

**SERVICES FOR CHILDREN WITH  
TOURETTE SPECTRUM DISORDERS**

SERVICES FOR CHILDREN WITH TOURETTE SPECTRUM DISORDERS:  
A CONVOLUTED PATH

By

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## ABSTRACT

Children diagnosed with Tourette Spectrum Disorders (TSD) have multifaceted needs. Dwindling resources in children's mental health services have lead to decreased services and increased wait times. Children with complex mental health needs and their families are greatly impacted. This paper looks at the difficulties associated with TSD, and reports on parents' views of service needs for families of children diagnosed with TSD. Five mothers of children diagnosed with TSD were interviewed in an exploratory, qualitative study to learn what parents say about service needs. The findings indicate that easy access to complete information, getting a diagnosis, and comprehensive treatments to cope with TSD are their priority service needs. Difficulties accessing needed services are highlighted.

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*I dedicate this work to the memory of my dear father,  
Walter L. Macdonald, who always said:*

*“A job worth doing is a job worth doing well.”*

TABLE OF CONTENTS

|                           |    |
|---------------------------|----|
| 1. INTRODUCTION.....      | 1  |
| 2. LITERATURE REVIEW..... | 8  |
| 3. METHODOLOGY.....       | 19 |
| 4. MAKING MEANING.....    | 25 |
| 5. DISCUSSION.....        | 44 |
| 6. CONCLUSION.....        | 57 |
| 7. BIBLIOGRAPHY.....      | 60 |

## APPENDICES

|    |   |    |
|----|---|----|
| A. | Recruitment Flyer.....                      | 72 |
| B. | Eligibility screening form.....             | 73 |
| C. | Consent form.....                           | 74 |
| D. | Demographic information form.....           | 79 |
| E. | Interview and note guide (abbreviated)..... | 80 |
| F. | Service appraisal questionnaire.....        | 85 |
| G. | Diagnosis as reported by mothers.....       | 86 |
| H. | Member checking letter to mothers.....      | 87 |
| I. | “What was helpful” scale.....               | 88 |

## INTRODUCTION

The state of children's mental health care in Canada presents a significant national health challenge (Kirby, 2006; Waddell, McEwan, Shepherd, Offord, & Hua, 2005).

Mental health problems are the leading health problems that Canadian children currently face after infancy. At any given time, 14% of children aged 4 to 17 years (over 800 000 in Canada) experience mental disorders that cause significant distress and impairment at home, at school, and in the community. Fewer than 25% of these children receive specialized treatment services (Waddell et al., 2005).

In 2006, after completing a lengthy process of cross-country hearings, Senator Michael Kirby, Chair of the Standing Committee on Social Affairs, Science and Technology, submitted a report to the Canadian Parliament entitled "Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services." This comprehensive report highlights the weaknesses of our national mental health system, and recommends several significant policy reforms. It emphasizes that profound change is necessary to make an effective difference in the lives of Canadians impacted by mental health problems. Within this report, Senator Kirby specifically notes the poor state of children's mental health in Canada. "Children and youth are at significant disadvantage when compared to other demographic groups affected by mental illness, in that the failings of the mental health system affect them more acutely and severely"

(Kirby, 2006, section 6.1). The report also emphasizes that with children, this impact in a significant way includes their family and, in particular, their caregivers.

I am a social worker, working in the field of children's mental health in Ontario since 1994. Over the past thirteen years I have personally experienced significant changes in the availability and delivery of children's mental health services. Between 1993 and 2003, funding for core services in children's mental health in Ontario dropped by 8% while the number of children requiring service more than doubled (OPSEU, 2005). These changes have resulted in decreased staffing, lengthy waiting lists, and fewer treatment opportunities. Overall, funding cuts have negatively impacted the care received by the children and families seen in our clinic. It is an ongoing challenge to determine where it is most important and most effective to direct limited resources in order to have the greatest impact on children and families with considerable needs.

Since 1999, I have been working in a hospital based out patient psychiatry clinic for children and youth experiencing emotional and behavioral problems. In my work I often meet children who are diagnosed with Tourette Spectrum Disorders or TSD. These children present numerous challenges to their caregivers at home, at school, and in the community. In my experience this group of children is often misunderstood; perceived to be totally out of control, defiant and incorrigible. Given their often disruptive behaviours, it is difficult to see that

children diagnosed with TSD are most often sad, frightened, and bewildered, while their parents and other caregivers are often at a loss about how to help them.

In my role as a social work clinician, I am responsible for first identifying these children and their needs, and then providing treatment and support to them and their parents. This group of children has a highly individualized and complex set of needs. They have both neurological and mental health issues, making them a difficult group of children to adequately assess and treat. My responsibilities include finding creative and efficient ways to meet these needs.

In addition to providing child and family based treatments, I have been part of the development of a psycho-education group for parents of chronically inflexible and explosive children, many who are diagnosed with TSD. In providing this group intervention I have become acutely aware of the high level of distress and frustration experienced by parents as they work to provide the best care for these challenging children. Parents are often embarrassed and frustrated by a child who exhibits unexplained behaviour at home, school, the public, and in the company of extended family and friends. They desperately want to find ways to better understand and make a difference in the lives of these children (Traficante, 2004).

**Case example:**

Mary is the mother of a handsome eight-year old boy named Walter. He reminds her so much of his paternal grandfather, both in looks and disposition. Walter loves playing with building blocks and talks incessantly about his favourite cartoon character. Walter is a friendly, outgoing boy who will strike up a

conversation with any adult, and Mary is proud of how thoughtful he can be.

However, life with Walter is not that easy. He has an especially hard time getting along with children his own age. His peers seem irritated by his constant touching and his need to be the one “in charge” of all their games. Most of the time the friends end up playing with Walter’s younger sister and he has a temper outburst. Lately the children have stopped coming over at all and Walter’s sister told him that they are not allowed to play with him anymore. Although Mary loves Walter dearly, she is irritated by the constant little noises and sniffs that he makes. It seems like he is deliberately trying to annoy everyone in the family. It is impossible to get through a meal in peace between the noises, the battle to keep him seated at the table, and the constant complaining about what is served for dinner. It seems Walter is fussy about everything. He has a short list of foods that he will eat and he insists they be arranged a particular way on his plate. He is very particular about the feel of his clothing, refusing to wear certain fabrics and insisting that all the tags be cut out. While shopping for a new winter coat Walter had a meltdown in the store because all of the coats felt too puffy. The other shoppers glared at Mary and one woman told Walter he was a “very bad boy”.

Since October of Gr. 2 the classroom teacher has called Mary every week complaining that Walter is disrupting the class, rarely gets his work done, and that his printing is totally illegible. Walter told his mom that sometimes he has to work at a desk in the hall because he is too noisy and the other children don’t like him. He is getting into fights with the other children several times a week and often ends up in the school office during recess, getting suspended four times in two months.

Each time the principal suspended Walter for aggressive behaviour on the playground, Mary took him to the family doctor for help. At first the family doctor told Mary that Walter was a typical boy and not to worry about him. However, when Mary broke down crying in her office after the fourth suspension, Walter was referred to a community paediatrician who diagnosed him with ADHD and sent Mary to a parent-training course. After six months of medication but very little progress, Walter was sent for a consultation with a hospital specialist where he was diagnosed with TSD.

Initially, Mary felt a great sense of relief because now there was a name to explain what was going on with Walter. However, simply having a name for the condition was not enough. The school principal still said that there is zero tolerance for any violent

behaviour and the next suspension Walter gets will be for twenty days. Walter wanders the playground alone, and there is a new classroom teacher who needs to understand Walter for Grade 3. Mary thought that now Walter had a diagnosis, someone would be able to guide her to the necessary resources and services, but that someone is nowhere to be found.

Mary is sad, exhausted, overwhelmed, and feeling very alone. Parenting Walter takes all her time and energy. There is not much left over to search for information, support, and services that might help the whole family learn how to cope better. (This composite case study is typical of the story of countless parents whose children are diagnosed with TSD.)

Good quality care for this unique population of children requires a specific expertise and a potentially large number of service hours that is difficult to provide with dwindling resources. “Twelve years of funding cuts have created major gaps in service for some of our most vulnerable children” (OPSEU, Canada News Wire, 2005). Although in the face of funding cuts clinicians have tried to create more streamlined access to assessment and treatment with the resources available, as Senator Kirby’s committee found, these children and families continue to suffer and go without the level of care that they are seeking.

Social workers and other professionals are being asked to respond to this crisis situation by providing brief, more focused, assessment and treatment to a greater number of children. Hence, it is not surprising that there have been proposals to design and provide efficient TSD specific assessment and treatment in our clinic. These proposals have been initiated and designed by professionals looking to provide quality service based on what they think is most important. In 2004 for example, a group of three specialist physicians, recognizing the need for collaboration to better serve this population of children, created a pilot “Tourette

Pathway” consultation clinic across neurology, psychiatry and developmental paediatrics. This service was developed in response to needs identified by the physicians providing the service, but was not sustained, as it did not meet the pressing needs of the referring physicians. The referring physicians were seeking more comprehensive care, rather than consultation only, for their young patients diagnosed with TSD, because they were unable to begin to meet their high needs. Given the feedback from the referring physicians, and the ongoing distress of the parents I was meeting in the clinic, I became interested in knowing what the caregivers of children diagnosed with TSD would identify as the most important of their service needs.

In the Master of Social Work, Critical Analysis of Practice program I have learned that there are small but effective changes that I, as an individual social worker, can make in my practice that would greatly contribute to the lives of children and families (Traficante, 2006).

There is always an organizational power hierarchy, covert or overt, and there is also, in most cases, an opportunity for critical dialogue. Social workers can initiate this dialogue in ways that maintain their professional integrity as well as co-create an environment in which such discussion increasingly thrives (Deweese, 2002, p. 84).

Dwindling resources dictate that priorities are established. Nationally, Senator Kirby’s committee found

that the system is fragmented and under funded, that intervention occurs far later than is necessary, that there is a critical shortage of mental health professionals, and that young people and their families are not being involved in workable, long-term solutions to their serious mental health problems (Kirby, 2006, 6.1).

Rather than the clinicians as experts deciding which services to offer, I think it is timely and wise to hear from the recipients of the services before making decisions about where to most effectively direct resources. “The limited influence lay people have on research in its planning phases, despite timely discussion, emphasizes the power held by the researchers, who may have their own goals for advancing knowledge” (Oliver, 1999, p. 143). Although it may mean adjusting priorities, I believe that the parents, the primary caregivers of children with TSD, should have a dominant voice in naming their most important service needs.

Potts and Brown (2005) challenge us to undertake an anti-oppressive research stance, recognizing our own privilege as service providers and working to dismantle the unjust systems that keep us in that privileged space. I think that social workers can take the lead on putting faces to the problems, and giving a voice to the recipients of service. Despite the power imbalances, I believe that there are ways to bring these voices forward that will have an influence on future service design. Therefore, the focus of this thesis will be to give them voice, to bring forth the knowledge and lived experience of people such as Mary and her son Walter, in order to begin to influence decisions about services offered to address the mental health needs of children and families associated with TSD.

## LITERATURE REVIEW

Tourette Spectrum Disorders (TSD) are a group of disorders that occur on a spectrum that describes the complexity of behaviour observed in Tourette syndrome (TS), Tic disorders (TD) and other milder variants that frequently include accompanying co-morbid diagnoses and conditions. Several authors indicate that Tourettes is best described as a spectrum of disorders (Dedmon, 1990; Kurlan, 1997; Kurlan et al., 2002; Termine et al., 2006). It is this combination of TS or TD with other childhood psychiatric disorders that most often leads parents to seek medical help for their child (Termine et al., 2006). This cluster of problems is not well known to non-specialty service providers (Dedmon, 1990; Stern, Burza, & Robertson, 2005) although research suggests that 88% of 3500 clinic patients worldwide diagnosed with Tourettes have co-morbid conditions (Robertson & Cavanna 2007). A number of authors and service providers refer to TS and co-morbid disorders as TS Plus (Packer, 1997; Robertson & Stern, 2000; Robertson, 2003; TSF of Canada), or as TS complex (Coffey & Park, 1997), or TS spectrum disorders (Santangelo et al., 1996), in order to better describe this cluster of problems. For the purpose of this paper, the terminology TSD will be used to describe a primary diagnosis of Tourette Syndrome (TS), Tic Disorder (TD) and other related variants - including the presence of at least one other co-morbid childhood psychiatric disorder.

TS is a childhood-onset neuropsychiatric disorder that is characterized by multiple motor tics (involuntary jerky muscular movements, such as excessive eye blinking) and one or more vocal tics (phonic tics; involuntary noises, such as repeated throat clearing) which last for longer than a year, though do not necessarily occur concurrently (Robertson & Stern, 2000). Historically, the syndrome, named after George Gilles de la Tourette, consisted of multiple motor tics, coprolalia (inappropriate swearing), echolalia (repetition of the speech of others), and motor inco-ordination (motor impairment that interferes with daily functioning). Today it is the small minority of cases that meet these criteria (Robertson, 2003, p.3).

“The condition is thought of as lifelong and tends to vary in severity over time in individuals” (Stern, et al., 2005, p. 16). “The cause of Tourettes syndrome remains unknown, although it is undoubtedly an “organic” condition and has been dubbed a model neuropsychiatric syndrome given the reach of its symptoms into both domains” (Stern et al., 2005, p. 15). Research suggests that the prevalence of TS is about 1% of school children aged 5 to 17 years (Stern et al., 2005). TS occurs worldwide (Tanner & Goldman, 1997). It is found in all cultures, countries, and racial groups; it occurs three to four times more commonly in males (Robertson & Stern, 2000). TS is a category within the tic spectrum and is one of the manifestations of childhood tics. The majority of studies find that about 10% of children have tics (Robertson, 2003). “Tics are motor or vocal, involuntary, purposeless, sudden and rapid, repetitive, and stereotyped

productions" (Zinner, 2000, p. 372). Tics usually appear by 7 years of age and show considerable variation over a waxing-and-waning course (Carter et al., 2000).

It is important to formally assess for the behavioural and emotional problems known to cluster clinically with Tourettes (Coffey & Park, 1997). Many individuals with TS also meet criteria for ADHD, OCD, and /or other learning and behavioural difficulties, including self-injurious behaviours (Carter et al., 2000; Packer, 1997; Robertson & Stern, 2000; Robertson, 2003, Tanner & Goldman, 1997).

A large study of 3500 individuals from 22 countries reported that only 12% of the patients had no co-morbidity. The most common problem was ADHD found in 60%, obsessive-compulsive behaviour (OCB) in 32%, obsessive-compulsive disorder (OCD) in 27%, mood (affective) disorders in 20%, and anxiety disorders in 18%. Conduct disorder and oppositional disorder were found in 15% of patients (Stern et al., p.13).

Spencer et al. also reported that TS and TD patients showed high levels of co-morbidity with ADHD, mood, anxiety, conduct, and oppositional disorders (Spencer, Biederman, Harding, Wilens, & Faraone, 1995). Family studies provide support for a genetic association between TS, chronic motor or vocal tic disorder, and obsessive-compulsive disorder, and some forms of attention deficit hyperactivity disorder (Saccomani, Fabiana, Manuela, & Giambattista, 2005). Mansueto and Keuler (2005) propose that a subgroup of individuals presenting with both OCD and Tourettes are best understood by the adoption of a Tourettic OCD conceptual framework, in order to successfully address the blended features

of their presentation. A significant number of children with TS experience episodic rage attacks (Budman, Rockmore, Stokes, & Sossin, 2003). “Although tics may be outwardly visible, it is these associated psychopathologies that may have the most impact on schooling, social and work functioning” (Stern et al., 2005, p. 13).

Learning difficulties are also associated with TSD (Collins, 2005; Packer, 1997). TSD can have a significant impact on academic functioning for children. Compulsive rituals or obsessive thoughts, and ADHD symptoms, can interfere with learning and increase stress, resulting in more difficulty to suppress tics and inhibit impulses increasing the chances a child will get into trouble (Packer, 1997). It has been noted that anxiety producing events such as changing schools, or family arguments, are associated with an increase in TS symptoms (Silva, Munoz, Barickman, & Friedhoff, 1995).

The management of TS with co-morbid disorders is significantly more challenging than is the management of TS on its own (Robertson & Stern, 2000; Wilkinson et al., 2001). “Multimodal treatment is recommended for patients with clinically significant behavioral and emotional features” (Coffey & Park, 1997, p. 285). This would include pharmacotherapy, behaviour therapy, individual therapy, family work and parent guidance, and educational assistance and advocacy (Coffey & Park, 1997; Packer, 1997; Stern et al., 2005).

In addition, it has been found that children with TS and co-morbid disorders have a significant impact on the family, including family relationships,

the family's social life, and family finances (Wilkinson et al., 2001). Caregivers of children diagnosed with TS and co-morbid disorders experience considerable burden (Wilkinson et al. 2001; Cooper & Livingston, 2003). A cross-sectional survey study by Cooper and Livingston (2003) compared parents of children diagnosed with asthma and parents of children diagnosed with TS. The study found the parents of children with TS experienced greater burden in the domains of relationships, well being, and daily activities and that they were more likely to be psychologically ill. These findings suggest that the stress of TS is over and above the general effects of having a child with a chronic, severe illness (Cooper & Livingston, 2003).

The parents of children with TS identified behaviour problems, disputes in the school, and disputes in the family as the most distressing signs in their children (Cooper & Livingston, 2003). TS plus ADHD is identified as more challenging for parents, and lower family functioning was associated with poorer social and emotional adjustment of the child (Carter et al., 2000). About 25-70% of patients diagnosed with TS in clinical settings, report episodic behavioural outbursts and anger control problems (Budman, et al., 2003). When rage episodes are present, parents note this as the symptom of most concern (Budman et al., 2003; Dooley, Brna, & Gordon, 1999).

De Lange and Olivier (2004) conducted an exploratory study on mothers' experiences of aggression from their adolescent children diagnosed with TS. The authors reported that in addition to increased intervention for the children, these

mothers are often in crisis and in need of counselling supports. A recent two-year study following 86 children with children with TS and/or OCD found that psychosocial stress, particularly as perceived by the parent, was strongly predictive of future depressive symptoms in the children (Lin, et al., 2007). Education for the parent and family is important. “Often neglected is the emotional response and adjustment of the siblings in the family. Siblings may be both genetically and emotionally at risk and need education and support” (Coffey & Park, 1997, p. 286). TSD cause a significant impact on quality of life to a number of people and the relatively high numbers have wide implications including service provision and training (Stern et al., 2005). “The prominence of and perceived importance of comorbid symptoms mandates that physicians who care for children with Tourettes syndrome must address these needs and must offer appropriate counselling and behavioural or pharmacological interventions” (Dooley et al., 1999, p. 441).

Social work has an important role to play in the assessment and treatment of children with TSD. Among service providers there is a lack of education and awareness of the wide range of indicators and symptoms of TSD. However, early diagnosis and treatment are crucial to avoid psychological and neurological harm (Collins, 2005). Social workers interface with children at many different system levels including primary health care, schools, specialty clinics, and children’s mental health treatment centers, giving them an opportunity to intervene with children exhibiting unexplained behaviour problems. Therefore, it is important

that social workers first be able to recognize the signs and symptoms of TSD and then be able to assist the parents to get an accurate diagnosis (Collins, 2005; Dedmon, 1990; Sullivan, 1994).

Social workers are often the first to suspect TSD, and Collins (2005) recommends adoption of a biopsychosocial paradigm in order to ensure that children are not misdiagnosed. Appropriate referrals by social workers to specialists including child psychiatrists, neurologists and developmental paediatricians can facilitate the process of getting a timely diagnosis (Collins, 2005).

Parents report a long and distressing process to get a diagnosis (Sullivan, 1994). Shimberg reports an average of seven visits to professionals before they get a diagnosis (as cited in Collins, 2005). TSD are complex and best served by a multi-disciplinary network of professional resources that is responsive to changes over time (Sullivan, 1994). Further advocacy, linking, and liaising with other professionals including educators is important for ongoing assessment and access to specialized services (Collins, 2005; Sullivan, 1994). The social worker's psychosocial assessment information is important, providing assessment information that may influence treatment recommendations (Collins, 2005; Dedmon, 1990).

Once a diagnosis is received, the social worker can provide the family with accurate information about TSD and help them first to understand what the diagnoses means for their individual child and family, and later to adapt to life

with TSD (Collins, 2005; Dedmon, 1990). Often the greatest need identified by parents is contact with others impacted by TSD. Sullivan (1994) emphasizes the importance of linking parents to credible sources of information such as the national Tourette Syndrome Foundation.

Dedmon (1990) advocates a family-centered approach using a psychosocial assessment to determine how things are going in the family, especially in relation to the TSD. Social work can provide family intervention by helping parents to deal with their feelings of loss, grief, and guilt related to how they understood their child's behaviour (Sullivan, 1994), how they came to receive the diagnoses, and how they interpret what is known about TSD (Dedmon, 1990). Parents may experience shame or guilt if they feel responsible for transmitting the disorder to their child, or if they have regrets about how they responded to their child before having a diagnosis (Collins, 2005; Dedmon, 1990). The social worker can encourage the affected child to participate in the process, and provide them with information about TSD and how it impacts them individually (Dedmon, 1990). The affected child also needs help to deal with feelings about the diagnosis and effects on self-esteem. "A social worker is capable of developing coping strategies, sorting out emotional issues, and building self esteem in their work with children with TS" (Collins, 2005, p. 487).

In addition, siblings may benefit from social work intervention to help them understand what TSD are, and how this diagnosis impacts their affected sibling and the family as a whole (Collins, 2005). Social workers can directly

provide, or refer the child and family for specialized counselling for depression, anxiety, or extreme behaviour, as appropriate (Dedmon, 1990). Cognitive behaviour therapy (CBT) and habit reversal training (HRT) are specialized treatments that can be provided by, or accessed through, social workers trained about TSD (Collins, 2005). Finally, social work can play a role in helping parents and children to find ways to educate others including extended family, friends, educators, and peers about TSD and how this impacts them specifically (Dedmon, 1990; Sullivan, 1994).

Overall, it has been identified that this group of children and their families have significant needs that need to be addressed both medically and socially. In a study looking at how families of children diagnosed with ADHD coped with this chronic disorder, it was noted that there was an overemphasis on teaching parents how to parent, and an “astounding lack of attention paid to providing emotional and physical support, assessment, intervention and referral services to the family members to help them cope with the disorder” (Kendall, 1998, p. 855). There is considerable literature on TS from a medical perspective looking at phenomenology, pharmacological treatments, and etiology, (Budman et al., 2003; Hendron, 2002; Leckman & Cohen, 1999; Robertson & Stern, 2000; Robertson, 2003; Schapiro, 2002) and there is a small literature about accommodating TSD children in school and family environments (Hendron, 2002). However, a search of the social work literature produced only three articles on the subject of

Tourettes. It is striking that so little has been written in the literature to identify needs from a social perspective, and in particular from the parents' point of view.

Balling & McCubbin (2001), who looked at parental caregiving needs, identified a failure on the part of health care professionals to recognize parental expertise and incorporate it into the plan of care for children with a chronic illness. Racino (1998) in a study of children with chronic disorders reported that families learn from their first contact with professionals that the professionals believe they know what is best for the family.

In a review of twenty-five years of studies looking at the needs of parents of disabled children, Sloper (1999) concluded that although considerable information had been gathered, it was yet to be incorporated into practice. "There needs to be a change in research priorities from finding out what the problems are to finding out the solutions, with full involvement of both parents and professionals at all stages of the process" (Sloper, 1999, p. 95). In response to an emphasis on evidence based practice, public accountability, and efficient, effective services, Mitchell and Sloper (2003) followed this up by conducting a study with parents of disabled children, and the children themselves, to ascertain what they would identify as quality indicators of service.

Evans (1996) encourages the involvement of consumers in health research because they have a vast amount of intimate and long-term knowledge to offer. The parents of children diagnosed with TSD have many needs, and yet there is a

major gap in the literature about what parents themselves would identify, as their service needs.

## METHODOLOGY

Main Research Question: What do parents say about service needs for families of children diagnosed with Tourette Spectrum Disorders?

Exploratory studies, aimed at learning about areas where little is yet known, are well suited to the use of a qualitative approach (Patton, 2002). In order to begin to describe what parents of children with TSD perceive to be the service needs of children and families, this is an exploratory project using a grounded theory (Strauss & Corbin, 1998) framework to gather qualitative information through a standardized open-ended interview (Patton, 2002). This needs assessment is based in ground theory using qualitative information provided by caregivers (normally parents, step-parents, grandparents) currently responsible for children with TSD.

Eligible respondents were 18 years of age or older, English speaking parents of a child diagnosed with TSD. “Parent” was defined as the biological parent, step-parent, or grandparent providing primary care for a child defined as a person less than 18 years of age, diagnosed with TSD. To be eligible for the study, the TSD diagnoses had to specifically include Tourette Syndrome (DSM-IV-TR, 2000) or Tic Disorder (DSM-IV-TR, 2000); and at least one of Attention Deficit Hyperactivity Disorder (ADHD) (DSM-IV-TR, 2000), Anxiety Disorder (DSM-IV-TR, 2000), Obsessive Compulsive Disorder (OCD) (DSM-IV-TR,

2000), Obsessive Compulsive Behaviour (OCB) (Stern et al. 2005), Oppositional Defiant Disorder (ODD) (DSM-IV-TR, 2000) or Mood Disorder (DSM-IV-TR, 2000).

Clinicians at McMaster Children's Hospital and executive members of the Tourette Syndrome Foundation of Canada-Hamilton Region Chapter were contacted and given a recruitment flyer (Appendix A) advertising the study. Interested participants who contacted the researcher were screened for eligibility (Appendix B). Those meeting the criteria were given information about the purpose and nature of the study and an interview time was scheduled. Participants were interviewed at their home, office, or in the clinic, according to their preference. Participants attending the clinic were given a free voucher to cover the cost of parking. At the scheduled research interview the respondent was first asked to review and sign a consent form (Appendix C). All respondents agreed to have the interview audio recorded. The study had received Ethics approval through the HHS/McMaster University Research Ethics Board, Project Number: 07-193(S).

Participants first completed a brief demographic information form (Appendix D). The standardized open ended interview (Patton, 2002) was conducted using a prepared interview and note guide (Appendix E). All interviews were audio recorded and in order to facilitate the interview process, written notes were taken by the researcher throughout the course of the interview (Patton, 2002). Each participant was provided with a copy of the following

definition to reference during the interview. “Service needs are specialized care provided to children and/or families by professionals and others who are not the adults responsible for providing the everyday care for your child.” (Appendix E)

The interviews, which lasted 60 to 90 minutes, contained groups of questions that focused on different aspects of parental service needs. The first set of questions in the interview focused on the experience of seeking service, and set the context for the next set of questions that elicited the respondent’s ideas about service needs. After answering these questions, in order to broaden the discussion, each participant was asked to complete a Service Appraisal Questionnaire (Appendix F). This twenty-item scale was a list of services developed by the researcher from information found in two articles, “Tourette syndrome in children: Knowledge and services” by Rachel Dedmon (1990) and “Gilles de la Tourette’s syndrome and its impact in the UK” by Stern et al. (2005). Before completing the questionnaire participants were asked to think about their own child and family, as well as other children and families known to them who have a child diagnosed with TSD. Then from their own point of view, they were asked to rate the level of need for, or importance of each of these services to their child, on a five-point scale. Once completed, participants were asked to comment generally on the services listed, and whether or not they had any further ideas about service needs after reading the list. After leaving each interview the researcher wrote a memo noting general impressions about the

affective experience of meeting with each participant, emerging themes, and identified researcher bias (Charmaz, 2006; Patton, 2002).

It is customary to compensate participants for their time (Patton, 2002). As a thank you for participating in this project, all participants received an information package about materials available for parents and children at the Family Resource Center, McMaster Children's Hospital, Chedoke Site. The information package included a free parking voucher to use while visiting the resource center. Each participant agreed to be contacted at a later date to review a written summary of their interview to review and comment on the accuracy of meaning as interpreted by the researcher. One participant stated that the summary would be a helpful tool as it listed all her concerns about the need for future services.

Each audio recorded interview was transcribed, verbatim by an experienced transcriptionist. Member checks were conducted to allow respondents to confirm their ideas (Charmaz, 2006). After receiving the transcribed interview document for each participant, a summary was written by the researcher using the format of the standard interview questions. This summary, with a covering letter (Appendix H), was mailed to the corresponding participant who was then contacted by telephone for feedback. Participants were asked to say whether or not they thought the summary was accurate, and whether or not they wanted to revise, delete or add information to the summary. Three participants were reached directly by phone, the fourth left feedback in a

voicemail message, and the fifth was not reached at all. Two messages were left with a telephone contact number to call if she wanted to give any feedback. All of the participants reached reported being satisfied with the summary, with two mothers noting one specific detail each that needed correction. Upon receipt of the summary, one participant commented how interesting it was to read about “her case” and expressed an interest in learning more about what the other participants reported. Two mothers specifically asked to receive a copy of the final report.

Description of the Sample:

In total, five parents, all mothers, participated in the study. Two other mothers expressed an interest and scheduled an interview, but then decided to cancel because their child diagnosed with TSD was requiring more of their time than usual. The five participants were all biological mothers of children diagnosed with TSD. Three of the mothers were age 30-39, one age 40-49 and one age 50+. All mothers were married, English speaking, born in Canada, and living in an urban area. One mother completed high school, and the other four completed college/university. All five mothers reported a total household income greater than \$60,000, with between four and eight people living in the family home.

The five biological children of the participant mothers all met the initial screening criteria for TSD. All five children were diagnosed with Tourette syndrome, four with OCD, and one with OCB. In addition, two children were

diagnosed with both ADHD and Anxiety, and one with ODD. The table (Appendix G) indicates the diagnoses as reported by the mothers. In addition, two mothers reported on diagnoses not asked about during the eligibility screening. One mother reported that her child also had a diagnosis of a nonverbal learning disability (impressive verbal, reading, spelling and rote memory skills but very weak motor, social, sensory, and visual-spatial abilities). The second mother reported that her child had two additional diagnoses, sensory integration dysfunction (difficulty integrating sensory information) and trichotillomania (compulsive hair pulling).

Three of the five children were female and two male and ranged in age from 7 – 17 years of age. Three of the children were under age 12 and attending elementary school. The other two were adolescents attending high school. All five were Canadian born, English speaking and attended school in a regular classroom.

## MAKING MEANING

Content analysis using an inductive approach was applied to the data (Patton, 2002). As the transcripts were received they were first each read through entirely and then coded line-by-line (Charmaz, 2006). Next, along with a review of the corresponding memo (Charmaz, 2006), the data from each transcript was organized using an analytical framework (Patton, 2002). A summary of each transcript was prepared in point form, following the format of the questions used in the standardized open-ended interview (Patton, 2002). In addition, at the end of each summary a section entitled “general impressions” was added. This consisted of a list of statements each beginning with “I heard” and contained the main thoughts, key issues, and sentiments of the respondent, as interpreted by the researcher. This technique was devised by the researcher to provide reflexivity and voice in the analysis (Patton, 2002), as each participant would be asked to respond to the accuracy of meaning conveyed in the summary that they received.

The next step in the analysis was to read and re-read the transcripts and transcript summaries many times, in order to generate a compilation of main ideas, in vivo codes, (Charmaz, 2006) and sensitizing concepts (Patton, 2002). Respondent quotes found within the transcripts supporting these interpretations were also noted. Focused coding (Charmaz, 2006), resulted in six main themes emerging from the analysis including “digging for answers”, “feeling the impact”,

“feeling supported”, “bits and pieces”, “left dangling” and “finding ways to cope”. Each theme with supporting quotes is presented below. In addition, a summary of service needs and concerns about services are reported, followed by a compilation of the respondents’ ideas into an “ideal service design”.

*Digging for answers:*

Generally the mothers became concerned about their child early in elementary school. Sometimes the teacher was the first one to raise concerns namely difficulty focusing, temper outbursts, and self harm behaviour in the classroom. Sometimes it was the mother who first noticed differences with their child including excessive crying, staring into space, sleepless nights, ritualistic behaviour, hair pulling or violent tantrums. Four of the mothers interviewed first sought services with their family doctors who responded in various ways. One child was immediately referred to a neurologist for consultation and diagnosed with TSD. Two of the family doctors monitored the situation for up to a year, eventually referring the child to a paediatrician for further assessment. One mother described going to the family doctor repeatedly over a four-year period, having the doctor dismiss her concerns. “Her response was, that if no one in the school seemed concerned about it, if they didn’t notice anything, then it was probably nothing other than nerves and not to worry about it.” (Respondent P4) It was not until the classroom teacher raised concerns about TSD that the family doctor agreed to investigate further, eventually referring the child to a paediatrician who immediately diagnosed TSD. Another mother described being

surprised by the school's suggestion that she take her child to see the family doctor about temper outbursts and tic-like behaviour. "We thought, you know, why would we, why would we need to contact our doctor about anything. Our [child] is absolutely fine!" (Respondent P2) The first experience of seeking service for this mother was going to a psychologist for private psycho-educational testing a year later, after the problems at school persisted.

Interestingly, most of the mothers mentioned that it was hearing another parent describe a child they knew with TSD that first got them wondering whether or not their child might have TSD.

The light bulb sort of went off when we were at lessons and there was a woman there who's son had Tourettes and she was talking about how difficult it was and she said her niece has it but right now the only real thing they see is this hand flapping and I thought oh my gosh, and when she imitated it, it's exactly what [my child] does. (Respondent P1)

One mother recognized OCD-like symptoms and brought her child for assessment to the adult anxiety clinic where she herself had been successfully treated. All of the mothers described searching through information, including books and the Internet, in an effort to understand what was going on with their child.

I didn't expect to have to do so much digging to find out what is available and where to go for help... You don't know what to do and you don't have the time to invest to figure out where to go, what to do, and how to get it. (Respondent P3)

A couple of the mothers commented on the difficulty identifying TSD because the manifestation of symptoms is so highly individual and often attributed to other diagnoses.

So when I went home and looked it up on the Internet it's sort of like you know you had Tourettes was the umbrella and all these other things fell underneath and [my child] was displaying all of these things that fell in line with that. (Respondent P1)

One mother, although very concerned about the difficulties her child was experiencing, was initially surprised by the seriousness of the eventual diagnosis. “Ever since she was a toddler we've called her our funny little kid ‘cus she always did funny little things, we just didn't know why.” (Respondent P5)

The mothers reported a lengthy assessment and diagnosis process that usually happened over a number of specialist visits. The process typically started with the family doctor, followed by a paediatrician and/or neurologist, with all children eventually seeing one or more psychiatrists who offered a second opinion and/or confirmation of the TSD diagnosis. Sometimes the TSD diagnosis were not communicated right away, or only one diagnosis such as anxiety was communicated, but the mothers reported becoming aware after a period of time that the doctors had been considering TSD for some time. One mother, who described the doctors moving at a pace she and her husband were comfortable with, only understood that her child had been diagnosed with OCD. Although TS was often mentioned in the context of treatment recommendations, for a long period of time she did not realize that her child had actually been given this

diagnosis as well. Two mothers, in an effort to understand the complexity of their child's presentation, requested further investigation into the possibility that their child may also meet criteria for Aspergers disorder, which they did not.

*Feeling the impact:*

The mothers spoke with intensity about their feelings, expressing many different emotions connected to trying to understand their child, trying to get answers, receiving a diagnosis and then looking for ways to cope. The first feelings identified were usually those of confusion, worry, and fear about their child's unexplained behaviours. The feeling of fear was expressed most strongly by the mothers whose children were getting hurt or threatening self-harm. One mother conveyed great distress when recalling that her child required stitches after having a particularly violent outburst. Another mother talked about being scared and alarmed to see her eight year old child becoming depressed, terrified of her own obsessive thoughts, and compulsively rubbing her skin until it was bleeding. Mothers also expressed worry about the inevitable periods of "waxing" or increased symptoms. It was quite distressing for mothers to anticipate, and then watch their child struggle with pain. Two mothers described long bouts of intense tics that left their children with sore joints, aching muscles and disturbed sleep. "Even the quiet times aren't quiet because you're just waiting for that shoe to drop." (Respondent P4)

One of the most difficult decisions faced by the mothers was whether or not to medicate their child. Knowing that the medications used in treating TSD

were originally developed for adults with other disorders definitely increased their concern. “The other thing is there’s not even really any specified medication for Tourettes.... and then reading what the side effects are and everything or not knowing what the side effects may be down... down the road is extremely scary.”

(Respondent P4) One mother talked about taking a long time to agree to medication and feeling grateful that the doctor introduced the medication to her child slowly over a long period of time. When her child experienced more severe and intrusive symptoms however, she was terrified of adding a second medication. Worried about long-term effects, both parents together decided not to add the second medication until challenged by a friend. Once the second medication was started, the child experienced considerable relief which left the parents feeling very badly.

And you say I can’t believe I didn’t do this sooner yeah. Oh it’s... I have to tell you that’s probably the hardest part of this whole several years of dealing with this, I think the hardest thing on my heart is guilt. (Respondent P5)

After carefully chronicling her story of seeking service, a story of determination with endless disappointments, one mother simply concluded, “It’s a struggle you know, it’s not easy.” (Respondent P2)

*Feeling supported:*

The mothers talked also about times that they felt supported, especially when it seemed that people were doing more for them and their child than they expected. One mother described feeling supported when she contacted her

personal counsellor with concerns about her child. “She was very helpful... I think actually went out of her way, you know, to do one on one CBT with [my child].” (Respondent P2) One mother reported feeling appreciative to have a quick response and access to out-of-area service when her child was in crisis. “The doctor said like you’ve got to see this kid, you’ve got to do whatever it takes to, and I think she maybe fudged the rules a little bit to take her.” (Respondent P5) Another mother talked about the extra efforts of a specialist who in her opinion provided phenomenal care.

[The doctor] would um get things off the webMD and different things for me to read... have them printed up and ready for me the next time I came in, and would say anytime [my child] needs someone to talk to until he gets to someone, tell him you know he can come in and see me. (Respondent P4)

When it was time for her child to move onto high school this same mother felt “lucky” when a school secretary intervened with the new learning resource teacher. “So she spoke to her personally ahead of time, she asked my permission, filled her in on the whole situation, said you know [my child] was coming and keep an eye out.” (Respondent P4) It made a significant difference to the mothers when the school staff was supportive. “We have had some excellent teachers thank God that have been very understanding.” (Respondent P5) One mother whose child had great difficulty interacting with teachers most school years recalled a supportive exception. “The teacher was actually very wonderful. Very understanding and would be proactive about setting up situations so that it

wouldn't cause my child to have meltdowns. So that grade was actually not... not too bad." (Respondent P2)

Although attending meetings and finding the time to contact the Tourette Syndrome Foundation seemed daunting to most mothers, they reported feeling supported if they did.

When I did join I was really desperate for help and I needed information. I needed to network with other parents and people and I was kind of at a breaking point with it where I just felt hopeless. Like I didn't know what to do you know. Yeah definitely, and the people were wonderful. Really giving of their time and willing to talk about their own personal experiences and yeah it was really helpful and it still is. (Respondent P3)

It made a difference when professionals interacted and shared information about TSD and specific children with other care providers, especially educators. One mother described the positive effect of having the psychologist communicate her child's high level of impairment by sharing the results of a psycho-educational assessment with the teachers. "It sort of helped, to sort of again counteract the image of her as a bad kid." (Respondent P2) Another mother recounted how helpful it was for the school staff to hear from the psychiatrist that her son did not fit the profile of a potentially violent student.

The doctor even said to the principal you know like he is not the type that would do that, because the principal brought up Columbine and everything in the meeting, and he's like he's just not the type to do that. (Respondent P3)

Overall, mothers report that when they feel supported it makes a tremendous positive difference. "That helps all the way around with the support

here and the support at the school. There's just no way that we could have gone through it without all of them." (Respondent P4)

*Bits and pieces:*

Accessing services after receiving a diagnosis proved to be a confusing and frustrating experience for some of the mothers. Two mothers commented on what it was like to work through the local central referral agency. One mother stated that the intake worker was "really good, really nice and I liked her a lot" (Respondent P2) but she never spoke to her again.

I feel that's unfortunate because you know a parent expects some kind of ongoing support but the way the system works the person you speak to and tell the whole story to then is not the person who is going to be your, your caregiver as it were. (Respondent P2)

The second mother was looking for a one stop comprehensive service.

But then that wasn't a direct thing either it was the intake assessment which is fine but it sort of seemed like everything became so convoluted you know I had to jump all these things to get to the next thing. (Respondent P1)

Typically the mothers acquired information about TSD and related services through fragments of communication with several different sources such as doctors, teachers, websites, counsellors, and other parents.

And I kind of thought... it will come all together you know. But it doesn't, once you find out you know you're sort of dealing with bits and pieces all over the place... I guess I imagined that it would be more comprehensive and I also didn't realize that I would do a lot of the seeking out of stuff on my own. (Respondent P1)

One mother was happy to benefit from a government sponsored home support and tax rebate program for special needs children that she heard about

from the parent of a child with Down Syndrome. However, she expressed great frustration that she was not informed by professionals about the programs earlier, thereby missing out on several years of benefits. A second mother, surprised to hear that her adolescent child might have qualified for extra support or respite when younger from the same program, also expressed frustration and regret that she was not informed about it.

I can't tell you how many cat naps I have from exhaustion and I just can't seem to find the time to sit down and say for even half an hour phone and phone and phone and ask, and ask, and ask. It's just so difficult to find out a lot of things. (Respondent P4)

Another frustration expressed by some mothers was getting service from different professionals in different locations. This was particularly true for the parents only having access to specific services if they paid for them privately. One mother made regular trips outside of the region to access private services that were unavailable or oversubscribed in the local publicly funded system. Another mother described sporadic visits to four different professionals around the city, each providing aspects of treatment for her child's anxiety problems.

I just think what people are missing is that it's not just you know saying a child has something and that's the end of it. It affects the parent, the family, and the child. It's a big deal. It's. It's a lot. So to go and hunt these things down on your own I, I don't think it's easy or fair. I wish that it was easier. (Respondent P1)

*Left dangling:*

The mothers participating in the study each recounted, in varying degrees, ways that they felt unable to obtain services or information when they needed it.

One mother described her child receiving an occupational therapy assessment through the school board, but then only being offered volunteer students sporadically providing sports activities as treatment. This mother accessed both occupational therapy and speech therapy treatments privately, commenting that she felt “lucky” to have the resources to purchase them.

But for mental health right now, I would say especially kid’s mental health in Ontario, it is a two-tiered system. If you have the money to go privately you can get much more help than if you go through the public system and... like I said before, I just feel for the families that can’t afford to do that and those kids are falling through the cracks. (Respondent P2)

Another mother talked about her paediatrician continually directing her to access services privately. “The one thing that keeps coming up is well you have money and I’m thinking... do we though, I mean we have four kids, I don’t work.” (Respondent P1) This same mother thought it was ironic that insurance companies cover drugs but not therapies.

You can drug your child so they’re comatose but to actually deal with the problem no... and I think that’s so unfair because I think it punishes the children and the parents for something that isn’t your fault you know. (Respondent P1)

Another experience mothers commented on was that of being “cut off” when the treatment was not working or was deemed unnecessary. One mother called for assistance when the principal threatened to suspend her child, but calls to the clinic were not returned. “We were not a success story and they felt there was nothing further that they could do for us and they basically didn’t want us on their books.” (Respondent P2) She thought at least her child would have been

referred to another service, but that did not happen. “So here we were faced with this dilemma with no support and so I really did not appreciate that we were sort of cut off.” (Respondent P2) Sometimes the specialist service provider decided that their particular service, for example medication, was not needed and closed the file.

The doctor felt that because my child was receiving sufficient support it was probably best to keep my child off medicine... so that was good but in terms of actual day to day help and support... I didn't feel that we got a lot (Respondent P2).

Another mother seeking family counseling was sent to her husband's EAP provider but felt dismissed when she asked for more support. “Okay those are your problems, you got it off your chest, get on with life type of thing.” (Respondent P4) She felt the whole family could benefit from more support but that service is unavailable to her.

Sometimes children were connected to a service provider but the recommended treatments were not available. One mother reported waiting three years for a group treatment for her child.

I don't know either some restructuring or something was going on so we had phone calls saying you know this is becoming available this month we'll call you back, and then we never got a call back, so there was a real long waiting period for us to get into our next group which I was frustrated with because um... my child really did benefit from that first one. (Respondent P3)

Also, one mother who was very satisfied with available information about OCD and services to help her child specifically with OCD, described feeling lost in how to deal with the added diagnosis of Tourettes. “I mean I do understand that Tourettes is much more or much better helped with medication, and there's

really not a lot of therapy or behavioural modification that can be done for Tourettes. Am I missing something?" (Respondent P5)

Finally, one of the scariest worries for mothers is thinking about the future. One mother, knowing her child would soon turn eighteen years of age and no longer be eligible for service in the child mental health system, talked a lot about her fears, and her child's fears for the future. "He's absolutely terrified that once he turns 18 that he's going to be out on the street with no support." (Respondent P4) She wondered who would monitor the medication, provide the therapy, would there be financial support if he could not work, and whether or not she would be able to cope.

Obviously I will but is there anything that's going to be put in place that will help me manage it? ... Well this is yeah moving into the real world and how do we do this? ... It's really hard to be on a timeline when you don't know what the Tourettes timeline is. (Respondent P4)

*Finding ways to cope:*

During the interview mothers were asked specific questions about service needs including what they expected to happen, what actually happened, what helped, what did not help, and what services they thought were missing. They each had comments about what was helpful as it pertained to their own individual child and family. Collectively these included the following:

- getting constructive suggestions and reassurance from counsellors;
- getting second opinions about diagnosis from specialists;
- learning parent strategies including the collaborative problem solving approach;

- meeting other parents whose children have TSD or other child mental health problems;
- attending information workshops, CBT groups for children, anger management groups for children;
- getting letters from doctors to support school accommodations;
- getting skill building occupational therapy techniques;
- finding website information about TSD and specific learning disabilities;
- having family based meetings;
- watching videos about TSD as a family;
- having supportive and knowledgeable teachers;
- airing of public education commercials about TSD;
- being directed to specific information resources, access to the Family Resource library;
- educating school peers about TSD;
- finding an understanding driving instructor;
- working with professionals who offer and provide emotional support to child and parent;
- child meeting other children who struggle with TSD or other child mental health problems;
- finding videos and books geared to children with characters the child can relate to; and,

- finally, getting information and resources through the Tourette Syndrome Foundation of Canada and Tourette Syndrome Ontario.

Towards the end of each interview each participant was given a twenty-item scale to complete. The scale listed twenty service needs that appear in the literature. Participants were asked to rate, on a five point scale from *doesn't matter at all* to *most critically important*, the level of need for twenty specific service needs that appear in the literature. (Appendix I) The one item out of twenty that all five mothers endorsed as being *most critically important* was information about the diagnosis. This was consistent with comments the mothers made during the interviews when they were outlining how extensively they searched for information about TSD.

A lot of the really good information I got was either from the library books or from the Tourettes society itself ... the internet was very, very limited if I wanted to know what all the different elements of Tourettes were I would find some of them on there. I wouldn't find a lot of them. It was very hard to find (Respondent P4).

When the scale categories *most critically important* and *really, really important* were combined in the analysis, all five mothers endorsed getting a diagnosis and then individual child therapies, specifically counselling, habit reversal training, psychotherapy and cognitive behavioural therapy, as very important. These ratings are consistent with the mothers' interview comments about the importance of getting a diagnosis and the ongoing need for overall skills training. One mother talked about the hardship of getting a late diagnosis.

Again in retrospect if he had been diagnosed back then maybe we could have had it more under control sooner, had more information

along the way. He would have been younger so it may have been easier to grow into rather than hitting him right when he was making the transition into high school and everything else.  
(Respondent P4)

In terms of skills training for her child, one mother commented on the difficulty coping with everyday frustrations. “I think what they need is to deal with their environment in a way that their self esteem can stay intact.”  
(Respondent P3) Another mother asked for an advanced version of a child treatment group where her child had learned new skills.

Wonderful ideas but very primary, so you know and [my child] benefited so much from it and loved being there so much that [my child] would love to go back for another 9 weeks for... the kids that now know what they’re doing, but you know, could I don’t know, take it a step further you know. (Respondent P5)

The next most frequently endorsed service needs, with four out of five mothers rating them as very important, were child anger management training, parent training for managing child behaviour, and support for parent mental health. “A support for parents, basically how to deal with a kid who is you know... inflexible... oppositional and ah... emotional, you know highly emotional. How to do that without losing your own sanity.” (Respondent P2)  
One mother described trying to cope on her own.

But you know like for me I just felt like I needed parenting strategies. Ways to cope or even just someone for me to talk to because it’s a lot to deal with you know, like the medication really helped with the fits, but when she was having those fits, like I was having anxiety attacks, it just you don’t know what to do.  
(Respondent P1)

Completion of this scale prompted the participants to elaborate on the need for respite, a complete service resource guide, increased family and sibling support, publicly funded specialty services, and the importance of social opportunities for the children. Participants also identified gaps in service needs including comprehensive publicly funded assessment and treatment, family focused TSD information sessions, crisis support, and TSD focused recreational camps.

Mothers in the study looked for professionals specially trained to provide assessment and treatment for children diagnosed with TSD. Together they named a number of professionals that they thought should be delivering service to this group of children and their families; psychiatrists, psychologists, neurologists, paediatricians, social workers, child life specialists, child and youth workers, family therapists, psychotherapists, parenting experts, occupational therapists, and speech therapists.

In summary the service needs identified by the participants during this study were:

1. complete and accurate information about TSD and related services;
2. diagnosis by specialist;
3. publicly funded comprehensive assessment and treatment;
4. medications developed specifically for children diagnosed with TSD;
5. crisis intervention and support for child and parent;
6. child interventions including counselling and specific skill training;

7. parent intervention including information, ongoing support and skill training;
8. family intervention including information and support for siblings;
9. training for educators;
10. education for family doctors;
11. liaison and collaboration between specialists and school staff;
12. respite;
13. more family and child oriented video and book resources;
14. specialty recreational camps and social opportunities for children and teens;
15. education for the public; and,
16. transition services from child into adult services.

The concerns about service identified by the participants were:

1. access;
2. timeliness; and,
3. fragmentation

*Ideal service design:*

Hospital based, specialty service, centrally located in the region, providing publicly funded comprehensive assessment and treatment for children, parents and families with links ensuring continuity of care to adult services. This specialty service would include a complete TSD information and resource center, and a comprehensive training program for all professionals involved in providing

care for children diagnosed with TSD. The service would also provide training for and links to social opportunities, including recreational camps, where children with TSD can meet and interact with other children also diagnosed with TSD, as well as networking opportunities for parents and families.

## DISCUSSION

The main finding of this exploratory study is that mothers of children diagnosed with TSD want easy access to information and comprehensive services in order to decrease stress and increase the quality of life for themselves, their children and their families.

The mothers participating in this study consistently communicated that they were under a high level of stress trying to successfully parent and alleviate the distress of their child diagnosed with TSD. The experience of these five mothers is echoed in the literature where it is reported that parents and families of children diagnosed with TSD experience high levels of stress that negatively impacts their quality of life (Cooper, & Livingston, 2003; De Lange & Olivier, 2004; Wilkinson, et. al., 2001). In addition, it is reported that parents of children with other mental health problems similarly experience high levels of stress (McCleary, 2002; Yatchmenoff et al., 1998). This finding is in keeping with a number of studies of parents of children with chronic physical health problems or disabilities who also report living with high levels of stress (Keller & Honig, 2004; Noh, Dumas, Wolf, & Fisman, 1989; Wray & Maynard, 2006).

One of the greatest sources of frustration and stress described by the mothers in this study was the ongoing search for information about TSD and corresponding services. The mothers indicated that their greatest need is to get

information about TSD for themselves, their partners, the child diagnosed with TSD, and their siblings. Although the importance of meeting this need is discussed in the literature by most authors reviewing intervention for the families of children diagnosed with TSD (Dedmon, 1990; Collins, 2005; Stern et al., 2005), it continues to be an unmet need. It is reported in the literature that the most frequently noted service need of parents of children with chronic health conditions is the need for information about the child's condition, its treatment, and its long-term implications (Perrin, Lewkowicz, & Young, 2000). In addition, these authors found that physicians, with specialist knowledge about the implications of the children's conditions, regularly underestimated the amount of information that parents desire (Perrin, et al., 2000). Similarly, data collected with the Brief Child and Family Phone Interview (BCFPI) (Cunningham, Pettingill, & Boyle, 2002) during intake interviews in the province of Ontario, indicates that parents of children with mental health problems overwhelmingly endorse wanting more information about their child's problems (D. Buchanan, personal communication, July 25, 2007). Given this strong evidence of parents' expressed need for information, it is surprising that the effectiveness of a specific TSD information sharing intervention has not yet been thoroughly examined.

All of the mothers indicated that getting a diagnosis is very important. The literature indicates that getting a diagnosis of TSD is one of the most difficult aspects of service to negotiate, with families often taking a circuitous path before a diagnosis is confirmed (Collins, 2005; Dedmon, 1990; Sullivan, 1994). All of

the participants of this study reported their child being assessed by at least three physicians before being given definitive TSD diagnosis, and most described this pursuit as a frustrating and confusing experience. Eventually however, all of the participant mothers' children were seen in a specialty clinic where the diagnosis of TSD was confirmed. Perhaps this experience accounts for the mothers naming the need to get a diagnosis as second to their need of getting information about TSD.

The next priority service need that was strongly endorsed by the mothers was the need for child specific interventions aimed at increasing their ability to cope with the effects of living with TSD. All of the mothers talked about wanting to find ways to teach their child coping skills. Collectively this included skills to better manage their anxiety, obsessive thinking, mood, behaviour, anger outbursts, social skills, tics and compulsions, and overall level of self-esteem. The literature is clear that the single most effective intervention for TSD is medication, targeted to address various aspects of the symptoms of TS, TD, and co-morbid disorders (Robertson, & Stern, 2000; Stern et al., 2005). Four of the five mothers acknowledged that medication was helpful for their child, and all of the mothers were also looking for coping skills to complement the benefits, if any, of the medication(s).

Although the literature suggests that there are therapies including CBT, anger management, social skills training and HRT, available for this group of children, there is limited evidence that these interventions are helpful to children

diagnosed with TSD. For example, there is limited application of CBT treatment to the complexity of TSD. Although CBT is considered to be an evidence-based treatment for OCD, Mansueto and Keuler (2005) outline the limitations of this treatment approach with compulsive and tic-like behaviours. Similarly there are no studies looking at the outcomes of anger management or social skills training for this specific population. Lambert and Christie (1998) reported a small improvement in self-esteem but no change in social, academic or parental scores on behaviour following the evaluation of a social skills group for boys with TS. HRT is showing some promise in the area of tic-reduction, (Deckersbach, Rauch, Buhlmann, & Wilhelm, 2005; Piacentini & Chang, 2005) but is not a readily available treatment.

It is evident that more attention is needed to develop interventions aimed at improving child coping skills that successfully address the complexity of TSD. A longitudinal study by Lin et al. (2007) reported that children diagnosed with TSD experience higher levels of stress overall, and that the level of psychosocial stress, particularly as perceived by the parent, is a predictor of future depressive and OC symptom severity. These results emphasize the importance of monitoring child health by listening to parent report, and finding effective ways to intervene in order to decrease overall stress for children diagnosed with TSD.

Next in importance the mothers identified a need for parent training, and parent support. Several authors have identified both of these as important needs for parents (Collins, 2005; Cooper & Livingston, 2003; Dedmon, 1990; De Lange

& Olivier, 2004; Sullivan, 1994). In particular, Cooper and Livingston (2003) noted a need for specific interventions with parents focused on relationships, and for mothers, assistance with daily activities and respite.

It has been noted that mothers of children with externalizing behaviours are more stressed and burdened (Cooper & Livingston, 2003; Kendall, 1998; Noh, et al., 1989). De Lange & Olivier (2004) highlighted a need for counseling for mothers of children diagnosed with TSD exhibiting with aggressive behaviour, with a specific focus on alleviating their concerns, fears and anxieties.

An article reviewing the literature about parenting adolescents with ADHD proposed that parent stress may be reduced by providing information and parent training, and would provide more benefit if parents also received support to view themselves as competent, in order to improve parenting self-efficacy (McCleany, 2002). Also, parents in a study surveying 1,412 families about service needs for children with disruptive behaviours, ranked the need for provision of counseling and behavioural management strategies for the parents within the top five service options (Hazell, Tarren-Sweeney, Vimpani, Keatinge, & Callan, 2002).

Wigley et al. (2000) reported on a drop in clinic based support group for parents provided through a Tourettes specialty clinic in the UK. Initially, parents preferred to be on their own and reported having discussions about how to control “bad behaviour” and get support at school. This evolved into a monthly meeting with the parents asking a professional to facilitate, to provide guidance and

advice, and to have guest professionals to share information about different aspects of TS. The authors reported that although the initial intention behind providing the parent support forum was to reduce the need for regular appointments with clinicians, this did not happen. However, parents attending the group reported a decreased sense of isolation, a sense of increased support, and requested that the group continue. Overall, the literature provides a well documented need for the provision of parent training and support that backs the expressed needs of the mothers in this study.

A secondary finding is the importance of education and training of others who interact with children diagnosed with TSD and their families. The mothers eloquently expressed their frustration and distress in having to deal with professionals, and the general public, who have limited or no knowledge about TSD. In contrast to this, when others were well informed or willing to become informed, the mothers felt supported and more confident about how their children would fare in different situations.

In 1990, Dedmon wrote a comprehensive article about TS published in Health and Social Work urging social workers to become better informed about this often misunderstood condition. Fifteen years later, Collins (2005) noted that little has changed.

Social work and social work education have virtually ignored a crucial area of study that includes populations challenged with even the most common neuropsychiatric disorders.... children with TS are often under-diagnosed and misdiagnosed because of the lack of education and awareness of the wide range of indicators and symptoms of the disorder (Collins, 2005, p. 477-478).

Unfortunately, this lack of knowledge extends to many professionals charged to provide care for this group of children, including physicians and educators. The mothers talked about family doctors' lack of knowledge about TSD and the need for more access to specialists. Waddell et al. (2005) noted that there are fewer than 500 trained child psychiatrists in all of Canada. It is well recognized that there is a shortage of professionals trained to recognize, assess, and provide adequate care for this population of children. "The major current handicaps for the community of people affected by the syndrome in the UK are delayed diagnosis, non-specialist management and inadequate educational support" (Stern et al., 2005, p.18).

Most educators are not trained about TSD (Packer, 1997) but "the importance of increasing knowledge about TS among educationists cannot be overemphasized" (Stern et al., 2005, p. 16). One of the unintended consequences of "zero tolerance" in the school system in Ontario has been the high rate of suspension and expulsion for special needs children (CBC News, April 13, 2007). This would include children diagnosed with TSD. Packer (1997) reports that it is imperative to communicate the complexity of TSD with educators in order to build trust between the school staff and the parent, and to properly provide for the children's academic needs.

In regard to experiences with the public, mothers recounted times where adults and other children stared at their child, interpreted their behaviours as deliberately rude and annoying, and told them that they were "bad". These kinds

of experiences are also confirmed in the literature. “The social isolation, stigma and rejection with its many personal consequences, experienced because of the nature and manifestation of the condition and compounded by the lack of awareness and understanding, are still daily features of the family’s life” (Sullivan, 1994, p. 44).

TSD symptoms may be viewed as bizarre, disruptive, and frightening, provoking ridicule and rejection from peers, neighbours, teachers, and family (Collins, 2005). According to Packer (1997) the education of school staff and school peers can have a significant positive impact on the child diagnosed with TSD, as well on their parents and siblings. Packer (1997) advocates the use of educational videos to provide information to key people interacting with the child. Dedmon (1990) reported that parents, fearing that their child may be ridiculed, restrict their outings and affiliations with community groups. One mother talked about the positive effect that a series of television commercials, designed to educate the public about TS, had on her son’s high school community. Many individuals, adults and peers, approached him to say they had wondered what his problem was until they saw the commercials. This provided a significant relief to both the mother and son.

A more novel finding in this study was the mothers’ report of being expected to access services privately and of being “cut off” from services when their needs did not fit the mandate of the service provider. Although a shortage of services and specialist providers was discussed in the literature, the pressure to

pay privately for missing services, or the experience of being excluded from specific services, was not highlighted. These experiences clearly provoked much distress, frustration, and confusion for the mothers in this study. It would be interesting to survey a larger number of parents to determine how commonly this happens.

Much of what the mothers described is similar to Ray's (2002) theme of "invisible work". In her study of 30 families of children with chronic health problems, Ray reported on the difficulty parents face in trying to keep a balance between the child's needs and the family's needs, while they try to negotiate the system.

In particular parents resented the time, effort and emotional energy that they needed to expend in administrative, coordinating, and advocacy roles. Unfortunately for parents these were often the most invisible parts of their caregiving roles... the findings of this study indicate that the area of greatest frustration, working the systems, is the area with the least support and services available (Ray, 2002, p. 435).

A major focus of this "invisible work" for the mothers in the study was that of seeking services to help her child and family in "coping" with the impact of living with TSD. This coping included interactions with the public, and institutions such as education and health care, where expectations often increased, rather than eased, the level of frustration experienced by the child and family. The mothers in this study were often left feeling responsible for finding their own solutions to their problems. The placing of responsibility on individuals to make

changes, rather than on social institutions to make changes, can be understood within the context of structural theory (Payne, 2005).

Many of the problems encountered by the mothers were directly connected to system rules, attitudes, and resource allocations that were beyond their control. Mullaly (2002) refers to cultural, and structural forms of oppression, both of which apply to the experience of these mothers. In terms of oppression by gender, mothers are consistently burdened with the expectation of being the primary caregiver for children (Swift, 1995). These mothers, although all co-parenting with male partners, assumed the primary caregiving role for their child diagnosed with TSD. The mothers in this study, all white, married, and middle class, communicated feeling blamed, stressed and clearly overwhelmed by the responsibility of parenting their child with complex needs. It can only be surmised how much greater the burden of care must be experienced by mothers also oppressed by race, sexual orientation, poverty and culture.

When they described experiences of being rejected, excluded, and marginalized by both public and by institutional practices, the mothers of this study were illuminating the burden of living with the expectation to conform to dominant social and structural practices. Oppression at the cultural level is fueled by the media, which portrays the dominant cultural message of ideals, including the ideal family who is living free of mental health problems. The mothers described feeling punished, exhausted, confused, guilty, and frustrated when faced with issues of access, timeliness, and fragmentation of services, all forms of

structural oppression that they alone could not address. Generally, the mothers' response to this oppression was to seek ways for their child and themselves to "cope" by somehow coming just inside the margins of acceptable behaviour without complaining about the oppression of the larger systems. They spent much energy to "fit in". Although there is a place for supporting and strengthening individuals and families, thereby developing a sense of agency, to be truly effective, changes also need to occur at the structural level (Mullaly, 2002).

An anti-oppressive social work approach would seek to identify and make changes to oppressive social and institutional practices, in order to ease this burden. Bringing forth the voice of these five mothers is a beginning step to easing their burden. The greater challenge is to bring forth the voice of these mothers to make changes within the institutional structures. Mullaly (2002) advises social workers to have realistic expectations, engage in ongoing critical self-reflection, and to work with others in order to successfully practice from an anti-oppressive stance. It will be important to work to incorporate the ideas of the mothers in this study into current practice, while devising a forum for further collaboration and feedback with a wider group of parents and other consumers, including children diagnosed with TSD and their other care providers.

Senator Kirby has identified the poor state of children's mental health in Canada to be a major national problem. Clearly, sweeping changes to policies and economic priorities need to occur to enable improvement in the allocation of

resources, and equitable and timely access and delivery of services to all Canadian children and families. A plan to improve services for children diagnosed with TSD and their families locally must include a plan to highlight this need, and to support these recommendations provincially and nationally. Working collectively and collaboratively with individual parents, parent groups, and existing organizations including the Tourette Syndrome Foundation of Canada, and Children's Mental Health Ontario, will be key to truly bringing forth the voice of these five mothers.

Limitations:

This was an exploratory study with a small number of participants who were all married, white, Canadian born, middle class mothers, living in an urban center, and all were the recipients of specialist services for their child diagnosed with TSD. The findings represent the experience of these participants, and cannot be generalized to all parents of children diagnosed with TSD. It is unknown how factors such as poverty, same sex parenting, race, rural location, and/or cultural beliefs would influence the findings.

The interview questions were intended to guide the discussion and allow for accounts of different kinds of experiences and ideas. (Patton, 2002) However, the questions on the semi-structured interview guide were not piloted for reliability of meaning between respondents, and therefore may have elicited different kinds of responses from different participants.

Another limitation is the influence of researcher bias. “There is an inherent power in naming the issue to be studied and why it is worthy of study” (Potts & Brown, 2005, p. 265). I am aware that I have a biased opinion about needed services and service delivery. I have a strong belief that services are currently severely under-funded, and that recent system restructuring and the focus on efficiency, has resulted in the loss of many beneficial aspects of service that were previously provided. I know that my beliefs influenced my choice of research question, my research design, and my interview questions. Perhaps the parents would have posed a question(s) that was more meaningful to them. Perhaps they would have proposed an entirely different way of getting the answer as well (Potts & Brown, 2005). Also, although I worked diligently to accurately represent the experience and ideas of the participants, my bias may have influenced the analysis of the data. “Every researcher holds preconceptions that influence, but may not determine, what we attend to and how we make sense of it” (Charmaz, 2006, p. 67). I was very aware of my need to keep returning to the interview data and the memos to search for alternative explanations and negative cases (Patton, 2002) in order to provide an accurate and fair representation of what the mothers had to say.

## CONCLUSION

This thesis looked at parents identifying the service needs of families of children diagnosed with TSD. Children with TSD have complex needs and the caregiving demands on parents are considerable. This study identified that parenting a child with TSD is stressful, and the challenges of seeking services in an under funded and fragmented children's mental health system increases stress on the whole family.

The five mothers interviewed in the study expressed a great deal of frustration about seeking services, as well as gratitude for any support received. The mothers in the study clearly identified easy access to complete information about TSD, getting a diagnosis, and easy access to comprehensive treatment, especially coping skills to deal with the impact of TSD, as their priority service needs. These needs are supported in the literature about TSD, but access to publicly funded services is limited and fragmented. Locally, re-allocation of resources toward parent prioritized service needs might ease some of the burden, but to be truly effective, re-prioritizing resources for children's mental health, including professional training and public education about TSD, needs to occur provincially and nationally.

Areas for further research include surveying a larger and more diverse group of parents to see if the findings of this exploratory study apply to most families. It would also be important to hear what fathers, and also what children

diagnosed with TSD, have to say about service needs. It would be interesting to look at whether parents would be more satisfied with services if they received what these mothers asked for. For example, it would be interesting to involve clinic parents and Tourette Syndrome Foundation chapter members in designing and piloting a TSD psycho-education program including, a written guide to services. This program would be delivered to all families of children diagnosed with TSD, and other key care providers including educators. This intervention could then be evaluated, and outcomes comparing the provision of TSD psycho-education with written guide alone, to outcomes of provision of TSD psycho-education, written guide, and the assistance of a “clinician guide” to services, could be assessed.

Further recommendations resulting from the findings of this study include incorporating identified parent priorities into existing service designs, while working collaboratively with parents and existing organizations such as the TSF of Canada to make these needs more widely known. Senator Kirby’s report (2006) recommended increased education for teachers about children’s mental health issues, the development of school based mental health teams, increased training for mental health professionals, expanded use of limited resources through telepsychiatry, increased group therapy interventions, increased case conferencing between health, education, and youth justice service providers, inclusion of families in treatment planning, and that provision of clinical service

be determined by need rather than age. All of these recommendations, if implemented, could help to address concerns raised by the mothers of this study.

Waddell et al. (2005) noted that it is important to develop universal, targeted, and specific clinical interventions in order to begin to meet the mental health needs of Canadian children. The mothers of this study would agree. The needs of children diagnosed with TSD are complex, and educating others as well as themselves, is of the utmost importance in order to ease the burden of living with TSD on all.

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Appendix A



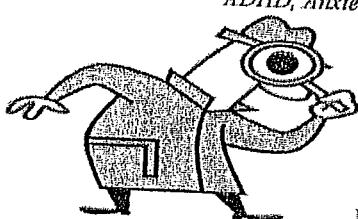
# Research Participants Needed

"Parents Identifying Service Needs"

Are you the biological parent, step-parent, or grandparent  
of a child diagnosed with

## Tourette Spectrum Disorder?

(Tourette Syndrome or Tic Disorder  
AND at least one of  
ADHD, Anxiety, OCD, ODD or Mood disorder)



I am a McMaster University MSW student who  
*wants to hear from parents about*

1) The experience of seeking service for their child and family

2) Parent ideas about service needs.



For further information please call Marlene Traficante at 289 237 9570.

| TSD<br>Parents and<br>Needs Study |
|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|
| Marlene<br>Traficante             | Marlene<br>Traficante             | Marlene<br>Traficante             | Marlene<br>Traficante             | Marlene<br>Traficante             | Marlene<br>Traficante             |
| Phone<br>289 237 9570             |

Appendix B

Screening Criteria

**1. Respondent is 18 years of age or older?**

Yes      No

**2. Current primary caregiver to the child?**

Yes      No

Nature of relationship:

- \*      Biological parent \_\_\_\_\_
- \*      Step-parent \_\_\_\_\_ or
- \*      Grandparent \_\_\_\_\_ of a child diagnosed with TSD?
- \*      Foster parents **SHOULD NOT BE INCLUDED**

**3. Child's diagnosis?**

A) Tic Disorder \_\_\_\_\_ Tourette Syndrome \_\_\_\_\_

B) ADHD \_\_\_\_\_ Anxiety \_\_\_\_\_ ODD \_\_\_\_\_ OCD \_\_\_\_\_ OCB \_\_\_\_\_ Mood \_\_\_\_\_

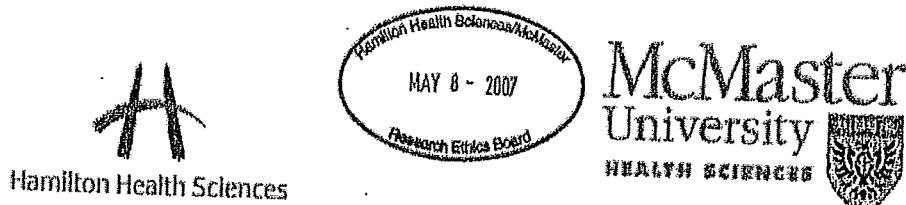
**Diagnosis includes one of A \_\_\_\_\_ and at least one of B \_\_\_\_\_**

Yes      No

**4. Meets inclusion criteria.**

Yes      No

## Appendix C



### **Title Study: Parents Identifying Service Needs**

**Investigator:** Marlene Traficante, Student  
Master of Social Work Program  
McMaster University

**Faculty Supervisor:** Dr. Susan Watt  
School of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
(905) 525-9140 ext. 23771

You are being invited to participate in a research study conducted by Marlene Traficante because you have a child diagnosed with Tourette Spectrum Disorder.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision. Feel free to discuss it with your friends and family, or your family physician.

#### **Why are we doing this study?**

I am a social worker at the McMaster Children's Hospital, Child and Youth Mental Health Program, Chedoke Site. I am also a student of the Master of Social Work program at McMaster University. I am doing a research project to complete my Master of Social Work thesis.

I have a longstanding interest in Tourette Spectrum Disorder and how to help children and families impacted by this disorder. I am a paid member of the Tourette Syndrome Foundation of Canada. In my work I meet many parents of children who meet criteria for Tourette Spectrum Disorder (TSD). I believe that parents have important ideas about

## Appendix C

service needs. I am looking for parents of children diagnosed with TSD who would be interested in talking to me about their experiences of seeking service, and their ideas about what service needs are. I want to write about your experiences and ideas, and compare this information to what is written in the academic and medical literature, to see if it is the same or different. I plan to share these findings with other parents, professionals and program planners through a written thesis report, a rounds presentation, a research poster presentation, and a published article.

### **What will happen during the study?**

**If you volunteer to participate in this study, we will ask you to do the following things:**

1. You will be asked to complete an information sheet for some demographic information like your age and education. This will take about 5 minutes.
2. You will be asked questions about your experience of seeking services for your child, and what services you would like for your child and your family. You will be asked permission to record this conversation on audiotape, and the interviewer will take written notes. This will take 1 to 2 hours depending on how much you would like to say.
3. During the interview you will be asked to complete a short questionnaire about service needs for children and families. This will take about 10 minutes.
4. At a later date, you will be asked to review a written summary of the ideas you talked about in the interview, and say whether or not you think the summary says what you wanted to say. This will take about 1 hour.

### **Will anything bad happen during the study?**

You may feel uncomfortable talking about your experiences. Sometimes it is upsetting to talk about trying to get help for your child and family. You do not need to answer questions that make you uncomfortable or that you do not want to answer. You may be disappointed if you talk about your experiences and ideas about services but there are no changes in the services that are available for you and your family. You may tell me something that I have a duty to report to the authorities concerning the risk of harm to self or others. For example, if you tell me anything indicating a child may be in need of protection, I am legally bound to report that to a Child Welfare Agency.

### **How many people will be in this study?**

This is a student study to gather beginning information about this question. I plan to interview 5 to 7 parents for this study.

## Appendix C

### **What good things could happen if I participate?**

It is important to hear from parents what they think about services offered for their child and family. You may feel good talking about your experiences. You may feel good having the opportunity to share your ideas about service needs. The results of this study will be shared with other parents, professionals and service planners. The information you provide might be used to plan for, and to provide better services for children and families. You, your child, or your family may not benefit directly from participating in this study, but you will add important parent knowledge to our understanding of how to be helpful to children and families when a child is diagnosed with Tourette Spectrum Disorder.

### **Payment or Reimbursement:**

To thank you for your participation in the study, you will be offered an information package about materials available for parents and children at the Family Resource Center, McMaster Children's Hospital, Chedoke Site. You will also be offered a parking voucher or bus tickets to help with both the cost of getting to the interview, and getting to the resource center. There is no fee to visit or use the resources at the Family Resource Center.

### **Who will know what I said or did in the study?**

Anything that we find out about you that could identify you will not be published or told to anyone else, unless we get your permission in advance. Some quotes from the interviews may be used in the written reports and presentations, but your privacy will be respected and your name will not appear anywhere in the report. We will not include any information that could identify you.

The interview notes, audiotapes, and questionnaires will be coded with a number and kept separate from your name and demographic information sheet. The audiotape will be labeled with a number code and transcribed into a written document by a paid professional transcriber. All of the information collected will be kept in a locked file cabinet in a secure research space at McMaster Children's Hospital, and will only be available to myself, and my faculty supervisor. The information will be destroyed one year after at the completion of the thesis using the hospital's confidential record disposal service.

### **Legally Required Disclosure:**

We may have to reveal certain personal information if the law requires it. For example, you may tell me something that I have a duty to report to the authorities concerning the risk of harm to self or others.

## Appendix C

### What if I change my mind about participating in the study?

Your participation in this study is voluntary. If you decide to participate, you can decide to stop at any time, even after signing the consent form, or part way through the study. If you decide to stop participating, there will be no consequences to you. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision to participate in the study or not, will not in any way affect your future or continuing access to services at McMaster Children's Hospital. If you decide to withdraw from the study, all of the information, including forms, notes, transcripts, and audiotapes will be destroyed.

### Information About the Study Results

You may obtain information about the results of the study by asking me to send you a written summary of the findings or by attending a presentation. You will need to give me your contact information if you want to receive a copy by mail, or if you want to be notified about a presentation.

Please contact me to share the study findings. My contact information is:

Name \_\_\_\_\_  
Mailing Address \_\_\_\_\_  
Phone \_\_\_\_\_  
Email \_\_\_\_\_

### Rights of Research Participants

I agree to participate in the research study by participating in a research interview. Further,

A) I agree to the taping of the interview \_\_\_\_\_

B) I prefer that the interview not be taped \_\_\_\_\_

I know that my direct quotes, without any identifying information, may be used in written reports of the research findings. Further,

A) I agree to the use of my direct quotes in written reports of the research findings. \_\_\_\_\_

B) I do not agree to the use of my direct quotes in written reports of the research findings. \_\_\_\_\_

If you have questions or require more information about the study itself, please contact Marlene Traficante, at 289 237-9570.

If you have any questions regarding your rights as a research participant, you may contact the Office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at 905-521-2100, ext. 42013.

Version date: April 18, 2007



Page 4 of 4

Appendix C



**CONSENT STATEMENT**

I have read the information presented in the information letter about a study being conducted by Marlene Traficante, of McMaster University. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

---

Name of Participant

---

Signature of Participant

---

Date

In my opinion, the person who has signed above is agreeing to participate in this study voluntarily, and understands the nature of the study and the consequences of participation in it.

---

Name of person obtaining the consent

---

Signature of person obtaining the consent

---

Date

Version date: April 18, 2007



Page 1 of 1

Appendix D

**Demographics Sheet (to be completed before interview with researcher)**

**Parent information:**

1. Postal Code (first 3 digits only) \_\_\_\_\_
  2. Male \_\_\_\_ Female \_\_\_\_
  3. Age of respondent       18-29       30-39       40-49       50 +
  4. Born in Canada       Yes       No
  5. English is my first language       Yes       No
  6. I am a single parent       Yes       No
  7. Highest level of education I have completed:  
 elementary school       some high school       completed high school  
 some college/university       completed college/university
  8. Total number of people living in my household \_\_\_\_\_
  9. Total household pretax income is:  
 0 – 9,999       10,000 – 19,999       20,000 – 29,999       30,000 – 39,999  
 40,000 – 49,999       50,000 – 59,999       Greater than 60,000
  10. My relationship to child:       Biological parent       Step-parent       Grandparent  
 Other (specify) \_\_\_\_\_
  11. I have been providing care for this child for \_\_\_\_\_ years.
- Child information:**
12. Age \_\_\_\_\_
  13. Grade \_\_\_\_\_
  14. In a special classroom       Yes       No
  15. Male \_\_\_\_ Female \_\_\_\_
  16. Child was born in Canada       Yes       No
  17. English is child's first language       Yes       No
  18. Child's diagnosis: \_\_\_\_\_

## Appendix E

### Interview Guide and Note Sheet

**Telephone introduction** – follow up with person identified as a possible research subject

'I have been given your name as someone who may be interested in participating in a research study that talks to parents of children diagnosed with Tourette Spectrum Disorders about service needs. First I would like to make sure you meet the criteria for participation in this study.'

Review the screening criteria for potential participants:  
**(Refer to Appendix B)**

If no, the potential participant does not meet all of the screening criteria, thank them for taking the time to express their interest and say good-bye.

If yes, the potential participant meets the screening criteria, continue with introduction:

'I am a social work student in the MSW program at McMaster University. I also work as a social worker at the McMaster Children's Hospital, Child and Youth Mental Health Program, Chedoke Site, where I meet many parents of children who meet criteria for Tourette Spectrum Disorders (TSD). I believe that parents have important ideas about how we should go about identifying service needs. I want to interview you about your experiences of seeking service, and your ideas about service needs. I plan to compare this information to what is written in the academic and medical literature to see if it is the same or different. At the end of the study I plan to share these findings with other parents, service providers, and program planners.'

1. 'Would you be willing to be interviewed about your experiences and your feeling about your interactions with services for you and your child?'

Yes → arrange appointment date, time, location

---

2. 'Would you be willing to have your interview recorded on audiotape?'

Yes \_\_\_\_\_ No → Explore why and try to allay concerns

'When you come in for this interview I will review the consent form in detail. If you cannot make our scheduled time, please let me know by calling me at 289 237-9570 where you can leave a message if you do not reach me directly.'

### **Interview introduction – at the scheduled appointment**

‘As we discussed on the phone, this is a study looking at how parents of children with Tourette Spectrum Disorders identify family needs for services. I really appreciate your willingness to talk with me today.’

‘I have a consent form that I would like to review with you.’ (Hand the respondent a copy of the consent form, **Appendix C**). ‘We will read through the form together. Please feel free to ask me any questions that you have as we go along. I want to make sure you understand everything talked about in the consent form.’

‘Do you have any questions? If you understand everything in the form, and you agree to participate, please sign it and I will give you a copy for your own records.’

Get signed consent; witness it; offer the subject a copy of the consent.

Hand the participant the Demographic Sheet

**(Refer to Appendix D)**

‘This is information I am gathering so that I can describe the people that participated in the study. It will not be attached to information that can identify who you are. You can choose to answer some or all of the questions.’

### **Interview Schedule**

‘Are there any other questions before we begin?’

‘Okay now we are ready to begin the interview. Remember, anything that we find out about you that could identify you will not be published or told to anyone else, unless we get your permission in advance. The interview will take 1 to 2 hours depending on how much you would like to say. I will now turn on the tape recorder to record our conversation.’ Or ‘As agreed I will not be audio taping this interview.’

‘I am going to ask you a number of different questions and then I will ask you to complete a brief questionnaire that will take about 10 minutes. Then I will have a few more questions and I give you time to add any other thoughts you have before we finish. Please feel free to ask me questions or to take a break as we go along.’

‘One of the questions parents have been asking is “What do you mean by service needs?”. What I mean by service needs is “specialized care provided to children and/or families by professionals and others who are not the adults responsible for providing the everyday are for your child.”

Hand a written copy of this definition to the parent for their reference during the interview.

**“Service needs are specialized care provided to children and/or families by professionals and others who are not the adults responsible for providing the everyday care for your child.”**

**A. Experience of seeking/receiving services:**

‘The first questions I will ask you today are about your experience of seeking service.’

1. When did you decide to seek help with your child?
2. Where did you go for help?
3. What happened when you sought help?
4. What services are you currently connected with?

**B. Expectations around services**

‘I am now going to ask you some questions about what you were expecting when you went looking for services.’

5. What did you think would happen when you first sought help around your concerns?  
(for your child, for your family)
6. What services did you think or expect would be available?  
(for your child, for your family)

**C. Opinions about service**

‘Now I have some questions about the services you received or wished you had received.’

7. What services have been helpful? (past, present)
8. What services have not been helpful? (past, present)
9. What services do you think are missing or do you wish were available

**D. Ideas about services**

‘Next I want to ask you more about your ideas for needed services’

10.If you were asking for services for children and their families what would you ask for?

11.Where would you like the services offered? (location, kind of agency or community group)

12.Who would like to offer those services? (health professional, community person, educator, allied health, parents)

13.When do you think these services should be offered? (at diagnosis, before diagnosis, developmental stage)

#### **E. Service Appraisal form**

'I really appreciate your participation in this project. We are more than halfway through the interview.'

At this point I will hand the respondent a brief questionnaire (Appendix F) about services that are discussed in the literature. I will ask the respondent to think about the needs of their own child and family, as well as other children and families a child diagnosed with TSD while rating the level of need for each service.

'Here is a questionnaire listing some of the services talked about in the academic texts and journals. Please rate the level of need for each of these services from your point of view.'

#### **(Refer to Appendix F)**

A number of service needs are discussed in the academic and medical literature. Some of them are listed below. Think about your child and family, as well as other children and families you know that have a child diagnosed with TSD. Please rate the level of need for each of these services from your point of view by checking a box. Please feel free to ask for an explanation of these terms.

#### **F. Response to Service Appraisal Questionnaire**

'Thank you for completing this questionnaire. I have a few questions related to the questionnaire.'

14. What are your thoughts about the services listed on this questionnaire?

15. Is there anything you would like to add to the list?

16. Is there anything that you think does not belong on the list?

### **G. Conclusion**

'Thank you so much for your participation in this study today. We are finishing up now.'

17. Is there anything else you think that I should know or that you would like to tell me?

18. Do you have any questions about today's interview or about the next steps in the study?

19. Do you know how to contact me if you have any further thoughts or questions?

'I am going to have this interview transcribed and then I will prepare a written summary of the information that you shared with me today. I would like to ask you if you think I have accurately captured what you wanted to say. May I contact you again and set up a time to review the written summary with you?'

Yes, I agree to be contacted to review a written summary of the interview.

No, I do not agree to be contacted to review a written summary of the interview.

For respondents meeting at the Hospital site or a community based location I will ask: 'Would you like a parking voucher or bus tickets to help with the cost of coming to meet with me today?'

For all participants I will state:

'I would you like to offer you this information package from the Family Resource Center, McMaster Children's Hospital, Chedoke Site as a thank you for your participation. You can visit the Family Resource Center during operating hours whenever you like. There is no fee for this service. Would you like a parking voucher or bus tickets to use if you choose to visit the Family Resource Center? Thank you so much again for your participation today.'

THE END

## Appendix F

### **Service Appraisal Questionnaire**

|   | Doesn't matter at all | Not all that important | Fairly important | Really, really important | Most critically important |
|---|-----------------------|------------------------|------------------|--------------------------|---------------------------|
| Getting a diagnosis   |                       |                        |                  |                          |                           |
| Medication  |                       |                        |                  |                          |                           |
| Information about the diagnosis                             |                       |                        |                  |                          |                           |
| Support from other parents with children diagnosed with TSD |                       |                        |                  |                          |                           |
| Parent training for managing child behaviour                |                       |                        |                  |                          |                           |
| Social opportunities for child diagnosed with TSD           |                       |                        |                  |                          |                           |
| Family counselling  |                       |                        |                  |                          |                           |
| Respite   |                       |                        |                  |                          |                           |
| Social skills training for child                            |                       |                        |                  |                          |                           |
| Assistance for managing child behaviour at school           |                       |                        |                  |                          |                           |
| Support for siblings  |                       |                        |                  |                          |                           |
| Support for parent mental health                            |                       |                        |                  |                          |                           |
| Counselling for child diagnosed with TSD                    |                       |                        |                  |                          |                           |
| Anger management training for child                         |                       |                        |                  |                          |                           |
| Habit reversal training for child                           |                       |                        |                  |                          |                           |
| Advocacy to obtain educational support for child            |                       |                        |                  |                          |                           |
| Psychotherapy for child                                     |                       |                        |                  |                          |                           |
| Education for peers of child diagnosed with TSD             |                       |                        |                  |                          |                           |
| Occupational therapy for fine motor problems                |                       |                        |                  |                          |                           |
| Cognitive Behaviour Therapy for child                       |                       |                        |                  |                          |                           |

\*Scale developed from information found in:

Dedmon, R. (1990) Tourette syndrome in children: Knowledge and services. *Health and Social Work, 15*, 107-115 Stern, J. S., Burza, S., & Robertson, M.M. (2005). Gilles de la Tourette's syndrome and its impact in the UK. *Postgraduate Medical Journal, 81*, 12-19

## Appendix G

TSD criteria of the children as endorsed by their mothers

|                                       | 1 | 2 | 3 | 4 | 5 |
|---------------------------------------|---|---|---|---|---|
| One of                                |   |   |   |   |   |
| Tourette syndrome<br>or Tic Disorder  | x | x | x | x | x |
| Plus at least one of the<br>following |   |   |   |   |   |
| ADHD                                  | x | x |   |   |   |
| Anxiety                               | x | x |   |   |   |
| OCD                                   | x |   | x | x | x |
| OCB                                   |   | x |   |   |   |
| ODD                                   | x |   |   |   |   |
| Mood                                  |   |   |   |   |   |

## Appendix H

July 2007

[Name]

[Address]

Re: Parents Identifying Service Needs

Dear [name],

Thank you so much for agreeing to participate in my MSW research project. It was truly a privilege to meet with you, listen to your story, and record your ideas.

I am currently reading and re-reading all of the transcripts to make sure I capture everything that you had to say accurately. For the project I interviewed a total of five mothers, whose children ranged in age from 7 to 17, two boys and three girls. I am in the process of looking at the information data to see what you said that was similar and different to each other and the literature.

I put together this summary of the main points from the transcript of your interview. Please take a moment to read this summary, and if you think that I missed something, did not capture what you meant, or misunderstood you in any way, I would really like to know so that I can correct it. Also, please let me know if you want to add or delete information to the summary.

**My cell phone number is 289 237 9570 and my work number is 905 521 2100, ext 77645.**

Please feel free to call any time. If you do not get a hold of me you can simply leave a message and I will call you back. I will also give you a quick telephone this week to ask your thoughts about the summary.

Thanks sincerely,

Marlene Traficante

**Appendix I**  
**“What Was Helpful” Scale<sup>1</sup> Response for the Five Participants**

|   | Doesn't matter at all | Not all that important | Fairly important | Really, really important | Most critically important |
|---|-----------------------|------------------------|------------------|--------------------------|---------------------------|
| Getting a diagnosis   |                       |                        |                  | XXX                      | XX                        |
| Medication  |                       | X                      | X                | XX                       | X                         |
| Information about the diagnosis                             |                       |                        |                  |                          | XXXXX                     |
| Support from other parents with children diagnosed with TSD |                       |                        | XXX              | XX                       |                           |
| Parent training for managing child behaviour                |                       |                        | X                | X                        | XXX                       |
| Social opportunities for child diagnosed with TSD           |                       | XX                     |                  | X                        | XX                        |
| Family counselling  |                       |                        | X                | XX                       | XX                        |
| Respite   | X                     | X                      | X                | X                        | X                         |
| Social skills training for child                            |                       | X                      | X                | X                        | XX                        |
| Assistance for managing child behaviour at school           | X                     |                        | X                | X                        | XX                        |
| Support for siblings  |                       |                        | XX               | XX                       | X                         |
| Support for parent mental health                            |                       |                        | X                | XXX                      | X                         |
| Counselling for child diagnosed with TSD                    |                       |                        |                  | XX                       | XXX                       |
| Anger management training for child                         | X                     |                        |                  | X                        | XXX                       |
| Habit reversal training for child                           |                       |                        |                  | XXX                      | XX                        |
| Advocacy to obtain educational support for child            | X                     | X                      |                  |                          | XXX                       |
| Psychotherapy for child                                     |                       |                        |                  | XXX                      | XX                        |
| Education for peers of child diagnosed with TSD             |                       | X                      | X                | XX                       | X                         |
| Occupational therapy for fine motor problems                | X                     | X                      |                  | X                        | XX                        |
| Cognitive Behaviour Therapy for child                       |                       |                        |                  | XXX                      | XX                        |

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<sup>1</sup> Scale developed from information found in Dedmon, R. (1990) Tourette syndrome in children: Knowledge and services. *Health and Social Work, 15*, 107-115; Stern, J. S., Burza, S., & Robertson, M.M. (2005). Gilles de la Tourette's syndrome and its impact in the UK. *Postgraduate Medical Journal, 81*, 12-19.