

stimulus grants

Developing a new behavioural outcome measure

by *Tamarah Kagan-Kushnir, MD, FRCPC* – recipient of ASO's Stimulus Grant 2004

Many exciting advances have happened in the field of autism in recent years, with improved and earlier diagnosis being one of the most notable. New diagnostic tools have helped professionals recognize and diagnose children earlier and more accurately. Unfortunately, tools that rigorously assess whether treatments are effective for individuals with autism are lacking.

Behavioural difficulties are common in children with Autism Spectrum Disorders (ASD). They often create significant problems for the child as well as their family, teachers and therapists. Behaviour problems are a frequent reason why parents seek assistance from professionals, and difficult behaviours are often a target of intervention.

Our ability to assess whether a treatment works, as well as to develop interventions for specific, distressing behaviour, is currently hampered by a lack of appropriate tools to detect changes in behaviour. There are many behavioural questionnaires available, but few have been designed specifically for autistic children and as such are often inappropriate. Of those that were designed with autistic children in mind, some do not reflect recent advances in our understanding of ASDs. Others were designed for diagnostic purposes, and not to assess treatment efficacy. Parents have not been consulted in the development of any of these tools. As primary care givers, parents are experts in their children's behaviour, and ultimately are the ones who will decide if interventions are working.

Developing a new tool or outcome measure that can detect changes in behaviour, is the focus of my research. The measure will be a parent questionnaire designed to be completed on successive occasions.

The project has multiple phases. The first stage, already underway, involves small focus groups of parents and professionals—people with first-hand knowledge about autistic behaviours and their impact on day-to-day functioning for the individual and their caregivers. The aim is to learn which behaviours pose difficulties or are a concern, so that these can be appropriately captured in the measure. Consulting with those who will use the tool will help to make it relevant.

The second part of the study focuses on gathering the list of behaviours generated and narrowing it to the most relevant and important. Additional focus groups and statistical methods will assist this process.

The measure will then be tested to make sure that it is user friendly, captures behaviours accurately, and is statistically sound. Future research will be done to assess how well it measures change in behaviour.

Autism Society Ontario's Stimulus Grant will help fund this research project, which I hope will improve our knowledge about what works best in treating children with autism. I am grateful to all the children who supported this grant through the *TOONIE FOR AUTISM DAY* campaign, especially to the families who have participated in my study so far, generously sharing their experiences, expertise and time.