment within a group setting. The group is co-led by two graduate student clinicians that are involved in a practicum at the TS clinic. The clinicians assist with the recruitment process for group, conduct screening interviews with children and families to determine appropriateness and fit for the group, co-lead the weekly group sessions with the participants that have agreed to participate in group, and receive weekly supervision from the group supervisor to help facilitate implementation of the group curriculum.

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Chapter III

Description of Program Evaluation Approach

Program evaluation allows evaluators to use research methods to study a program's effectiveness systematically and assist stakeholders in answering important questions about the value of a program (Rossi, Lipsey, & Freeman, 2004). Program evaluation is a process through which programs are evaluated to determine their quality. Additionally, program evaluation provides directions for improvement of the program and provides valuable information to others in their own program development. In addition to providing qualitative information about a program's functioning, program evaluation serves to also provide a framework for making evidence-based and informed decisions about the particular program. The methods of program evaluation are fluid and allow for an individualized approach based on the particular program's needs.

There are a multitude of models available for program evaluation. Evaluators must consider the scientific accuracy as well as relevance to the program under evaluation. Quantitative approaches involve the use of instruments such as rating scales, questionnaires, and surveys to make conclusions about a program through psychometric analyses and interpretations, while qualitative methods involve using interviews, focus groups, field notes, and copies of documents to understand individuals' subjective experiences. While there is a case for using quantitative methods due to their rigorous psychometric analyses, qualitative methods offer consumers of the evaluation more utility and practicality in reviewing the results ((Rossi, Lipsey, & Freeman, 2004).

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Maher's model of Planning and Evaluating Human Services Programs (2012) is a qualitative model for evaluating programs that allows for significant flexibility in the evaluation process. This flexibility is particularly important and relevant in evaluating the group program at the Rutgers TS clinic, as the stakeholders have unique and personalized questions that they wish to answer about the program and its value, for which a qualitative approach would be more valuable and appropriate. Maher's model is based on a systems framework which presents the evaluation process as consisting of four phases: clarification, design, implementation, and evaluation. While these phases are separate, they depend on one another for successful application and control. Due to this interrelated and dependent nature of the four phases, the overall planning and evaluation process is termed as interactive and reflexive (Maher, 2012). Maher's model allows the evaluator to determine things such as evaluation questions, data collection variables, data collection methods, and procedures. Maher indicates that in order for programs to be provided to a population, they can first benefit from sound program designs, which can be determined through a thorough and systematic program evaluation.

Maher provides several reasons for the importance of the evaluation phase. One reason is to ensure that the investment of resources is contributing some value to the target population. Another reason is that program evaluations can facilitate improvement in the program as it exists. A third reason suggests that a program evaluation can identify whether a program needs to be altered in some way in order to add to its value or perhaps even expand to other populations. A fourth reason is that an evaluation can assure the continuation of funding to the program by outside sources as it addresses specific external concerns. Finally, a comprehensive program

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evaluation is likely to result in the involvement of key stakeholders in matters related to continued program improvement.

According to Maher (2012), there are four qualities to a sound human services program evaluation: (1) practical: the plan designed by the program evaluation can be implemented by individuals in the organization in a way that is not disruptive to organizational routines, (2) useful: information generated by the evaluation allows stakeholders to make informed decisions about the program and identify targets for improvement, (3) proper: the program evaluation adheres to all ethical standards and legal requirements that are relevant to the program, and (4) technically defensible: the evaluation plan includes methods, procedures, and instruments whose reliability, validity, and accurateness can be justified, given the program evaluation questions.

Maher (2012) identifies twelve major activities of the evaluation phase, which are sequential, interrelated, and reflexive (Maher, 2012): (1) identify the client that has expressed interest in the development and improvement of a program, (2) determine the client's needs for program evaluation that may not be readily apparent, (3) place the program to be evaluated into "evaluable" form by describing the design of the program based on its design elements in order for it to be clear to everyone as to what is being evaluated, (4) delineate the program evaluation questions that will inform relevant stakeholders about the program's value and how to proceed in improving the program, (5) for each program evaluation question, specify the data collection variables that will allow data to be collected to answer the question, (6) describe the data collection methods, instruments, and procedures that will allow data to be collected, (7) describe the methods and procedures for data analysis that will be used to make sense of the data that have been collected, (8) specify program evaluation personnel and responsibilities, (9) delineate

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guidelines for communication and use of program evaluation information for each program evaluation question, (10) construct program evaluation protocols by placing information generated about how to answer each question into a coherent form, (11) implement the program evaluation as delineated in the evaluation plan, and (12) evaluate the program evaluation with respect to its soundness.

The purpose of this dissertation is to evaluate the existing group treatment program at the Tourette Syndrome Clinic at Rutgers University. Utilizing Maher's framework for program evaluation, the program will be placed into evaluable format in order to identify the essential program elements to make clear the aspects of the program that are being evaluated. Additionally, program evaluation questions will be generated by relevant stakeholders and graduate student group leaders regarding the program and data collection variables. Further, procedures will be specified that will allow the questions to be answered. Since the TS program has not been formally assessed, this dissertation will contribute valuable information to the stakeholders regarding its appropriateness, value, and effectiveness. Additionally, this evaluation will prepare the program for future outcomes research.

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Chapter IV

Evaluable Program Design

Placing the Program into Evaluable Form:

According to Maher (2012), placing the program into evaluable form allows for sound evaluation to occur. An evaluable program is one that reflects a program design that indicates (1) clarity – the extent to which written information that describes each program element exists as well as the degree to which the design of the program is understood by the client, evaluator, and relevant stakeholders, (2) compatibility – the degree to which each design element appears to be consistent with all other elements, and (3) development status – the extent to which the implemented program is developed in terms of its resources. In order to place the TS program into evaluable form, the development of a program design document is required. This is a written description of the essential program elements that serve as the basis for the evaluation phase.

Data Collection Variables:

In order to answer the program questions relevant to this evaluation, data collection variables need to be identified in order to effectively document the program design. The identified data collection variables include the population served by the program, the needs of the population, purpose and goals of the program, eligibility standards and criteria, policies and procedures of the program, methods and techniques used to facilitate goal attainment, materials used in conjunction with methods and techniques, equipment supporting program operations, facilities in which the program is implemented, components and activities of the program, budget that supports the operation of the program, personnel responsible for implementation, incentives

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for personnel and participants to follow through with the program, and a program evaluation plan allowing data to be gathered and analyzed about the worth of the program (Maher, 2012).

Data Collection Methods, Instruments, and Procedures:

Methods facilitating the collection of the identified data consisted of conducting semi-structured interviews with the program director, group supervisor, practicum students, and administrative director overseeing the functioning of the TS group program. The evaluator created a list of interview questions for the directors/supervisor and another list of questions for the practicum students (See Appendix A). The questions allowed for elaboration, flexibility, and follow up. The questions served to obtain information about the identified data collection variables from the directors, supervisor, and clinicians. Another data collection method included a thorough review of the program documents such as TS program policies and procedures, group curriculum, screening guidelines, needs assessment, and measures collected prior to the intervention and after the intervention. The last data collection variable was the informal observations of the weekly supervision groups consisting of the group supervisor and the practicum students. All information collected was kept confidential and no identifying client information was reported. The information gathered through these means was used in creating the program design document.

Program Design Personnel and Responsibilities:

The evaluator was responsible for conducting interviews with the directors, group supervisor, and practicum students. The evaluator also had the responsibility to conduct informal

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observations of the group supervisions. Furthermore, the evaluator gathered and reviewed relevant program documents discussed above from the director of the program.

Guidelines for Communication and Use of Program Design Information:

The information gathered from the program design document contributed to the program evaluation phase and facilitated the process of addressing the program evaluation questions posed by the director. Findings were communicated to the director by the evaluator.

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Chapter V

Evaluable Program Design Document

Target Population:

The target population of the social-emotional group program at the Tourette Syndrome clinic consists of children and adolescents diagnosed with tic disorders, who are experiencing social difficulties. However, children with tic disorders who are experiencing minimal social difficulties but may be at risk for future difficulties are also targeted by the program. Children with tics that can benefit from learning about tics, learning ways to better cope with and problem solve difficult social situations, and increasing their confidence in and acceptance of themselves are typically targeted by the program. The program serves children all over the state of New Jersey due to the positive reputation of the program, low cost of services, specialty of services, and lack of similar available group programs addressing social difficulties. The age composition of the groups largely depends on the clients expressing interest in the group in a given year. Historically, there have been child groups (approximate ages 7-12) and teen groups (approximate ages 13-16). The program conducted during the 2016 year consisted of 5 children ages 9-12. Four of the participants were male and one was female. While not an ideal composition in terms of sex, this is a likely outcome given that TS is significantly more prevalent in the male population.

Program Purpose and Goals:

The social-emotional program at the TS clinic has been running for several years and has been revamped and altered several times throughout its course. While different program

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components such as parent training and the group curriculum were revised over time, the goals of the program have remained consistent throughout the years. A 10-week group curriculum is implemented by two graduate students, who are also clinicians in the TS clinic. The group meets weekly in a classroom at the Graduate School of Applied and Professional Psychology.

Clinicians meet weekly with the group supervisor to discuss the upcoming lesson and to prepare for implementation of group lessons and activities. The value that is intended through the implementation of the program is to build the members' comfort and acceptance of their tics, to help them feel more confident in addressing interpersonal difficulties due to their tics, to increase socialization between members, and to increase student clinician experience in providing group therapy to children with TS. The goals of the program are representative of information obtained from literature on psychosocial functioning of children with TS, a needs assessment survey completed by parents of children with TS, and clinical observations and expertise of the previous and current directors and supervisors of the clinic.

One goal of the program is to bring together children and families affected by TS, as this is often the first time that children are meeting other children with TS. As children and families often are not a part of the TS community, are not familiar with available resources, and/or might not participate in the large scale events orchestrated by the New Jersey Center for Tourette Syndrome (NJCTS), the program allows them to connect with and to relate to one another. Furthermore, as schools often do not identify students with tics that are in need of additional services (Packer, 1997) and do not have programs that target the social challenges and needs of this population, students can benefit from meeting peers like them.

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A second goal of the program is to provide the children with knowledge and tangible skills that will help them adjust to situations that their tics make challenging for them.

Collectively, results from the needs assessment, literature review, and clinician experience identified four main areas of need: tic education and experience with tics, identification of thoughts and feelings, learning to cope with difficult thoughts and emotions, and problem solving. The curriculum is based on these identified needs and teaches participants skills relevant to these areas. Specifically, these skills are (1) psychoeducation about tics to increase knowledge and understanding, (2) cognitive challenging to increase acceptance of tics and normalize the experience, and (3) social problem solving to increase ability to deal with tic related situations in social and family settings.

A third and perhaps overarching goal is to help children develop and/or increase acceptance of their tics and to develop a healthy attitude toward their tics. This is intended to be accomplished through the group curriculum lessons, normalization of tics, as well as the child and parental connections that result from participation in the program.

A final goal is to provide graduate students with training, knowledge, and experience in providing a Cognitive Behavioral Therapy group intervention for children with tics. This training is facilitated through the hands on experience of co-leading the group and through weekly supervision related to the group process.

Group participants and parents are given pre and post group measures to complete that collect baseline functioning prior to group participation and functioning after group completion. The measures provided prior to group are (1) Child Attitude Toward Tics, which was adapted to a tic specific version from the Child Attitude Toward Illness Scale (Austin & Huberty, 1993); (2)

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Tic Impact Scale, parent and child versions, which was adapted from the Tourette Syndrome Impact Survey for Children (Conelia et al., 2011) to only include questions related to impact of tics on a child's life; (3) Yale Global Tic Severity Scale (YGTSS) (Leckman et al., 1989); (4) Child Behavior Checklist (CBCL) (Achenbach, 1994); (5) demographic questionnaire created and used by the TS clinic for intakes; (6) diagnostic report form developed by the TS clinic; (7) TS Acceptance and Action Questionnaire (Best, 2009), and (8) two identified group goals, collected from parent and child. The measures collected upon group completion are (1) Attitude Toward tics (CATIS), (2) Tic Impact Scale (TIS), parent and child versions, (3) Yale Global Tic Severity Scale (YGTSS), (5) TS Acceptance and Action Questionnaire; (6) form inquiring about the extent to which identified goals were met, and (7) consumer satisfaction survey developed by the TS clinic. Additionally, clinicians meet with parents after group to debrief and to provide feedback regarding the child's progress made in group.

According to Maher (2012), it is important for a program's goals to be specific, measurable, attainable by the target population, relevant to the population, and that a timeframe is set for each goal. The program's goals are directly related to the population needs and are summarized in terms of these characteristics in table 1.

Table 1:

Characteristics of Social-Emotional Group Program Goals:

Identified Goal of Program	How Goal is Measured	Is Goal Attainable by Participants?	Is Goal Relevant to Participants?	Goal Timeframe
Connect children and families affected by TS	Not measured	Yes	Yes	By completion of program

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Continued – Table 1.

Teach tangible skills to manage challenging situations	Not measured	Yes	Yes	By completion of program
Increase Acceptance of tics	TS Acceptance and Action Questionnaire.	Yes	Yes	By completion of program
Provide quality training to graduate students	Not measured	Yes	Yes	By completion of program

Eligibility Standards and Criteria:

Recruitment for group participation takes place by sending the group flyer to the New Jersey Center for Tourette Syndrome (NJCTS), which regularly sends email blasts to its members, by notifying a neurologist affiliated with the TS clinic to provide information to patients, by informing the principal investigator for a Rutgers genetics study of TS to disseminate information to families, by notifying clinicians who are seeing children and families for individual therapy to address tics to discuss the group with clients that might benefit, and by informing new families calling into the clinic for services about the group. All interested families are then scheduled for a screening appointment at the TS clinic.

Student clinicians interview interested families and their children to determine eligibility for group, using a screening format and questionnaire guide developed by the TS program (See Appendix B). Clinicians identify the goals of the interview as providing information about the group and determining whether the group is a good fit for the child. Clinicians ask parents and children about hopes and expectations for group, feelings toward the child's tics, quality of life

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interference of tics, and challenges resulting from having tics. The clinician then provides an explanation of the goals of group and allows opportunity for questions.

Children and teenagers with TS are eligible to participate in the social-emotional group. Children who have co-occurring conditions such as OCD and ADHD are also eligible. Children who have social difficulties are prime for participation, but children who may have less significant social difficulties are eligible as well. Eligibility in these cases largely relies on whether it is believed that the child will benefit socially from participation in the group. Children's developmental ability to interact with others and capacity for abstract thinking is also considered in the screening process. All potential cases are reviewed and discussed in supervision to determine appropriateness for the group.

Exclusion criteria include substance abuse, psychosis, severe developmental disabilities, limited verbal abilities, and significant cognitive deficits. The group can be effective and beneficial for children with high functioning autism, with some necessary modifications.

Policies and Procedures:

The TS clinic at Rutgers University is a subspecialty clinic of the Rutgers Psychological Services clinic. As such, the TS clinic abides by the policies and procedures of the Rutgers Psychological Services clinic, outlined in the clinic handbook. Additionally, the TS clinic follows its own policies and procedures that relate specifically to the functioning of the TS clinic and updated annually in the TS Program Policies and Procedures manual.

The director of the TS program and the supervisor of the group program are responsible for verbally disseminating information to graduate students about expected program procedures

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and reviewing the TS Program Policies and Procedures manual. During recruitment time for group, weekly supervision meetings review the referrals to group and guide student clinicians in the selection process. Once the group is composed, the group supervisor provides group materials to student clinicians for review and meets with them to review the program curriculum and to outline procedures for the group, including length of the group sessions, group rules for participants, attendance expectations, progress note logging, and any other logistical concerns that arise. Subsequent weekly supervision sessions focus on reviewing the curriculum, troubleshooting any problems that may have arisen in previous group session, and preparing for the following group session.

Methods and Techniques:

The personnel participating in the functioning of the social-emotional program utilize the following methods and techniques to facilitate the program's goal attainment: (1) Recruitment and screening procedures to recruit and identify the target population of children that would benefit from the program; (2) collection of pre-intervention data in order to identify child and parent goals for group, and collect information about how tics impact the child's life; (3) implementation of the 10-week CBT group program to facilitate the acquisition of knowledge and understanding of tics, normalization and acceptance of tics through cognitive challenging, and problem solving skills in social situations related to tics; (4) weekly supervision sessions with student clinicians to facilitate student learning and training in group treatment for the target population; and (5) post-group information gathering to measure program success and

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participants' experiences, as well as debriefing with parents about participants' progress made in group.

Materials:

The following materials are used in conjunction with the methods and techniques of the program outlined above: (1) group flyer specifying the goals of the group, logistical details such as length of group and location, and contact information to schedule a screening appointment (See Appendix C); (2) screening interview guide for clinicians conducting screening interviews; (2) pre-group measures for parents and children to complete (See Table 2) as well as consent and assent forms for parents and children to sign providing permission for group participation; (3) written group curriculum called My Tics and Me separated into 10 sessions with goals, materials, activities, and descriptive details as well as examples of each identified activity for each session (discussed in further detail in the components, phases, and activities section); (4) materials to facilitate group session activities including paper, crayons, worksheets, etc.; and (5) post-group measures for parents and children to complete (See Table 3). The following two tables outline the specific pre-group and post-group measures completed by participants and their parents, their intended purpose, how they are used, and their expected utility:

Table 2.

Description of Pre-Group Forms Used by the TS Group Program

Name of Form	Purpose of Form	How Form is Used	Expected Utility of Form
Demographic Questionnaire	To collect information about child's developmental, medical, family, treatment, education, and social history	Parent completes form during screening interview and clinician reviews with parent	Facilitates discussion during interview, to identify any areas of concern, and gathers comprehensive picture of child

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Continued – Table 2.

Diagnostic Report	To identify psychiatric and/or educational diagnoses other than TS	Clinician interviews parent during screening interview	To identify diagnoses aside from TS that might influence child's life and participation in group
Child and Parent Group Goals	To identify parents' and children's goals for group	Clinician interviews child and parent during screening interview	Determines participants' goals for group and whether they align with program goals
Acceptance and Action Questionnaire	To identify child's acceptance of his/her tics	Child completes form during screening interview	Obtains baseline data of tic acceptance prior to implementing group curriculum
Child Attitude Toward Illness Scale (CATIS)	To measure child's attitude toward their tics	Child completes form during screening interview	Obtains baseline data of attitude toward tics prior to implementing group curriculum
Tic Impact Scale (TIS), Child and Parent	To identify parent and child's views of the impact of tics on child's life	Child and parent complete form during screening interview	Obtains baseline data of impact of tics prior to implementing group curriculum
Yale Global Tic Severity Scale (YGTSS)	To identify presenting tics and their severity	Clinician interviews parent and child during screening interview	Obtains baseline data of presenting tics and their severity prior to implementing group curriculum
Child Behavior Checklist (CBCL)	To identify any presenting behavioral and emotional problems	Parent completes form during screening interview	Identifies behavioral and emotional difficulties that may be of concern

Table 3.

Description of Post-Group Forms Used by the TS Group Program:

Name of Form	Purpose of Form	How Form is Used	Expected Utility of Form
Child and Parent Group Goal Achievement Form	To rate parents' and child's perceived achievement of goals	Parent and child complete form during last session of group	Identifies whether parents and children felt the group met their personal goals

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Continued – Table 3.

Acceptance and Action Questionnaire	To identify child's acceptance of his/her tics	Child completes form during last session of group	Identifies whether child's acceptance of tics after participating in group
Child Attitude Toward Illness Scale (CATIS)	To measure child's attitude toward their tics	Child completes form during last session of group	Identifies child's attitude toward their tics after participating in group
Tic Impact Scale (TIS), Child and Parent	To identify parent and child's views of the impact of tics on child's life	Parent and child complete form during last session of group	Identifies child's and parent's perceptions of the impact of child's tics on his/her life after participating in group
Consumer Satisfaction Survey, Child and Parent	To rate parents' and child's satisfaction with group and to identify strengths, weaknesses, and any additional comments about group	Parent and child complete form during last session of group	Provides feedback to group leaders and supervisors about client satisfaction with group

Equipment:

Equipment used in the support of program operations includes computers, printers, telephones, and white boards. Computers are used to view group materials and write up progress notes as well as to input data from forms for record keeping on a secure and confidential drive, printers are used to print relevant materials for use in group, telephones are used in communicating with families about group, and white boards are used in group to facilitate lessons and activities.

Facilities:

The TS clinic group program is housed in the Rutgers Graduate Program of Applied and Professional Psychology. Groups take place in a designated classroom with desks, chairs, and a

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white board. Another classroom is reserved for parents as a waiting room, where they are able to interact with one another while waiting for their children to be finished with the day's group session. Finally, the TS clinic director's office is used for group supervision sessions.

Components, Phases, and Activities:

Target individuals are recruited to take part in the social-emotional group once per year, with recruitment and screening procedures beginning around October-November and group typically beginning in January-February. Group is led by two student clinicians and typically contains 4-6 children, allowing for more individualized attention. The group conducted in 2016 consisted of 5 children.

One component of the program is the recruitment and screening phase, which consists of circulating information about the group to organizations and individuals discussed earlier, and conducting screening procedures with individuals interested in participating. The screening process also includes completion of the pre-group forms discussed earlier.

The main component of the social-emotional program is the 10-week group curriculum called My Tics and Me. This curriculum is provided by student clinicians once per week for 1.5 hours to the group participants. The activities of each session are summarized in table 4.

Table 4.

Summary of My Tics and Me Curriculum:

Session Numbers and Module	Session Goals/Activities
1-2: Tic Education, Normalization, and Externalization of Tics	Recognize that tics constitute only one aspect of identity, share how tics affect lives, learn basic facts about tics, share knowledge about tics with peers, dispel myths about tics

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Continued – Table 4.

3-4: Thoughts and Feelings Identification	Build emotion vocabulary, recognize and identify emotions in self and others, identify internal “self-talk” (thoughts), identify emotional triggers, understand link between thoughts and feelings, understand link between thoughts, feelings, and behavior in specific situations
5-6: Coping with difficult thoughts and emotions	Understand benefit of having variety of tools to cope with challenges associated with tics, practice identifying automatic thoughts and coming up with alternative possibilities, identify common maladaptive thinking styles and inaccurate thoughts, learn strategies to challenge maladaptive thoughts, practice challenging maladaptive thoughts
7-8: Problem solving – Responding to teasing and talking about tics	Learn different ways to respond to teasing about tics, learn problem solving steps to respond to teasing and other interpersonal problems, recognize everybody has unique characteristics, conditions, or qualities about themselves, learn strategies to explain tics to others, practice talking about tics with others
9-10: Putting it all together	Learn to brainstorm and choose best solution to solve specific problems, learn to apply problem solving skills across situations, share thoughts and feelings about graduating from group, share lessons learned in group, review skills covered in the previous groups

Another component of the program is the training and supervision of student clinicians.

The activities of this phase include weekly one-hour supervision sessions with the group supervisor in which the curriculum, activities, challenges, and feedback are discussed.

The final component of the program is the post-group procedures, which consist of children and parents completing the post-group measures discussed previously. Children and parents are given the opportunity to provide feedback about the group to the clinicians. Additionally, this phase includes a follow-up session with parents to discuss their children’s progress and potential recommendations moving forward.

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An indirect—albeit important—component resulting from the program is the social connections formed by parents of the children. As parents are led to a classroom in which they wait for their children to finish with group, they typically initiate conversation with one another and sometimes proceed to continue communicating outside of the bounds of the group. A previous version of the curriculum included a parent component that focused on educating parents about TS, with topics being developed from parent feedback on what they would be interested in learning about. However, this component was removed, mostly because parents were at significantly different developmental levels of their knowledge of TS and consensus on what to focus sessions on proved to be a challenge.

Budget:

The TS clinic and its operations are funded by a large endowment provided by a parent of a child with TS, donations from the New Jersey Center for Tourette Syndrome (NJCTS), and revenues from providing therapy to clients. This money is used to provide TS clinic staff and postdoctoral fellow with salaries, provide student clinicians with a stipend, and to fund any materials needed for individual and group treatment. There is no specified budget for group. Materials required by the curriculum are typically identified prior to group and are purchased with the funds generated by clinic operations.

Personnel:

The following personnel are responsible for implementation of the social-emotional group program: (1) the clinical director of the TS clinic, who oversees all program-related

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functions in addition to all clinical and research operations of the clinic, (2) the social-emotional group program supervisor, who participated in the collaborative effort to write the group curriculum and who oversees the weekly supervision groups with student clinicians, (3) two doctoral-level student clinicians, who are responsible for conducting screening procedures, co-leading the weekly groups, preparing materials for group, communicating with parents regarding group and their children's progress, and conducting post-group feedback procedures.

Incentives:

There is no additional salary or monetary reward given to the clinical director or the group supervisor for participation in the group program. Student clinicians receive an annual stipend as part of their practicum experience at the TS clinic, which—outside of the group program—includes individual therapy to clients. Another incentive for student clinicians is the acquired training in facilitating a CBT social-emotional group for children with TS.

Hypothesized incentives offered to group participants include increased confidence, increased social skills, increased problem solving skills, and the development of friendships.

Program Evaluation Plan:

A formal program evaluation plan that allows data to be gathered and analyzed in order to make judgments of worth about the program on an ongoing basis does not currently exist. Consequently, a program evaluation has not occurred to date.

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Chapter VI

Program Evaluation Plan

Data Collection Variables:

The data collection variables used in evaluating the quality of the TS group program included goals of the program, activities facilitating the connection of children and families with TS, knowledge and skills provided by the group curriculum, activities facilitating increased acceptance of tics, and graduate student training experience. These variables were directly connected to and representative of the questions that the director of the program wished to have answered about the program through the current evaluation.

Data Analysis Methods, Instruments, and Procedures:

Data collection methods utilized in the program evaluation included interviews with the program director, group supervisor, and the administrative director facilitating the functions of the TS program. These interviews were used to identify goals of the social-emotional program, identify questions to be answered by the program evaluation, and facilitate the acquisition of information in order to answer the program evaluation questions. Interviews were also conducted with two student clinicians in order to obtain feedback about the group program and student training experience. Additional methods used to answer questions specified by the program director consisted of a review of the program documents, which included the group curriculum, instruments and measures used during the screening process and after group completion, and a review of the needs assessment. Informal observations of weekly supervision groups that consisted of the group supervisor and student clinicians were also used as a data collection

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method. Information gathered from the director, administrative director, group supervisor, and student clinicians was collected through face to face interviews with the evaluator. Program documents and measures were provided to the evaluator by the program director for review. All information collected was kept confidential and no identifying client information was reported. The information gathered through these means was used in facilitating the program evaluation to examine the worth of the social-emotional program.

Program Evaluation Personnel and Responsibilities:

The evaluator was responsible in conducting interviews with the directors, group supervisor, and practicum students. The evaluator also had the responsibility to conduct informal observations of the group supervisions. Additionally, the evaluator collected relevant program documents discussed above from the director of the program.

Guidelines for Communication and Use of Program Evaluation Information:

The information gathered from the methods discussed above contributed to the program evaluation and addressed the program evaluation questions posed by the director. Findings were communicated to the director by the evaluator. Dissemination of the program evaluation information to staff and relevant stakeholders will be at the discretion of the program director.

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Chapter VII

Program Evaluation

Identify the Client:

The client is the Director of the TS Clinic at Rutgers University. The client is responsible for overseeing and approving all aspects of the program including curriculum development, screening process, regular functions and processes of the group program, and graduate student training and supervision.

Client's Needs for Program Evaluation:

The client wishes to better understand and identify the value of the social-emotional program for children with TS. The client wants to know whether the program is being implemented as intended. Specifically, the client wishes to know whether the program is addressing its goal of connecting children and families affected by TS, whether the program is teaching tangible skills to children with TS, whether the program is helping to increase acceptance of tics, and whether graduate students are obtaining quality training in the program. The client expects this knowledge to be gained through a systematic review of the available program documents, interviews with students running the group program, as well as informal observations.

Program Evaluation Questions:

The broad question that this evaluation is serving to answer is whether the social-emotional group program at the Rutgers TS clinic is valuable to the target population. More

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specific questions that are encompassed by the broad question were identified by the director and can be seen in table 5:

Table 5.

Specific Program Knowledge the Client Wishes to Acquire:

Current Knowledge	Desired Knowledge
Client lacks knowledge as to whether the program is meeting its goal of connecting children and families affected by TS	Client has knowledge about whether the program is facilitating connections between children and families affected by TS
Client lacks knowledge about whether the program is providing group participants with tangible skills to navigate challenges resulting from TS (ie. psychoeducation, coping and identifying difficult thoughts, and problem solving)	Client has knowledge about whether group participants have acquired tangible skills to navigate TS related challenges
Client lacks knowledge about the program's effectiveness in increasing participants' acceptance of their tics	Client has knowledge about whether the program is effective in increasing participants' acceptance of tics
Client lacks knowledge about the quality of training provided to graduate students through the group program	Client has knowledge about the quality of training perceived by the graduate students

Goals of the Program:

As previously discussed, there are four main goals that were identified by the program director: (1) connect children and families affected by TS, (2) provide group participants with knowledge and tangible skills to navigate challenges posed by their tics, (3) increase participants' acceptance of their tics, and (4) provide a positive training experience in group CBT

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for tics to graduate students. Each of these goals will be reviewed and evaluated based on the available data.

Connecting Children and Families Affected by TS:

One of the goals of the social-emotional program at the TS clinic is to connect children and families that are affected by TS. Many children with TS experience impaired peer relations and difficulty maintaining friendships (Bawden, 1998; Storch et al., 2007) and much stress is placed on the children's families, particularly when they do not have access to resources and social support (Wilkinson et al., 2008; Schoeder & Remer, 2007). Therefore, facilitating social interactions for both kids and families where kids can identify with peers and parents can receive social support is a particularly important goal.

The TS group program facilitates these connections in several ways. By being a specialty program for children with tics, the program serves to bring children with TS together on a weekly basis and allows for a natural social interactions process. Additionally, the interactive and game-based structure of the group facilitates cooperative interactions between participants. Group members work together in learning about their tics and practice applying learned skills in a supportive and interactive manner. While children are in group, parents wait in a classroom with other parents. This unstructured time also facilitates interaction between parents and provides them with a chance to get to know one another. The opportunity to speak with clinicians affiliated with the TS clinic also provides parents with opportunities to inquire about available resources.

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Currently, there are no specific questions in the post-intervention forms that directly inquire about the social connections perceived by parents and children as a result of participating in group. Therefore, reviewing parent and child pre and post group goals, relevant feedback provided on the consumer satisfaction forms, and observations made by student leaders will help provide insight into whether the group facilitated a connection between children and families.

In reviewing the goals identified by children, this investigator looked for key words or phrases that identified a desire for social connection with others. Most of the child participants identified a goal that was related to making new friends. The post group forms invited children to review the goals they set for themselves prior to group and identify whether they felt they experienced no accomplishment of the goal, some accomplishment of the goal, or full accomplishment of the goal. A review of the post forms indicated that most children who identified such a goal acknowledged full accomplishment of this goal. A review of parent goals also identified key words or phrases that identified a desire for their child to develop a social connection with others. One goal was identified that met this criteria and some accomplishment of this goal was noted on the post-intervention form.

Overall, there was some indication that children and parents who had personal goals for the children to make friends mostly felt that this goal was met by the group. There were no goals that provided insight into social connections made by parents. It is difficult to draw conclusions from the available information, as there are currently no specific questions inquiring about social connections formed as a result of attending the group. Additionally, since not all participants and parents identified goals related to social connections, there was no way to gauge social connections made by participants and parents that identified alternate goals for the group.

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A review was also conducted of the strengths, weaknesses, and comments sections of the consumer satisfaction surveys in order to identify any feedback that was provided about social connection. While there was no qualitative feedback from children about social connections, most parents indicated that a strength of the group was that their child was able to meet and interact with other children like him/herself. Additionally, most parents commented that they would have liked to have participated in more structured parent sessions.

According to group leaders, the group was a good opportunity for the children to meet others that had tics just like them, as not many have had this kind of opportunity in the past. Leaders indicated that the camaraderie was helpful to the children and that most children met their goals of making new friends. This was consistent with the review of the goals forms and parent comments on the consumer satisfaction surveys. Furthermore, both group leaders agreed that some form of a structured parent component to the group would have been helpful in connecting parents more and making better use of their time while waiting for their children to be finished with group.

Overall, there were some personal goals identified that were consistent with the program's goal of building social connections between children and families affected by TS, and most of the goals were indicated to have some or complete accomplishment. Additionally, consumer satisfaction surveys suggested that parents felt a strength of the program was that their children were able to meet and connect with other children with tics. Group leaders echoed this belief. Finally, feedback from both parents and group leaders called for a more structured parent component. While it appears that connecting children and parents affected by TS was a goal that

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was generally successful in being met by the group program, this was challenging to assess without a specific procedure in place for measuring the attainment of this goal.

Skills to Navigate Challenges Related to Tics:

The client also wishes to know whether the group program is addressing the goal of teaching participants tangible skills that will help them navigate challenges that are related to having tics. Specifically, the goals of the group curriculum titled *My Tics and Me* are to provide psychoeducation about tics to increase knowledge and understanding, to teach cognitive challenging in order to increase acceptance of tics and normalize the experience, and to teach social problem solving to increase ability to deal with tic-related situations in social and family settings. The curriculum was developed based on a needs assessment surveying parents of children with TS, a consideration of children with TS from a psychosocial perspective based on available literature, discussions with experts in the field of TS, and considering the treatment approaches of Cognitive Behavioral Therapy. The curriculum seeks to address the population's needs identified through these procedures. This section will focus on a review of the curriculum to determine whether it is addressing the three identified goals. Components of group such as homework, behavioral reward system, prizes, and reporting back information learned in group to parents will not be discussed, as the focus will remain on identifying how specific group lessons are addressing the three goals identified above.

Sessions 1 and 2 address the first goal of providing psychoeducation about tics to increase knowledge and understanding. The goals of session 1 are outlined in the group manual as building group rapport and cohesion, establishing group rules, recognizing that tics are only

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one part of the whole person, and discussing how tics affect the children's lives. Group members engage in a guided activity of identifying various things about themselves and making "me boxes" that include things about their interests and hobbies. This activity focuses on identifying similarities as well as differences between the group members and concluding that their tics are just one thing that make them different from peers. The other activity in session one focuses on identifying and sharing ways in which tics affect group members' lives. This activity allows members to identify both positive and negative ways that tics have impacted their lives and allows them the opportunity to share this information with each other. This session allows participants to consider and think about their own tics, while also learning about how tics affect other kids.

Session 2 involves learning basic facts about tics, sharing knowledge about tics with peers, and dispelling common myths about tics. Group leaders take participants on a scavenger hunt in which they have to answer questions about tics correctly in order to be sent to a location in which the next clue awaits. This activity allows group leaders to educate participants about tics and to address common misconceptions that the kids might have. Participants then engage in another activity in which they write up a "ticopedia" page about tics utilizing the knowledge they gained from the scavenger hunt. Members work together in compiling information and help each other identify facts about tics.

Sessions 1 and 2 appear to be consistent with their outlined goals of teaching members about tics and helping them learn about their own tics as well as the impact it has on their lives. The ticopedia activity allows group leaders to assess the knowledge members gained from the

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scavenger hunt and also allows leaders the opportunity to clarify, correct, and expand on the information members retained from the previous activity.

The second goal of the curriculum is to teach cognitive challenging in order to increase acceptance of tics and normalize the experience. Sessions 3, 4, 5, and 6 are relevant to this goal. Session 3's goals are identified as building emotion vocabulary, recognizing emotions in self and others, and identifying cognitions, which are referred to as "self-talk." Participants engage in a game in which they identify as many emotions as they are familiar with and then identify how the emotions present themselves in terms of physical presentation. Participants also engage in a game called "emotion charades," in which children take turns acting out various emotions using only body language and facial expressions, while the group attempts to guess the emotion being acted out. The idea of "self-talk" is then introduced and using cartoons and thought bubbles, participants practice identifying their own self-talk in various scenarios presented by the group leaders. Members practice identifying cognitions in neutral scenarios, tic-related scenarios, and eventually create their own scenarios to identify their thoughts. This session is the first step in teaching cognitive challenging and addresses its goals of increasing knowledge of emotions, identifying emotions, and increasing awareness of cognitions.

The goals of session 4 include identifying feeling triggers, increasing understanding of the link between thoughts and feelings, and understanding the link between thoughts, feelings, and behaviors in specific situations. Participants practice identifying various situations that trigger different feelings for them and practice using "I feel" statements in connecting their feelings to the situations. Various scenarios and thoughts are then presented in order to help members make the connection between their self-talk and their related emotions. Participants

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engage in another activity called “the diary of a ticcing kid” to identify some scenarios pertaining to their tics, identify thoughts related to the situations, and identify feelings stemming from their thoughts. Group leaders encourage participants to consider other ways of thinking in the given situations and then ask them to reflect how such alternative thoughts would affect their emotions. The activities of this session appear to be in line with its goals and focus on increasing understanding of the connections between thoughts, feelings, and behaviors.

Session 5 identifies its goals as understanding the benefit of having a variety of tools to cope with challenging situations, and practicing identifying automatic negative thoughts and coming up with alternative thoughts to the negative thoughts. Participants are first given a problem to solve but are not given the physical tools needed to solve the problem. The purpose of this is to demonstrate the importance of having the necessary tools to solve a problem. A discussion then ensues about toolboxes and the value of having different tools for various purposes. Participants engage in creating and decorating their own toolboxes and discuss strategies they have found to be helpful in dealing with challenging situations related to their tics. Group leaders then present the tool of flexible thinking, drawing on the ideas from the previous session about thinking of alternate interpretations of a particular situation. Participants practice flexible thinking and add it to their toolboxes. This session appears directly related to its goals of developing knowledge of various tools to cope with challenges and to develop the skill of cognitive restructuring as an important tool to manage difficult situations.

Session 6 is the final session that addresses the goal of teaching cognitive challenging. The curriculum identified the goals of this session as identifying common maladaptive thinking styles, learning strategies to challenge such thoughts, and practicing cognitive challenging.

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Group leaders discuss common thinking styles that lead individuals to respond negatively including catastrophizing, black and white thinking, and personalization. Participants then watch movie clips and practice identifying the various thinking traps shown in the clips. Group leaders explain the concept of being a “thought detective” in order to address negative thoughts and come up with more comfortable ways of thinking about a particular situation. The group proceeds to learn about various questions to ask when being a thought detective and practices challenging thoughts through a game of debate, where each team asks questions and identifies evidence to support a given thought. The point is emphasized that sometimes negative interpretations of events lead to negative emotions and identifying more helpful thoughts is a helpful tool to use in order to feel better.

These four sessions take participants through all of the necessary steps to teach cognitive challenging and are directly connected to this goal of the curriculum. Building an emotions vocabulary, identifying self-talk, discussing the importance of having various coping tools, learning how thoughts, feelings, and behaviors are connected and impact one another, understanding how differing interpretations can lead to different feelings, and practicing being a thought detective to identify negative automatic thinking and to identify coping thoughts are all essential parts that facilitate learning of cognitive challenging.

Sessions 7 and 8 are directly connected to the curriculum goal of teaching social problem solving to increase the ability to deal with tic related situations in social and family settings. In session 7, problem solving is introduced and explained to the participants, along with a discussion about ways in which problem solving can be useful. The participants are then taught the problem solving STEPS, which consist of (1) **S**tating the problem and how it makes you feel,

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(2) **Thinking** of your goal, (3) **Exploring** and examining solutions, (4) **Picking** a solution and making a plan, and (5) **See** how it worked. After learning these steps, participants create cards that outline these steps and add them to their toolboxes, which they created in an earlier session to collect all of the tools they learn about in group. Social examples of situations are given and participants are provided with opportunities to practice the problem solving steps they learned. Teasing is then introduced to the group and various video clips are shown to illustrate different teasing situations. Participants are given an opportunity to discuss situations in which they have been teased and discuss their thoughts and feelings. The problem solving STEPS are then discussed in relation to being teased and group leaders help participants identify various things they can do in response to being teased. Participants are instructed to write down the strategies and place them in their tool boxes. They are also given the opportunity to practice their strategies in pairs, with one person being the “bully” and the other person practicing his/her strategies for responding to the bully.

Session 8 focuses on learning strategies to talk to other people about tics. Participants engage in an activity in which they identify things that make them different from others, with the goals of normalizing individual differences and identifying their tics as just another thing that differentiates them from peers. Group leaders then engage participants in a discussion about when it might be important to talk about their tics with others and how to talk to others effectively. Participants act out various scripts in explaining tics and engage in a discussion about which ways are effective and which are not. After this, participants have a chance to practice coming up with their own scripts for tics and practice acting out their script in group.

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The homework assignment facilitates this skill by having participants identify a person with whom to share information about their tics and practice talking to that person.

As evidenced in these two group sessions, it appears tangible skills are learned by participants that allow them to navigate challenging situations related to tics and bullying. Concrete strategies and skills are discussed and added to participants' tool boxes and opportunities for practice are provided during and outside of sessions.

Sessions 9 and 10 focus on practicing and reviewing all of the skills learned throughout the group in fun and interactive ways. Time is also allotted to reflect on all of the things participants learned and to provide their feedback to group leaders. This time is also used in helping participants complete the post-intervention forms.

Overall, a review of the group curriculum indicates that the group sessions are designed to directly address the goals of providing psychoeducation, teaching cognitive challenging, and teaching problem solving skills. Interviews with group leaders also suggested that the curriculum was consistent with its outlined goals. Leaders reported that participants responded positively to games and hands-on activities, which were included in each session. Leaders suggested that each child left group with at least a couple of solid skills and each child benefitted from group in some way. Both leaders noted that there were several things that made some lessons and concepts difficult for participants to understand. Leaders identified barriers as attention difficulties, understanding of social cues, differing learning styles, and differences in cognitive functioning as obstacles to retaining concepts. Sessions 5 and 6 were specifically identified as difficult for participants to understand, as the information presented was dense and there was less of a game-based component in these sessions.

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Leaders also expressed that it was unclear how much time should be devoted to the various activities outlined in the curriculum and this often led to having to rush through some activities as a result of taking too much time on others. Leaders noted that a guideline would have been helpful.

A review of the consumer satisfaction surveys revealed that most of the participants enjoyed attending the TS group. Additionally, most children reported that they learned useful things from going to the TS groups. Qualitative questions completed by participants indicated that some things they found most helpful about the group were breathing exercises, different ways to problem solve, and learning to talk to others about tics.

While a qualitative review of the curriculum sessions determined that the curriculum goals are consistent with the lessons and skills that are taught and that the curriculum teaches tangible skills to the participants, there is currently no structured way of measuring participants' acquired knowledge as a result of participating in group sessions, nor are there any post-intervention questions directly connected to concepts taught in the sessions. Identifying a way to measure this knowledge after administering the curriculum might be an effective way to determine whether participants are actually understanding and retaining the concepts. This might also serve to identify any points of difficulty in learning information in order to modify its presentation in subsequent editions of the curriculum.

Effectiveness in Increasing Acceptance of Tics:

The director desires to know whether the group program is effective in increasing participants' acceptance of their tics. Increasing acceptance of tics is another identified goal of

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the program. The curriculum currently interweaves lessons to increase acceptance of tics. For instance, the first two sessions focusing on psychoeducation serve to normalize the experience of tics and drive home the message that tics are only one part of participants' lives. Furthermore, sessions teaching cognitive challenging also target acceptance of tics by helping participants challenge negative beliefs and develop realistic beliefs about their tics.

The program currently has a measure in place that is meant to measure this acceptance. The Acceptance and Action Questionnaire-Tic Specific Version (AAQ-T) is used as a pre-intervention and post-intervention scale to measure acceptance of tics, and was adapted from the AAQ-9 (Hayes et al., 2004). The AAQ-9 is a 9-item measure of experiential avoidance and is frequently used in treatment outcome studies of Acceptance and Commitment Therapy (ACT). The concept of experiential avoidance relates to the unwillingness of an individual to remain in contact with private experiences such as bodily sensations, emotional responses, and thoughts. As a result of this avoidance, the individual takes steps to actively alter these experiences even though this avoidance may result in behavioral harm. Experiential avoidance has been implicated in a broad range of clinical disorders and higher levels have been associated with higher levels of general psychopathology, anxiety, depression, fears, trauma, and a lower quality of life (Hayes et al.). Significant decreases in pre-post avoidance have resulted in a greater openness to experiencing aversive private events (Best, 2009). The AAQ-9 was shown to have an internal consistency of $\alpha=.70$ as well as sound divergent and convergent validity (Hayes et al.).

The AAQ-T is a 15-item measure adapted from the AAQ-9 by Stephanie Best and Scott Compton of Duke University to specifically measure tic-related experiential avoidance. The results can be classified on a continuum from "avoidant" to "accepting." The total score ranges

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from 0 (accepting) to 60 (avoidant). In their pilot review of the measure using 10 interviewees, the authors concluded that on the whole, the AAQ-T was acceptable, comprehensive, and understandable to individual with tics as well as individuals that were asymptomatic. Overall internal consistency in a sample of 225 was found to be $\alpha=.90$ and convergent validity was found to be good. However, additional research of this measure would be needed to establish reliability and validity and as it currently stands, the AAQ-T is not a psychometrically sound measure.

In an attempt to measure whether the group program impacts acceptance of tics, the AAQ-T is given to participants prior to and post group participation. However, there is no analysis in place to determine whether the difference in scores is significant and there is a concern expressed by the director that the small sample size will not identify significant differences in a statistical analysis. A review of the score differences suggests that there is an overall decrease in scores and an overall increase in acceptance of tics. However, limited conclusions and meaning can be derived from this due to the lack of reliability and validity data on the measure, and the uncertainty of difference in scores being reflective of legitimate change based on group participation.

Quality of Training to Graduate Students:

The director is interested in learning about graduate students' experience in the quality of training received in the social-emotional group program. Information about the type of training as well as the experience of the student clinicians was obtained from informal observations and interviews with two student clinicians that were involved in implementing the group program.

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Training for the group social-emotional program consists of providing the group curriculum to student leaders in the beginning of the year in order to provide them with time to review the curriculum and ask questions that might arise, meeting with the group supervisor and director prior to initiating screening interviews to review screening questionnaires and procedures, and meeting for weekly hour-long supervision sessions on the days that group meets with the group supervisor to discuss the upcoming group lesson.

Overall, the training was found to be beneficial and helpful in running the group program. One thing that was noted was the day that supervision was provided, which was the morning of the day that group would take place. Group leaders indicated that this did not always provide enough time to adequately prepare activities for group such as videos and ideas for games.

Leaders also reported that there was no time designated to debriefing and processing after group sessions. While preparation for group lessons and activities was adequate, the next time supervision would take place would be the morning of the following group. With the focus of the meeting being on preparing for that day's lesson, there was not enough time to also discuss how the previous group went and to troubleshoot any challenges that might have surfaced.

Leaders found the supervision sessions valuable in regards to obtaining direct feedback about ideas for the upcoming group session from the supervisor. They also found it helpful to discuss certain concepts and to hear examples and ideas from the supervisor about how to effectively present the content. Leaders felt that having the supervisor observe some of the group sessions might have been helpful in providing direct feedback regarding the leaders' therapeutic techniques. Additionally, they felt that doing this would allow the supervisor to directly observe group participants and gain direct insight into the group dynamics, which would result in

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relevant and meaningful discussions about applying the curriculum to the specific group members.

Another comment related to the screening procedures. Leaders reported that the 1.5 hour time frame that was allotted for screening was at times not enough to collect all of the comprehensive information required by the screening process. Leaders found informal discussions about the children's lives and the impact of tics in their lives valuable and useful in determining their appropriateness for group. Leaders also wondered if all of the forms given at the screening interview were necessary. Specifically, the CBCL and the demographic questionnaire were reported to take a lot of time, which could have potentially been used to spend more time getting to know the children.

At present, there are no procedures in place for collecting feedback from student clinicians to determine satisfaction with training received and to obtain feedback about the various functions and activities of the group program.

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Chapter VIII

Recommendations for Program Implementation

In Chapter XI, implementation of the TS social-emotional group program was evaluated to answer specific questions outlined by the director of the program. These questions included whether the program is successful in meeting its goals of connecting children and families affected by TS, whether the program successfully provides participants with tangible skills to navigate challenges resulting from TS (ie. psychoeducation, coping and identifying difficult thoughts, and problem solving), whether the program is effective in increasing participants' acceptance of their tics, and whether the program provides quality training to graduate students. This chapter will highlight the strengths of the program design that are relevant to these questions and will also provide recommendations for further improvement. These recommendations are meant to provide feedback and guidance to the director and relevant stakeholders that are seeking to take steps to improve the program and its evaluation process.

Goals of the Program:

Strengths:

The goals of the program were identified as: (1) to bring together children and families affected by TS, (2) to provide the children with knowledge and tangible skills that will help them adjust to situations that their tics make challenging for them (ie. psychoeducation, cognitive challenging, and problem solving), (3) to help children develop and/or increase acceptance of their tics, and (4) to provide graduate students with training, knowledge, and experience in providing a Cognitive Behavioral Therapy intervention for children with tics.

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These goals appear to be in line with the needs of this population as seen in the literature (see Chapter II), a needs assessment conducted prior to the group program implementation, as well as clinical observations and expertise of the program director and stakeholders. Feedback from children and parents and identification of their goals highlighted consistency between their goals and the goals identified by the program.

Recommendations:

Maher (2012) recommends that program goals should be identified in SMART format and possess the following properties: (1) **Specific**: clearly delineating a valuable accomplishment for the target population, (2) **Measurable**: referencing quantitative indicators that help guide the client in deciding to what extent the goal has been attained, (3) **Attainable**: given the needs of the population and relevant context, the goal is considered as one that can be attained by the target population, (4) **Relevant**: the goal is considered important, given needs of target population, relevant context, and program purpose, and (5) **Timeframed**: referencing a particular period of the time within which the goal is expected to be attained. Placing the current program goals into this format will facilitate more effective measurement of the goals and will increase the likelihood of a worthwhile human services program (Maher, 2012).

It is also important to have processes in place that will facilitate the measurement of the identified goals. For example, there are currently no specific questions in the pre or post measures that inquire about social connections made by children and parents, the skills participants learned, and the training experiences of student clinicians. Creating and/or finding measures, or adding questions to already existing program forms will help collect data to measure these goals.

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Connecting Children and Families Affected by TS:

Strengths:

The TS group program brings together children with tics in a weekly interactive group that facilitates cooperation and social interaction. It also provides parents with unstructured time to spend together, which may facilitate interactions among parents. The general conclusion reached from examining children's goals for group, parent's goals for their children, consumer satisfaction surveys, and interviews with student clinicians, was that the TS group was successful in connecting children and families affected by TS. Most children and parents who identified goals for group that related to the children making friends indicated that this goal was met. Additionally, group leaders agreed that group participants made friends and connected with their peers.

Recommendations:

As the goal of connecting children and families affected by TS is an important target of the group, there are some additional ways to maximize this connection. Arranging several events outside of group sessions can provide additional opportunities for the children and parents to connect and interact with one another. Furthermore, student leaders can make it a point to share community resources and TS related events with parents in order to foster a connection to the TS community beyond the group program. Ensuring that parents are connected to NJCTS and are aware of events and communities focused on providing support and resources to families will help meet the group's goal.

Parents and group leaders also indicated a need for a more structured parent component to the group to increase social interaction among parents. A challenge in conducting such a group

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was identified by the director as parents being on different developmental levels in their knowledge of TS, rendering an educational component for parents to be difficult to formulate. One way to address this challenge might be to shift the focus away from providing education about tics and instead have these groups be parent-driven. For instance, asking parents about specific topics that they would like to discuss in the beginning of the group and structure sessions based on this direct feedback might be helpful in ensuring that all parents benefit from group in some way. Another way to address this challenge might be to make it a processing group, where parents can connect with each other based on some of the challenges they experience and facilitate conversations about ways to manage theirs and their children's difficulties. Finally, a third possibility might be to have parent sessions that parallel what their children are learning in group and also include some parent behavior management training to address challenging behaviors in the home. This will allow parents to understand what their children are learning in groups and will allow them to facilitate and generalize the acquisition of skills learned in group into every day life. Orienting parents to community resources that can provide additional social support once group is finished is another important point to consider.

Lastly, because the group does not currently have a way of obtaining feedback about whether parents and children experienced increased social connections as a result of participating in the group, it would be helpful to include a measure that will focus specifically on assessing this. Identifying an existing valid measure that taps into this construct, including questions on the consumer satisfaction survey, or creating an original checklist of several questions requesting feedback about this construct will serve to measure this program goal.

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Skills to Navigate Challenges Related to Tics:

Strengths:

The social-emotional group curriculum called My Tics and Me is determined to be consistent with its goals of providing psychoeducation about tics, teaching cognitive challenging to address difficult thoughts related to tics, and teach problem solving skills to manage challenging social situations. The concepts are delivered in ways that participants find engaging, interactive, and fun. Things learned in session are also assigned to be practiced for homework, further facilitating retention and generalization of skills. Feedback from both leaders and participants suggested general satisfaction with the group and suggested that participants learned useful skills.

Recommendations:

Based on feedback from leaders about difficulty of knowing how much time to spend on each activity and having this ultimately result in spending less time on other important topics, it might be helpful to identify approximate amounts of time to spend on session activities so the leaders can better prepare and anticipate the structure of the sessions. Having a general sense of how much time each activity should take will allow leaders to monitor the time more effectively and will also allow them to modify activities as needed.

Another way to address the time management challenge is to shift the way the group is structured from the 10-session structure to a module-based structure. In other words, instead of having 10 specified sessions in which each concept is predetermined to take place over a certain number of sessions, the number of sessions allotted for each module would be dictated by the pace of the group. While not knowing the exact number of sessions in the program might create

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some ambiguity for participants and parents, it will ensure that enough time is being devoted to each activity and concept. Furthermore, this module-based structure will address another challenge presented by group leaders in regards to participant differences in learning and retaining information at the pace required by the current curriculum. Having more flexibility in how much time to spend on a given lesson will allow for differentiated instruction and lead to improved learning for the participants. A way to alleviate some of the ambiguity might be to provide a number range for the group (ie. group will be administered over 10-15 sessions) and abide by the limits of the range provided to parents.

While the curriculum is consistent with its goals of providing psychoeducation, teaching cognitive challenging, and teaching problem solving, there is currently no process in place for obtaining feedback about whether the participants are actually successfully learning and understanding the information being presented. Instituting a method for collecting information about whether concepts are being successfully learned will allow leaders and stakeholders to make important decisions about and modifications to the length of time devoted to modules and methods of delivering the information to continue improving the method of delivery. A way to measure this learning might be to include several representative multiple choice questions in the end of each module that assesses understanding of the major concepts presented. These questions will serve as direct feedback regarding comprehension and will assist the program in identifying points for improvement and modification in subsequent curriculum delivery.

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Effectiveness in Increasing Acceptance of Tics:

Strengths:

The program's curriculum appears to include group sessions that focus on increasing acceptance of tics. These sessions focus on educating kids about their tics, normalizing their experience, and teaching to challenge some inaccurate and negative thinking about their tics. The program currently has a specific measure in place to collect data on acceptance of tics. The AAQ-T is currently given before and after the group intervention to determine whether the group successfully impacts participants' acceptance of tics. Although a review of the available data on acceptance suggests a general trend toward increased acceptance after having participated in the group, limited conclusions can be derived from this review.

Recommendations:

Given the questionable reliability and validity of the AAQ-T, it might be prudent to improve the psychometric properties of this measure, should the director wish to continue using it to assess changes in acceptance. Establishing overall reliability of the measure and establishing the criterion of reference of the measure will help to make interpretable and meaningful results from administering the measure.

Another way to address the challenge of performing a quantitative analysis might be to shift to a qualitative analysis. For instance, 2-3 relevant questions might be selected from the AAQ-T and participants might be asked to identify whether the statements pertain to them in a "mostly yes" and "mostly no" format. "I feel embarrassed by my tics," "the bad things I think about myself because I tic must be true," and "I don't try out new things if I'm afraid I will tic"

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are examples of statements of acceptance from the AAQ-T that might be asked before and after participation in the group and evaluated qualitatively to see if there has been a change in acceptance. However, this type of analysis will limit the director in being able to conclude that the program is responsible for a change in acceptance.

A search of the literature did not yield any measures that are specific to measuring acceptance of tics. However, a measure called Acceptance of Illness (Felton, Revenson, & Hinrichsen, 1984) was found, with good reliability and validity. This measure is a self-report designed to measure the acceptance of an illness. It consists of eight items describing various negative consequences of illness such as limitations and low self-esteem and can be used to measure acceptance of any condition. This measure would have to be reviewed to determine relevance and appropriateness for the TS child population.

Given that there is concern over finding significant changes in acceptance through a quantitative analysis due to the small sample size of the group, finding a measure that has better established reliability and validity will still not address the issue of the small sample size. A way to address concerns over small sample size might be to collect data over several years of the group and combine the pre and post results into one analysis.

Quality of Training to Graduate Students:

Strengths:

Reports from group leaders suggested that the training provided for the social-emotional group was useful, effective, and relevant. Leaders found it helpful to review each session prior to its implementation and obtain ideas and implementation strategies from the supervisor.

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Recommendations:

Holding supervision sessions in days prior to the actual session will address concern raised about not having enough time to prepare. Additionally, in order to ensure that there is enough time to process how group sessions went, it might be helpful to either add an additional half hour or hour to the supervision session, where the first part of the meeting focuses on processing the session that already took place and the second part of the meeting focuses on preparing for the upcoming session. Another way to address this is to perhaps split the supervision up into two sessions, where one focuses on debriefing and the subsequent one on a different day focuses on preparation for the next session.

Leaders also suggested having the group supervisor observe several sessions in order to gain a better understanding of the particular group dynamics, so as to facilitate relevant discussions about challenges and ways to address them in group. Another way to increase the supervisor's understanding and familiarity with the group participants might be to have leaders audio or video record sessions and present relevant footage in supervision. This would allow leaders to obtain feedback about therapeutic techniques used and to consult about specific challenges that might arise. This method might be more feasible than having the group supervisor observe sessions, given the potential challenges of supervisor availability during the time of the group.

Leaders commented on the screening process and reported that they felt it was too lengthy while also questioning the necessity of using all of the screening instruments. Providing families coming in for screenings with the demographic questionnaire and the CBCL to complete

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prior to the screening interview will help with time management during the interview. The questionnaires can be sent back prior to the interview in order to allow clinicians to review the materials and note anything significant to follow up on during screening.

Furthermore, since the CBCL is given only prior to group and not after, the question arises about its function, since it does not appear that it is being used to measure whether the group has any impact on problematic behaviors. Providing the CBCL prior to the screening interview makes good sense if it is used in order to identify any behaviors that might be problematic during group and/or whether there are significant problems that might need to be addressed before being able to attend group.

Additional Reflections and Recommendations:

Recruitment:

An additional concern raised by the director outside of the primary evaluation questions addressed above was related to the effectiveness of the recruitment process and the challenge of recruiting a large enough group. The current recruitment strategy consists of sending the group flyer to NJCTS and having NJCTS send periodic email blasts to its listserv with this information, having a collaborating neurologist verbally inform TS clients about the group, having a collaborating researcher studying genetic factors linked to TS verbally inform clients about the group, having clinicians verbally inform existing clients of the group, and gauging interest in group from new families calling into the TS clinic for services. Another recruitment effort that was noted by the administrative director was an increased focus on community outreach to increase awareness of subspecialty clinics including the TS clinic and its services.

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Challenges of recruiting an appropriate group of children that meet the eligibility criteria and are of similar ages are expected, particularly because the group is specialized. One way to improve the dissemination of group information to the families that have access to the collaborators of the TS program (ie. neurologist and genetics study researcher) might be to provide their offices with the group flyers to give to families when they arrive for appointments. This is likely to increase family's exposure to information about the group and will also provide them with a direct source of information about goals of the group. Making flyers available to the general clinic staff so that they may provide further information to families that express interest in the TS clinic services might also help to distribute information about the group. Finally, another way to improve recruitment might be to consider contacting outpatient clinics that provide CBT and/or CBIT therapy and distribute group flyers to the offices so that they may share with their clients. Being present at NJCTS events can also help disseminate information about the group. Having a spreadsheet with contact information of families that call throughout the year to inquire about the group will help to facilitate follow up that TS program clinicians can conduct once it is time to schedule screening procedures.

Expanding Services:

Another topic to consider relates to ways in which the TS program can expanded to be more helpful to families. Wadman, Glazebrook, Beer, and Jackson, (2016) identified challenges that children with TS and parents reported children face in school as difficulty completing school work, difficulty managing emotions in school, and negative responses from staff and peers. School staff was also surveyed and tended to report lesser and different difficulties than that

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identified by children and parents, suggesting gaps in knowledge of school staff and warranting a need for education. Another study that examined focus groups of children with TS, parents, and health professionals found that misunderstanding about tics by teachers and peers largely contributed to the stigma and social maladjustment in kids with TS (Rivera-Navarro, Cubo, & Almazan, 2014). The authors recommend that increased understanding through education and training for school staff can help address these issues.

Expanding the TS program to include a school-based educational component for school staff and students would be a helpful way to address lack of knowledge and understanding identified in the literature. Additionally, providing consultation to educators about students with TS as well as discussing helpful classroom strategies will benefit educators, children, and parents. Providing these services to schools can also have a secondary gain of distributing information about the services offered by the TS clinic, particularly the social-emotional group program.

Another suggestion for expanding the services of the clinic is to conduct workshops for parents and educators that might focus on similar topics presented above. Workshops might focus on psychoeducation, parent management training, and classroom management skills. Such events would again serve a dual purpose: provide useful training to the community and help inform parents and educators about services offered by the TS clinic.

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Chapter IX

Evaluation of the Program Evaluation

The final activity in the program planning and evaluation process is to evaluate the program evaluation itself. According to Maher (2012), this evaluation allows the evaluator and relevant stakeholders to decide ways in which future program evaluations can be improved in order for them to better serve program planning actions as well as the whole planning and evaluation process. Furthermore, a sound program evaluation enhances the likelihood that a thorough evaluation of the program will continue to occur. Maher identifies four qualities of a sound human services program, which include practicality, utility, propriety, and technical defensibility. The current evaluation will be examined in regards to these four qualities.

Practicality refers to the extent to which the program evaluation was conducted in a way that allowed for its successful accomplishment. The evaluation should be implemented in a way that is not disruptive to organizational routines (Maher, 2012). The tasks of the program evaluation consisted of placing the TS group social-emotional program into evaluable form, creating a program design document to identify the elements of the program, and evaluating the program on whether it is valuable to the target population and whether it is addressing the goals of the program. These tasks were practical for the evaluator to perform without creating disruption to the routines of the program. Collecting data that facilitated the completion of these tasks included accessing program records and documents, interviewing the director, group supervisor, and group leaders, and observing group supervision sessions. These activities demonstrated practicality and were implemented in a way that did not disrupt the functions and routines of the program, which allowed for the tasks' successful accomplishment.

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The quality of *utility* examines the ways in which information gathered as a result of the program evaluation is useful to stakeholders, thereby allowing them to make informed decisions about the program and about ways to improve it (Maher, 2012). Information obtained from the creation of the Program Design Document will be useful to the director of the TS program, as such a document did not exist prior to this program evaluation. The evaluable format will allow stakeholders to assess program elements in a coordinated manner and will facilitate further program development and improvement. Furthermore, the results of the evaluation of program questions delineated by the director will be useful to stakeholders because it provides guidance to steps that can be taken in order to improve the program. The evaluation is also useful to stakeholders, student clinicians, and client participants in the program, as the information obtained through the evaluation can improve service delivery to children with TS, improve training to graduate students, and improve adherence to goals set out by the program.

The quality of *propriety* relates to ensuring that the program evaluation occurs in a way that adheres to ethical and legal standards pertinent to the program (Maher, 2012). Permission for the evaluator to have access to program documents was obtained from the director through the signing of a consent form. Additionally, consent to interview the group supervisor and group leaders was provided, as well as permission to use their answers in this program evaluation (see Appendix D). Information was gathered and reported in a manner that protected the confidentiality of the participants and all collected data was kept in a secure location. Evaluation procedures adhered to guidelines set by the Institutional Review Board. Further, the evaluation was approved by the Institutional Review Board (IRB Protocol # E16-427).

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Lastly, the quality of *technical defensibility* refers to the degree to which the evaluation's methods, procedures, and instruments can be justified with respect to matters of reliability and validity, given the program evaluation questions (Maher, 2012). The Program Design Document that was used was developed by Dr. Charles A. Maher and outlined in his resource guide called *Planning and Evaluating Human Service Programs, A Resource Guide for Practitioners*.

Interview questions were designed by the evaluator, with different questions aimed at the director and supervisor of the TS group program versus student clinicians in the program. These questions were created in order to directly and accurately obtain information needed to create the Program Design Document and to obtain feedback and insight in order to answer questions about the program identified by the director. While reliability and validity data cannot be obtained on these questions created strictly for use in this evaluation, they appear to be accurate and relevant to the program evaluation questions.

Recommendations for Continued Evaluation:

Questions identified by the director are also recommended to be placed into SMART format discussed previously in order to ensure that the goals are measurable. Furthermore, it is recommended that the program evaluation questions be reviewed in future evaluations to ensure that they are reflective and inclusive of what is important for the director to know about the program. For instance, while the director expressed interest in identifying whether the pre and post measures used are appropriate for what the program is attempting to measure, the program evaluation question only referred to the acceptance measure and did not facilitate inquiry into other constructs being measured.

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It is recommended that the interview questions created by the evaluator for interviews with the student leaders, director, group supervisor, and administrative director be reviewed and improved to be reflective of the SMART goals. Additionally, it is possible that the student clinician interview component can be eliminated once a feedback measure is put into place that will inquire about their training experience in the program.

Since a future goal of the program is to evaluate outcome data to determine whether the program is successful in improving quality of life and tic acceptance, it is prudent for future evaluations to look more closely into how such outcome studies can be made feasible, given the uncertainty of the current measures used as well as the small sample of participants that currently participate in the program annually.

Limitations:

It is important to consider limitations when interpreting the findings of the current program evaluation. One limitation of the present program evaluation was the use of a qualitative design rather than a quantitative design. Qualitative methods used in this evaluation consisted of interviews, review of program documents, and informal observations. Qualitative methods have some benefits to their use including offering utility for program decision makers, offering more practicality than quantitative methods, and extracting meaningful information from the data collected (Rossi, Lipsey, and Freeman, 2004). However, limitations of the particular qualitative methods identified in the current evaluation include lack of reliability and validity of the methods used. While meaningful and practical information is gained from using such qualitative methods, quantitative methods are superior in terms of their psychometric

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properties, which result in strong technical defensibility. Future plans for program evaluation should consider incorporating the use of quantitative methods.

Another limitation of the current evaluation is the potential for subjective researcher bias. Given that the evaluator is a graduate student that was previously a clinician at the training program in the TS clinic, this may have resulted in embedded researcher bias. The evaluator took steps to minimize this bias through self-evaluation for potential bias. Further, the fact that the evaluator was not one of the student clinicians leading the group program allowed for increased objectivity when evaluating group processes. Still, an outside evaluator not affiliated with the program in any way would have been preferable in maximizing the opportunity for an objective evaluation. Interviewing the director of the program as a stakeholder also had potential for subjective bias, as the director is involved in day to day activities and processes of the program. An important consideration regarding this limitation was that 2016 was the director's first year in overseeing the TS clinic and therefore the director's stake and involvement in the development of the various activities was minimal.

Lastly, feedback results from clients and student clinician interviews were only conducted with the individuals that took part in the group program during the 2016 year. Since students and participants from previous years may have had significantly different experiences than the ones currently sampled, and since it is possible that unique characteristics of the current sample may have skewed the results of the evaluation, the validity of the student sample may have been negatively impacted. Therefore, caution should be taken in generalizing the results and in considering these results to be representative of all years that the program has been implemented.

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Appendix A: Interview Questions and Answers

Supervisor Interview Questions: (director)

1. What is your role in the development and maintenance of the program?
 From a historical standpoint, group was typically overseen by the program director. When previous director began to oversee the TS clinic, it was decided that responsibility would be split between the group supervisor (person responsible for revising the curriculum for group) and the director and this division remains currently.
2. How and when was the TS group program formulated?
 Do not have exact time when it was formulated, but it has been in existence for over 10 years. It has been revised and changed over time. There were previously parent and sibling components to the group. Sibling group only ran for a few years because of wide age gaps in sibling participants creating some challenges. Parent group was more needs-based from asking parents what they thought would be topics of interest to them. Guest speakers were often present. Part of the problem with parent group was that parents would be at very different points in terms of knowledge about TS and it was challenging to make it effective for everyone.
3. What was the target population and has it changed over time?
 Target population is children and teens with TS that experience social challenges. See kids from all over NJ because of reputation, specialty of services, and low cost of services. This also speaks to the fact that there are not a lot of providers out there that are not servicing the community in this area.
4. What are the recruitment procedures?
 Send information to NJCTS, to affiliated neurologist to share on the medical side, genetics researcher to share on the research side, make existing individual clients aware of the groups, and inform new families calling in about the group.
5. What are the goals of the program?
 Not very familiar with the curriculum as it stands. Goal is to bring families and kids together. It is not uncommon that the group is the first opportunity that the kids are meeting other kids that have TS. Kids and families might be intimidated by the large events offered by NJCTS, also those events are rare (once or twice a year). We are the only facility offering this kind of group. It is a unique thing that we are doing. General function is to bring the kids and families together in order to help normalize the experience for them, which will help them become more accepting of their condition. Acceptance of tics is the most important goal and function of the group and we have been struggling to find ways to measure it. Another goal is to provide kids with tangible skills that will help them adjust to situations that their tics make difficult for them. Three skills have been cognitive challenging (to increase acceptance and normalization), social problem solving, and psychoed. Social problem solving in how to deal with tics in social

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situations and in their families. TS is so much of a visible disorder than others and it creates a lot more social challenges. There is only so much that can be accomplished in this area in individual treatment. Hearing peers help with cognitive challenging and work through problem solving is most effective in teaching these skills. Best way to teach these social skills. Group also serves to filter kids for individual treatment too.

6. How is each goal measured and evaluated?

We do not have a measure in place for evaluating the social interaction piece. In the past, social skills measure was given but that was abandoned because it's not addressing global social skills. Global self-esteem measures were also abandoned because they were more global rather than pertaining to the tics. This year, we cut down on symptom specific measures. They were given at baseline just to see if children would benefit from it. We measure acceptance through the acceptance questionnaire, but it is not a psychometrically sound measure, not much validity on it and we have a small sample so we're not sure if it is effective in measuring the acceptance.

7. What challenges does the program present?

Finding ways to measure acceptance. Screening and recruitment is also challenging (ie. getting together a group of similar ages with a sufficient amount of participants. Also, being able to assess and monitor what the participants are gaining from group.

Specific questions for program evaluation to answer:

Are parents and kids getting out of it what we're intending them to get out of it? What do they think is helpful about the group? Are the things that parents and kids are finding beneficial about the group in line with what we are trying to accomplish through the group?

Are we effective in targeting the things we are trying to improve? Particularly acceptance of tics and feeling confident to tackle problems that tics cause in child's life?

Are there ways we can expand the program that will be helpful to families? Are there ways to overcome the barriers to parent groups encountered in the past?

Given that it is a unique service we are giving and we end up with a small group in the end, why is it that we are ending up with such a small group? How can we improve recruitment? Is there a different format (as opposed to the 10 weeks) that would be more appealing?

How are practicum students experiencing the program? How can we make sure that we are utilizing the group as positive training opportunity for all practicum students?

Is this curriculum consistent with goals for the program?

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Is the program a valuable service to the community and a valuable training opportunity for practicum students?

Supervisor Interview Questions: (group supervisor)

8. What is your role in the development and maintenance of the program?
Group have been running for several years, before group supervisor was a student and continued when he was a student at GSAPP. Several years ago the groups were under enrolled (4-5 years ago). Groups started off strong but over time enrollment shrank. Some years the groups did not run even though students were available to run them. Group program was a relative weakness of the TS clinic. During fellowship, agreed with the director at that time that the group was not meeting the needs of the community and made a decision to revamp the groups. Thought about needs of TS kids from a psychosocial perspective. Also did literature search to understand the needs of kids with TS and their needs (needs assessment). Surveyed the TS community (parents) by putting together a brief questionnaire and partnered with NJCTS to distribute it to the TS community for feedback. Also sent out questionnaire for expert feedback. The program is a clinical training program with the aim of being able to contribute to the community. Research is drawn directly from the participants of the program and relevant for the clients that we serve.
9. What is the eligibility criteria for group participants?
Individuals with TS, including other co-occurring conditions, who are developmentally able to interact with other children and have some ability for abstract thinking. Children who have significant social difficulties are prime for group, children who have less difficulties can also benefit. 10-12 year olds is the prime age. Designed to help people who are at risk and struggling or to prevent from developing difficulties. Hard exclusion criteria: substance abuse, psychosis, developmental disabilities, limited verbal abilities, severe cognitive limitations. Program can be implemented for high functioning autism but requires modification, and we have done this in the past, carefully adapted to fit the kids in the group
10. What materials are used in implementing the program?
Previous curriculum was primarily developed based on clinical intuition. Programs were less structured and not completely TS specific, didn't focus on the idea of a life with TS. There were various version of the program. Current program identified several needs of kids with TS: parents thought kids would benefit about education about tics, learning about how common tics are, learning about course of tics over time, how to respond to teasing in general and in relation to tics, co-occurring conditions, definitions of tics, meeting other people with tics, problem solving strategies, strategies for calming down, etc. Collectively, review of the needs assessment, lit review, and clinical experience, four main areas were identified: tic education and experience with tics (normalization,

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externalization of tics), thoughts and feelings identification (also relates to notion of calming down, what they're thinking, feeling, and how it impacts their actions), learning to cope with difficult thoughts and emotions (cognitive restructuring), and problem solving (clinical experience indicated that kids are often asked about their tics), teach kids to talk about their tics in various situations. Problem solving framework is used because talking about tics varies based on the situation, setting, and who is asking. Children are armed with a variety of specific tools on the kinds of answers to provide based on the situation they are in.

11. What are the goals of the program?

Provide practicum students with experience in providing group intervention, provide format for children to learn skills and navigate their day to day encounters while living with tics, become educated about their condition, and develop a certain level of acceptance as well as a healthy attitude toward tics. The program is an attempt to represent integration of research and clinical experience. From a research perspective, we were trying to pick up CBT interventions and components of social emotional learning, tailoring them to the needs of kids with tics. Group model was important to use because parents wanted their kids to meet other kids with tics, felt it was important for kids to be exposed to other TS kids as they often feel like they are the only ones with TS. For children to really benefit from group, they really need to have fun in group. We placed great emphasis on developing developmentally appropriate games and art projects in order to facilitate the skills training

12. What challenges does the program present?

The biggest challenge with the curriculum is that certain parts (like cognitive component) have a lot of information. Moving forward, there is potential to see it not as a 10 week program but more of a 10 step program. Rather than leaving out certain things in a module, perhaps increasing the length of the module will help address needs better.

Specific questions for program evaluation to answer:

1. How do we capture the particular goals of the group? How do you measure when someone has built resilience?
2. How can we develop a more ideographic questionnaire?
3. Outcome piece is biggest question: how to quantify the gains the parents are saying their children are making. Children are gaining greatly according to them and their parents, but the data on standardized measures are not suggesting these gains, discrepancy between qualitative information received from parents and results from standardized measures
4. Difficulty obtaining post data, some parents choose not to do it, how can we improve this?

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Supervisor Interview Questions: (administrative director)

1. What is your role in the functioning of the TS program?
Provide administrative support and oversight to the program. Coordinating with the executive director of NJCTS (one of our funders) and people at the genetics study (one of our collaborators). Manage a budget, make sure the budget sticks, supports program director in the functioning of the program, support and market the program in any way that is useful for the program.
2. What is your role in the functioning of the social-emotional group at the TS clinic?
Ensure the financial viability of the entire TS program. NJCTS historically gave money to support the director position. They provide funding annually. The TS clinic also received a large endowment to support the program from a parent of a child with TS (parent was alum of Rutgers), Parent wanted to endow a program that provided services for people with TS. This allows financial support for the director position, part of postdoc position, and stipends for graduate students. Revenue from seeing clients is also added into the pot to support the program, which includes the group. Marketing the services of the TS clinic is another role.
3. What are the policies and procedures that guide the TS program?
Clinical service delivery falls under the auspices of the clinic and the TS clinic follows the general clinic policies and procedures in addition to the own specialty clinic policies.
4. What do you see as the goals of the group program?
Less involved with the group program to identify its specific goals. Some goals appear to be providing the opportunity to share and not feel alone and to directly addresses the stigma of TS.
5. Strengths and challenges of the program?
No direct involvement with the program. Improving recruitment is a goal to address a challenge: general clinic is doing more outreach to community letting them know about subspecialty clinic services. Challenges to group are pretty typical, if it is specialized, recruitment is challenging.

Student Clinician Questions: (group leader #1)

1. What were the program goals for the group participants?
The goal was not to reduce tics or tic management. Although pre and post YGTSS in past years has shown a reduction, this was not a direct goal of the group. Goals were to educate kids about life with tics, empower them, give them some skills in how to cope and how to handle social situation, and teach them how to speak about their tics.

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2. How did the program curriculum address these goals?
The curriculum provided education about tics, taught problem solving, and provided lots of interactive opportunities to help them learn and become more comfortable with their tics. Not every lesson was necessarily effective for every kid but there was enough variety and selection of topics that every kid benefitted in some way.
3. Was the curriculum understandable?
Mostly, there were like 2 weeks that were dense and difficult (revolving around problem solving, sessions 5 and 6), but overall it was age appropriate and designed in a way that lessons were reviewed and dispersed throughout. The group of kids that we had had a lot of learning challenges and there were times that the kids didn't understand but it seemed to be a function of their profile as a learner rather than the group material.
4. Did you encounter any difficulties implementing the program?
If so, what were the difficulties? Sessions 5 and 6 required a lot of explaining of a lot of different concepts. It didn't lend itself to fun activities and games as much as other sessions. There were some activities that we did revisions to (family feud was changed to jeopardy) and a few activities were changed to game based. I think these alterations fit the group better. Also, because group had one girl and the rest boys, participants and leaders felt having another girl would have been better socially. Also there was a wide variety of learning profiles, ie. rigid thinking and poor social skills but good memory, vs learning challenges and cognitive deficits but socially participating. Some behavioral challenges were present, ie. hyperactivity needed a lot of management. Required a lot of individualized plans.
5. How did the group participants respond to the curriculum?
They remembered all the games they played. Everyone walked away with one or two really solid skills or things they learned. Everyone benefitted. Many of them didn't have any experiences with other kids with tics before the group, so the camaraderie was very beneficial to them.
6. What were the strengths of the program?
Interactive and game based. For the most part, things were presented in a fun way. It wasn't all tic related. This group and its activities wouldn't be redundant for someone in individual therapy. Material was generalizable and relevant. Amount of weeks and session length seemed appropriate. Leaders being connected to the clinic was a good resource. It helped being able to collaborate and work with people well versed in TS and working with challenges kids with tics face.
7. Describe the training and support received in implementing the program:

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Supervision time was sufficient. Felt prepared going in. One problem was that we were always planning for that week, instead of being a week or two ahead to allow for modifications to occur with supervisor. Supervision provided a good chance to hear feedback and bounce ideas off of supervisor. It may have been beneficial for supervisor to visit the group to understand the kids better, in order to provide more direct feedback on kids and leader performance.

Additional Comments:

Intake process:

Unnecessarily long and time allotted (1.5 hours) was not sufficient. It took me 2 hours to complete. Face to face interview is important. Maybe just a short interview and YGTSS would have been enough. Also maybe some questions could have been filled out online as prescreening to allow more time for the interview portion during the actual screening interview. Group goals were important to discuss and the face to face time was also valuable. Other than these piece of information, the other forms completed by parents and kids did not really add any useful information prior to start of the group

Weaknesses:

Program may have benefitted from a larger group. Some weeks we had 3 kids due to absences. Maybe time with parents could have been utilized better, like a more structured program. We also didn't have an opportunity to be prepared by people that have run the group before. Maybe a conversation or maybe notes on adaptations or realizations from running past groups would have been helpful.

Student Clinician Questions: (group leader #2)

1. What were the program goals for the group participants?
To normalize tics, have kids understand that they're more than just their tics, promote kids' comfort in talking about tics to others, problem solving, how to respond to situations such as teasing and bullying, psychoed regarding thoughts, feelings, and behaviors, and how they affect their actions, learning what different actions they can take, and meet others with tics and make friends.
2. How did the program curriculum address these goals?
Different sessions specifically targeted the goals. The way sessions were structured were meant to specifically address goals. Comorbidities like ADHD made it difficult for some kids to understand and generalize the skills. Curriculum was consistent with the goals.

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3. Was the curriculum understandable?
To the clinicians, yes. Some kids got concepts, for some kids, it took a bit longer. ADHD got in the way of allowing kids to focus. Some kids were more immature, and some kids on the Autism spectrum had more difficulty understanding concepts. Spectrum participants felt some social situations were not relevant to them, and it was challenging to apply those situations to such participants.
4. Did you encounter any difficulties implementing the program? If so, what were the difficulties?
Timing: how much time to spend on an activity. The curriculum does not specify time and you have to use your discretion at figuring out how much time to devote to activities. You sometimes have to spend more time when kids might not be getting a concept and this might cut into the group time and into other activities.
5. How did the group participants respond to the curriculum?
They loved the games, anything that was hands on they really enjoyed. The activities also seemed to be appropriate to situations that the kids generally dealt with and encountered. Kids became competitive during games sometimes and some kids had difficulty with frustration tolerance. They responded positively to role play bullying; they really liked acting games. Games and activities was where they paid the most attention and were most involved.
6. Do you think the curriculum addressed the goals of participants?
For the most part. A lot of them identified wanting to meet new friends and learn more about tics, and I believe it addressed these goals. It was difficult for a girl to make friends in the group because the group was all boys, so it would be important to either have more than one girl in the group or have an all boy's group. A lot of them can talk more about their tics with others. Generally, they felt more comfortable in talking about tics.
7. Did you encounter any challenges during implementation? If so, what were they?
Different learning styles of the participants and attention challenges due to ADHD made it challenging to administer the curriculum.
8. What were the strengths of the program?
The games and the fact that kids got to interact with peers that are also experiencing what they are experiencing. Seemed mostly everyone learned something that will be helpful to them in their lives.
9. Describe the training and support received in implementing the program:
Weekly hour supervision sessions took place the morning before the group each week. Focused on reviewing the lesson for that day and making sure to plan for activities for the day. It was helpful to hear examples from the supervisor about how to explain concepts to the group and how to word things. Timing of supervision could have been more structured in terms of how much time is allotted to addressing certain things. Having an

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agenda to make sure we hit everything we needed to would have been helpful. It would have been also helpful to have it earlier than the day of, because it would allow us to prepare for the session better (ie. finding videos and jeopardy questions). There was no processing after group about how it went. Reviewing what the kids did and how to address behaviors that occurred would have been helpful with troubleshooting the challenges of the session. More structure to the supervision sessions would have been helpful. Talking to co-externs and coleader in addressing issues that might surface during group was helpful.

Additional Comments:

Even though there was a check in with parents in the end of each session, they did not fully understand what the kids were learning. More of a parent component would be helpful so that parents can get something out of the process as well.

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Appendix B: Group Screening Guidelines

Rutgers TS Groups Screening

Screening components

- 1) Parent meeting - gather information and tell about groups
- 2) Child meeting - mainly to build rapport and tell about the groups. Can also ask some questions about experience with tics.
- 3) Parent and child together - Complete YGTSS
- 4) Parent and Child complete questionnaires when the other is in the waiting room

Introduction

Bring parent and child in together to briefly introduce yourself and orient them to the meeting...

Thanks so much for coming in. We're so glad to that you are interested in learning more about the groups at the Tourette Syndrome Program. Our goal today is to determine whether they seem like a good fit for you.

Provide an orientation of what will occur (you will meet separately and together, and complete questionnaires while waiting).

GET CONSENT/ASSENT if not already a clinic client

Introductory Remarks to PARENTS

So just to clarify, the goal our meeting today is a bit different than a regular intake evaluation -- we won't be doing an extensive diagnostic interview, developmental history, family history, etc.

Instead, we'll talk together about your child's experience with tics, I'll spend some time telling you about the group, and we'll discuss what you are hoping your child will gain by coming to group. We will also do one formal interview about your child's tics.

Before we wrap up, I'll also be giving you a few questionnaires to complete while I meet with your child briefly. So the goal is to see if we think your child would benefit from participating in the groups.

PARENT Questions – can use for children as well if relevant

General

How did you hear about the groups at the Rutgers TS program?

What got you interested in the groups?

What are you hoping your child will get out of coming to the groups?

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What did you tell your child about why he came here today?
Do you think he/she is interested in participating?

Your child's experience with tics

I'd like to ask you several questions about what it's been like for your child to have tics. I'll be asking a bunch of questions. Some or all may be applicable to your child, or perhaps most of them won't be.

What is your sense of how your child feels about having tics?

- Is he/she bothered by them in any way?
- Does he/she seem to like having them for any reason? Use them to get attention?
- Does he/she seem self-conscious about having tics?
- Does he/she feel different as a result of having tics?

Has your child ever expressed concern that the tics are getting in the way of living life?

- Interferes with his/her ability to do work?
- Make friends? Keep friends?
- Will make it harder to be successful? Harder to get a job one day?
- Does he/she seem ashamed of having tics? Try hard to hide them?
- Does he/she seem to say negative things about himself as a result of his tics? Or complain about "how bad it is" or "unlucky he/she is" to have them?
- As a parent, how have you managed having a child with tics? Are you worried your child's tics may interfere with his life in the future?

Has your child had, or is your child having, any challenges or difficulties as a result of his tics?

- Does your child ever talk about tics with others? Like who?
- Do his friends ever comment or ask questions about them, even just out of curiosity? Or teachers, or peers, or even strangers?
- How does your child respond? Does your child seem to handle it well?
- Has he ever been teased about his tics? How does he respond when that happens?

Brief diagnostic/behavioral history – **USE DIAGNOSTIC FORM TO RECORD**

When was your child diagnosed with tics?

Children with tics are commonly, but not always, diagnosed with other disorders or conditions.

- Has your child been diagnosed with any other conditions or disorders?
- ADHD? Anxiety? OCD? Depression?

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- Does your child have any behavioral challenges? Has your child ever been hit a peer or become aggressive before in school? [if yes, get some additional information keeping in mind the goal is to assess the possibly for aggression in the group. An incident or two of aggression does not necessarily exclude a child from group, but if it would be a red flag if it's a regular occurrence]

Background about the groups – **can discuss with parents as well as children**

As you know, tics are often chronic. They can impact children's lives in many ways. Our groups are designed to help children navigate life with tics. So, if your child is having difficulty now, then being in the group will provide a forum to learn skills. If your child hasn't had any challenges as a result of the tics, then participating in the groups will provide a forum to help build resilience and try to help prevent problems from developing.

So, the overarching goals of the groups are to help children:

- Learn about tics
- Discuss their thoughts, feelings, and experiences related to tics and the best ways to respond to them
- Learn skills to deal with common situations that may come up for children with tics, such as how to respond when asked about tics under different circumstances. For example, how your child will discuss his tics may vary if asked about them by a friend versus a stranger in the grocery store versus when he is teased about them on a playground.
- And do all this having fun

The groups are designed to be educational and to teach children concrete skills that they can take with them. But they are also designed to be fun. The learning is activity and game-based. For example, the children do a scavenger hunt to learn about tics, draw cartoons when learning about thoughts, and review the different skills they've learned in game format.

So how does all that sound? Do you think your child may benefit from this type of group like this?

Wrap up

Thanks so much for coming in. I'm going to have your complete these questionnaires now.

IF CHILD IS A FIT – It sounds like your child would be a great fit based on our conversation. Would you like to sign up? To secure a spot we need a deposit, etc....

IF NOT SURE ABOUT THE FIT – Thanks so much for coming in. I'm going to look over the questionnaires and discuss what we discussed with my supervisor. I will give you a call back within the week. What's the best number to reach you?

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IF CHILD IS NOT A FIT – SAME AS IF NOT SURE

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Appendix C: My Tics and Me Recruitment Flyer

NOW RECRUITING: Group for Children and Adolescents with Tics!

Many children with tics and Tourette Syndrome may experience anxiety, be teased or bullied, develop negative self-perceptions and avoid social situations as a result of their tics.

The Rutgers Tourette Syndrome Program offers a 10-week, group-based program beginning in February that aims to help children build resilience and develop the skills necessary to better navigate life with tics and associated conditions.

The program is based on the research-supported principles of cognitive-behavioral therapy (CBT) and is uniquely designed to help youth:

1. Learn about tics in a developmentally appropriate way
2. Build confidence
3. Identify and manage difficult thoughts and feelings
4. Navigate the various social issues that often come along with having tics, such as talking to others about tics and responding to teasing
5. Connect with other children with tics in a supportive environment



Who? Children and adolescents ages 6-17 with Tourette syndrome or chronic tics

When? Thursday evenings beginning February 11th for 10 consecutive weeks

Where? GSAPP Psychological Services Clinic, Rutgers University Busch Campus, 152 Frelinghuysen Road, Piscataway, NJ

Fee? \$25 for intake meeting plus \$200 per child for entire 10-week program

For more information or to register for the group,
call (848) 445-6111, ext. 40150 or ask your clinician

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Appendix D: Informed Consent Forms:

This Agreement is entered into by and between **Rutgers University Tourette Syndrome Clinic (TS Clinic)** and the Recipient ("**Alina Simanovskaya**") named on **Schedule 1** (attached hereto and by this reference incorporated herein) as of the Effective Date noted on **Schedule 1**.

- A. TS Clinic is providing certain Protected Health Information ("PHI") to Recipient in the form of a Limited Data Set for the purpose(s) identified in paragraphs 4 and 5 of **Schedule 1**.
- B. In connection with the provision of that PHI, pursuant to the Health Insurance Portability and Accountability Act and regulations promulgated pursuant thereto (collectively "HIPAA"), TS Clinic is required to obtain assurances from Recipient that Recipient will only use or disclose PHI as permitted herein.
- C. The parties enter into the Agreement as a condition to TS Clinic's furnishing of the Limited Data Set to Recipient, and as a means of Recipient's providing the assurances about use and disclosure. The provisions of this Agreement are intended to meet the Data Use Agreement requirements of HIPAA.

NOW THEREFORE, the parties agree as follows:

- 1. **Definitions.** Each capitalized term used in this Agreement and not otherwise defined, shall have the meaning given it in HIPAA.
- 2. **Term.** This Agreement shall commence on the Effective date and continue until terminated in accordance with Section 4 below.
- 3. **Recipient's Obligations.** Recipient shall:
 - a. Comply with all applicable federal and state laws and regulations relating to the maintenance of the PHI, the safeguarding of the confidentiality of the PHI, and the use and disclosure of the PHI.
 - b. Use and disclose the PHI only for the purpose(s) identified in paragraphs 4 and 5 of **Schedule 1**, as otherwise required by law, and for no other purpose.
 - c. Use appropriate safeguards to prevent the use and disclosure of the PHI, other than for a use or disclosure expressly permitted by this Agreement.
 - d. Immediately report to TS Clinic any use or disclosure of the PHI other than as expressly allowed by this Agreement.
 - e. Ensure that its employees and representatives comply with the terms and conditions of this Agreement, and ensure that its agents, Business Associates and subcontractors to whom Recipient provides the PHI agree to comply with the same restrictions and conditions that apply to Recipient hereunder.
 - f. Not identify or attempt to identify the information contained in the Limited Data Set, nor contact any of the individuals whose information is contained in the Limited Data Set.
 - g. Not use or disclose more PHI than the minimum amount necessary to allow Recipient to perform its functions pursuant to the purpose identified in **Schedule 1**.
 - h. Indemnify, defend and hold TS Clinic harmless from all costs and expenses (including attorney fees) for any claims that relate to a release of PHI or that relate to a breach of Recipient's obligations.
- 4. **Termination.** TS Clinic may terminate this Agreement and any disclosures of PHI pursuant hereto, upon 10 days notice to Recipient, if Recipient violates or breaches any material term or condition of this Agreement. TS Clinic may terminate this Agreement without cause upon 30 days written notice. Upon termination, Recipient shall promptly return or destroy the Limited Data Set received from TS Clinic in connection with the purpose

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identified on **Schedule 1**. If return or destruction of the Limited Data Set is not feasible, Recipient shall continue the protections required under this Agreement for the Limited Data Set consistent with the requirements of this Agreement and applicable HIPAA privacy standards. If Recipient ceases to do business or otherwise terminates its relationship with TS Clinic, Recipient agrees to promptly, and in a timely manner, return or destroy all information contained in the Limited Data Set received from TS Clinic.

- 5. Governing Law and Venue.** This Agreement shall be governed by the laws of the State of New Jersey. Venue for any claim, action, or suit, whether state or federal, between Recipient and TS Clinic shall be Middlesex County, New Jersey

IN WITNESS WHEREOF, the parties have executed this Agreement effective as of the Effective Date.

Tourette Syndrome Clinic:

Recipient:

By: _____

By: _____

(signature) _____

(signature) _____

Title: _____

Title: _____

Date: _____

Date: _____

INFORMED CONSENT FORM

You are invited to participate in a research study that is being conducted by Alina Simanovskaya, who is a student in the Graduate School of Applied and Professional Psychology at Rutgers University. The purpose of this research is to collect information about a group socio-emotional program at the Tourette Syndrome (TS) Clinic at Rutgers University that is provided to children and adolescents with tic disorders. The program is a Cognitive Behavioral program that is designed to help youth cope with Tourette syndrome and tics. The collected information will be used to evaluate the program's activities, procedures, and goals. You were selected as a participant due to your knowledge of and current involvement with the group program at the Tourette Syndrome Clinic. There will be approximately seven participants in the study.

If you are a supervisor or staff member at the TS clinic and decide to participate, you will be asked to meet with Ms. Simanovskaya approximately 3 times to answer questions about the program development, procedures, and activities. Each session will last 30-60 minutes. If you are a student clinician at the TS clinic and decide to participate, you will be asked to meet with Ms. Simanovskaya 1-2 times to answer questions about your experiences of implementing the program and its activities. Each session will last 30-60 minutes.

Ms. Simanovskaya will also conduct observations of the program and review program documents. Observations will take place in the Rutgers University Graduate School of Applied and Professional Psychology, where the TS Clinic program is housed. Observations and interview administration will begin once IRB approval is granted and will continue until April 2016.

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Your participation in this study is part of the program evaluation process. The interview questions and observations are not about individual graduate student clinicians and staff members, but about the program itself. Any information that is obtained in connection with this study that can be identified with you will remain confidential. This information will be kept on a password protected flash drive that will be stored in a secure location. No one will be identified by name, except the name of the TS group program.

There are no foreseeable risks to participating in this study. Your participation in this study is completely voluntary. You may choose not to participate, and you may withdraw at any time during the study procedures without any penalty to you. In addition, you may choose not to answer any questions with which you are not comfortable. Your decision whether or not to participate will not impact your relation with the TS clinic or with Rutgers University.

While there is no direct benefit to the research participants, individuals who choose to participate in the interviews and observations will increase the knowledge of the TS group program's current activities and practices. Information and resources related to facilitating and improving the program will be shared with the director and the supervisors at the completion of the evaluation.

If you have any questions about the study or study procedures, you may contact me, Alina Simanovskaya, 152 Frelinghuysen Road, Piscataway, NJ 08854, alina.siman@rutgers.edu, 347-979-1673. You may also contact my faculty advisor, Dr. Kenneth Schneider, 152 Frelinghuysen Road, Piscataway, NJ 08854, schneid@rci.rutgers.edu, 848-445-3980

If you have any questions about your rights as a research subject, please contact an IRB Administrator at Rutgers University at:

*Institutional Review Board
Rutgers University, the State University of New Jersey
Liberty Plaza / Suite 3200
335 George Street, 3rd Floor
New Brunswick, NJ 08901
Phone: 732-235-9806
Email: humansubjects@orsp.rutgers.edu*

You are making a decision whether or not to participate in the study. Your signature indicates that you have read the information provided above and have decided to participate.

You may withdraw from the study at any time, without penalty.

You will be given a copy of this consent form for your records.

Sign below if you agree to participate in this research study:

Subject (Print) _____

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Subject Signature _____ Date _____

Principal Investigator Signature _____ Date _____

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