

# ASD-CARC Trainees eNewsletter

## Volume 5 April 2009

FAREWELL

WELCOME



### CONGRATULATIONS

Danielle Savona for completing your MA in Child and Youth Studies under the supervision of Dr. Maurice Feldman and Dr. Tricia Vause in the fall of 2008. Thank you for all of your work in establishing the eNewsletter and coordinating all of the submissions for the past two years!

### WELCOME!

Carly McMorris is in her second year of her MA in the Clinical-Developmental Program at York University under the supervision of Dr. James Bebko. Her research examines short-term visual memory and attention in children with an ASD.



## Trainee Conference Summaries

Trainee  
Lindsay Arnal  
  
Training Site  
U of Manitoba  
  
Conference  
St. Amant  
Conference 2008

This year I had the pleasure of attending and presenting at the 17<sup>th</sup> Annual St. Amant conference, held in Winnipeg, Manitoba on October 4<sup>th</sup> and 5<sup>th</sup>. In addition to functioning as a residential care facility for individuals with developmental disabilities, St. Amant is also well known as an active research center. Each year, the conference highlights new research, practice and training methods with respect to several developmental disabilities including autism. Several posters, symposia, and lectures are held each day as an opportunity for fellow researchers, clinicians, practitioners, professors and individuals both working with and living with developmental disabilities to become familiar with ongoing research in the field. My poster presentation provided a summary of my Masters research entitled "A Comparison of Error Consequence

Procedures during Discrete-Trials Teaching with Children with Autism". Discrete-trials teaching is a highly effective method for teaching a variety of skills (e.g., basic visual and auditory discriminations, motor and verbal imitations, picture naming, instruction-following, and various daily living skills) to children and adults with developmental disabilities, including autism. Very little research has been conducted on the error consequence component of a discrete trial and thus I was very interested in examining this area further. My poster presentation highlighted the literature, methodology and results of my research. The goal of this study was to improve the effectiveness of discrete-trials teaching by comparing two ways to practice the correct response following an error. The study boasted several benefits for both the participants and the research area. For example, participants could benefit from the study by learning tasks commonly found in his/her educational curricula. Participants could also benefit if the findings of the study are available to staff and lead to im-

proved learning in other areas of the participants' lives. Lastly, the findings may lead to improved teaching strategies for other individuals with similar characteristics. Presenting at the conference was an excellent opportunity to share my work with fellow researchers and practitioners. Their feedback and questions are highly valuable and an asset in my learning experience as a student and researcher. I have valued my experiences at the St. Amant Conference and look forward to it next year!

During October 2008 I had the opportunity to present and attend a conference entitled Signing on the Spectrum: Meeting the Needs of Deaf Children with Autism. This conference focused on research and services for chil-

Trainee  
Gayle Goldstein

Training Site  
York  
University

Conference  
Signing on the  
Spectrum: Meeting  
the Needs of Deaf

## Trainee Conference Summaries cont....

dren who are Deaf and also have an Autism Spectrum Disorder, which is the focus of my dissertation work. This was a wonderful chance for me to find out what research is happening in this area and where the demands continue to be required. I also had the opportunity to meet with other researchers, professionals, and students who are focused on better understanding this population of individuals. In addition to presenting with Dr. Bebko, I was also able to attend a few presentations myself. One particular presentation focused on the diagnosis and assessment of ASDs, with a specific focus on how deafness can impact or impede this process. The presenters also emphasized how important a multi-disciplinary team is to complete the assessment process and to begin or continue the intervention process. Additionally, there was a particular focus on the type of measures used to diagnose in addition to differential diagnosis in children who are considered to have a hearing loss. A second presentation focused on the language and communication of children who are Deaf and have an ASD. This presenter focused on the importance of providing these children with a visual language, primarily American Sign Language (ASL) and that this language should be provided in many different settings to promote its use. Given that ASL is purely visual, there is also a focus on building eye contact and use of exaggerated body and facial expressions. Overall, the presentations and posters presented at this conference tended to emphasize the importance of a visual language for these children and that like hearing children, early intervention is necessary.

Trainee  
Alissa Levy

Training Site  
York  
University

Conference  
ONTABA 2008

I attended the Ontario Association of Behavior Analysis Conference on November 20<sup>th</sup> and 21<sup>st</sup> in Toronto. One poster presentation that I felt was particularly relevant was presented by Julie Koudys and

Adrienne Perry. The poster identified treatment variables or “active ingredients” associated with best outcome. Research on Intensive Behavioral Intervention (IBI) demonstrates that a subset of children with autism show significant improvements, while other children demonstrate more modest gains. Given the heterogeneity of the population, variable outcomes are not unexpected. This variability is likely attributable to a combination of child, family and treatment characteristics. However, the impact of these variables remains poorly understood. Although several child and family characteristics have been linked to best outcome, the majority of research has focused nearly exclusively on quantitative treatment aspects, such as treatment intensity and duration. The poster presented a review of the IBI literature, including a systematic analysis of efficacy and effectiveness studies conducted in the past 20 years. Treatment variables or “active ingredients” associated with best outcome were identified, as well as variables linked to less than optimal outcome were presented.

The results indicated that greater improvements in IQ following IBI treatment were associated with programs that occurred in a community setting as opposed to home-based programs. In addition, programs where there was a measure of treatment fidelity, live supervision and weekly supervision showed greater changes in the IQ of clients. In addition, it was important that programs contained a component of supported peer interaction. This pattern of results was similar for creating changes in cognitive functioning but different for creating changes in adaptive behavior. The magnitude of change in outcome did not seem to vary as a function of therapist qualifications or initial training, treatment intensity or duration or school attendance. The identification of active ingredients in IBI programs, both qualitative and quantitative, is essential to creating and maintaining successful IBI programs.

Trainee  
Vicky Lopes

Training Site  
Queen's  
University

Conference  
Workshop by Dr.  
Matthew Johnson

I had the opportunity to attend a workshop, entitled, “Positive Parenting with a Plan: F.A.M.I.L.Y. Rules” that was given by Dr. Matthew Johnson. Dr. Johnson is a licensed clinical psychologist who has been teaching parents and professionals about his strategies for empowering parents with challenging children and adolescents since 1987. The program is appropriate for children in kindergarten to grade 12.

The parenting plan works on the premise of behavioural modification. Dr. Johnson states that the techniques adopted in his training program are not novel; yet have been organized into a clear and easy to implement model that can be applied by families of challenging children.

Dr. Johnson describes his ultimate goal of positive parenting as an effort to improve communication in the home through clarifying rules, consequences and rewards. He strongly believes that more effective parenting practices can be achieved by correctly and consistently implementing the program in the home.

The basic underpinnings of the program have been summarized by the acronym: FAMILY. ‘F’ refers to ‘Fashion a List of Rules for the Family’. The first step is to cooperate and agree on a list of rules that will be adopted and followed by the entire family. ‘A’ refers to the process of ‘Adding Good Habit Cards’. Good habit cards involve tasks that can be completed over and above weekly responsibilities (e.g., make a card for a sibling, reading a book to a younger brother, etc). ‘M’ refers to ‘Mix in Responsibility via Household Chores’. Family chores can be incorporated within the parenting plan in addition to

## Trainee Conference Summaries continued...

the basic family rules and good habits. 'I' refers to Institute a List of Rewards. This step involves coming up with a list of preferred items that can be used as rewards, which fit within the family's current financial circumstances. 'L' refers to 'Love and Encourage Your Child(ren) Daily'. This step serves as a reminder that parents should compliment and praise their children daily, show affection and let them know that they are loved unconditionally. Finally, the last step, "Y" refers to 'Youth Residential Treatment as Needed'. The last step is used as a last resort for very oppositional and defiant children who cannot be cared for within the home.

Dr. Johnson also includes a chapter in his book on childhood struggles that may interfere with compliance. In this chapter, he discusses children with disabilities, and other disorders (e.g., Conduct Disorder, Attention Deficit Hyperactivity Disorder). Although the framework for the program is clearly demarcated, the intervention should always be tailored to the individual needs of the child and family. For more information on the program, please visit their website at <http://www.family-rules.com/>. Detailed information on the program is also available in Dr. Johnson's book: Johnson, M. (2001). *Positive Parenting with a Plan: Family Rules*. Publication Consultants, Anchorage, Alaska.

Trainee  
Noemi Riendeau

Training Site  
UBC

Conference  
First Annual  
Golden Helix  
Symposium in  
Athens, Greece

A couple of weeks ago, I attended the First Annual Golden Helix Symposium in Athens, Greece. Each year, the Institute of Biomedical Genomics Research of Thessaloniki will be hosting an international symposium on various topics. This year was the first edition and the subject was Copy Number Variation and genomic alterations in health and disease. Since my research here in Vancouver is on Copy Number Variations and Autism Spectrum Disorders, I was really excited to attend this

conference, and meet some of the most famous researchers in this field.

The symposium featured about 20 different talks from invited speakers from around the world doing research in various fields, such as cancer, intellectual disability and clinical genetics. There were so many interesting topics that it would be impossible for me to discuss all of them, I will therefore concentrate my discussion on one specific research question: Is it possible, based on some phenotypic indices, to predict which subject is more likely to harbour pathogenic CNVs?

The first talk on the subject was called "Clinical profiles of patients admitted to array-CGH analysis" by Corrado Romano. He performed array-CGH on 274 patients, mostly presenting with Intellectual Disability and used a phenotypic scoring method published by Bert B. De Vries in 2001 [De Vries et al. *J. Med. Genet.* **38**:145, 2001] to categorize research subjects based on their presenting phenotype. Briefly, De Vries' scores are based on clinical evaluations of patients with regards to 5 different categories (positive family history, prenatal growth abnormalities, postnatal growth abnormalities, craniofacial dysmorphisms and systemic anomalies). In his original study, De Vries found that subjects with a score of 3 or more (range: 0-10), had a significantly higher chance of harbouring subtelomeric rearrangements detectable by karyotype (with a typical resolution of 5-10Mb).

Romano reported that using this score, he found that a higher proportion of subjects with scores of 3 or higher were found to have pathogenic CNVs with array-CGH, but that contrary to the initial study by De Vries, cases with pathogenic CNVs had also been found in his group of patients with scores of 0-2. This is an interesting study that relates to my thesis work. In fact, with the help of my supervisor Dr. Suzanne Lewis, I am assigning scores to subjects in my project the same way, and it will

be interesting to see what results I get in comparison. Another finding by Romano and his group is that the presence of seizures, or psychiatric disorders, made no difference in the prevalence of pathogenic copy number changes in his cohort.

The second talk on this issue was given by Marcella Zollino and was titled "Checklist of clinical signs to select patients for array-CGH and to validate the results". In this presentation, she reported array results on 161 patients that had been referred for chromosome testing in the clinic. Her results showed 35 patients to have pathogenic CNVs (26%). Because her group's detection rate is much higher than what is usually reported (around 10%), she concludes that her selection criteria, based on a score modified from De Vries, works to select patients more likely to harbour microdeletions and microduplications. An important point that I think she did not stress enough is that 109/161 patients had not had a routine karyotype and subtelomeric FISH testing done, which usually detects up to 15% of aberrations. How many of those 35 changes could have been detected by routine clinical testing? Surely this question will be answered once this study is published.

An interesting point that Zollino made during her talk about the development of a new scoring method was how she modified De Vries' score by taking out positive family history. Since most pathogenic changes detected using array-CGH aren't inherited from parents, it makes a lot of sense to me to take out points given for positive family history. Her group also reorganized the scoring in terms of major and minor anomalies, growth anomalies and craniofacial dysmorphisms. This way of scoring has been suggested to me by a member of my thesis committee, and this is definitely a way to look at it differently, that I will surely explore as I'm analyzing phenotypic data in correlation to pathogenic CNVs in writing my Master's thesis.

## Trainee Research Report: Tess Clifford, Queen's University

Sending a child to school for the first time is an exciting and anxiety-ridden experience for any parent, but for parents of children with intellectual disabilities, including autism, this is expected to be an even more difficult time. The goal of many early intervention programs and services for preschool-aged children with intellectual disabilities is to prepare them for school, and the importance of a successful transition to school is clearly recognized. Early experiences at school set the stage for later academic and social success. There are however very few reports documenting the experiences of children with disabilities and their families through this transition. As a master's student, funded by Autism Ontario, I was able to contribute to this literature. My interest was primarily related to examining changes in several areas of the children's and their families' lives during the time of transition, and to identify possible predictors of successful transition to school.

Twenty-one parents of children with or at risk for intellectual disabilities who were entering school for the first time in September 2006 volunteered to participate in this study. There were 19 mothers, one grandmother and one father with the average age being 34 years old. Each parent completed three one-hour telephone interviews, the first in the summer before school started, the second in the late fall, and the third in the late winter. Parents were asked a variety of questions about their child's skills and abilities, the services and supports they used and their own personal experiences. The parents were also asked to complete a survey about their child's quality of life, and each parent nominated a teacher to provide some information about the child's functioning at school.

The families involved in this study were living in a variety of communities across South Eastern Ontario. The

children of the parents participating included 6 girls and 15 boys with an average age of 4-and-a-half years. The majority of children were diagnosed with autism spectrum disorders, but there also were children with Down syndrome, developmental delay, Rett disorder, and several other neurodevelopmental disorders. The children were somewhat delayed in their daily living skills, but did not have many problem behaviours.

The parents in this study were generally coping very well and reported only mild stress. Parents reported most stress associated with financial and insurance issues. The parents agreed with many positive statements about how their life had changed because of their child, such as "I have learned to speak out for my child" and "I am more compassionate towards others." As well, parents were generally satisfied with their child's quality of life.

The families involved in this study reported using several services prior to their child starting school (e.g., speech-language therapy, behavioural management services, occupational therapy). However, the average number of services used decreased during the time of transition from between 3 and 4 services before school started to less than 2 later in the school year. Although this is not particularly surprising, it is important information for families since there are many services geared towards preschoolers that discontinue after the child begins school. Anecdotally, many parents reported a lot of frustration with lost or changing services. Our research team will be interviewing these parents again in a year, and will examine if the number of services used continues to decrease, increases or stabilizes.

Another component of this study involved examining the child's involvement and support in various areas. In general, it was found that the needs of

the children were supported in many areas of their lives including medical services, education, home, and recreational activities. However, over half of the parents reported that their child was not involved in any organized social activities (e.g., sports, clubs or lessons), and was not seeing a dentist on a regular basis. Several parents indicated that their child was not involved in organized social activities because he or she would need one-to-one support and they were not sure it would be provided. When parents were asked why their child was not seeing a dentist the majority indicated that it would be very difficult for their child (e.g., "he would not be able to sit still"), and some also suggested that oral health was not a major concern since the child did not have any adult teeth. Although these findings are worrisome it is not clear if these experiences are atypical for this age group.

Finally, some very interesting findings emerged regarding the child's quality of life and school readiness skills. Parental involvement in support groups was correlated with satisfaction with the child's quality of life and school readiness scores. That is, parents involved in support groups were more satisfied with their child's quality of life, but also had children with higher scores in the physical health and well-being domain of the school readiness measure. Previous research has found that parents involved in support groups generally see their child with a disability more positively than those who are not involved; therefore, they may be more likely to indicate satisfaction with their child's quality of life. It is also possible that in some cases physical health and well-being may limit the child's involvement in the community which may then lead to lower scores in quality of life. The relationship between parent support group use and school readiness and quality of life is not yet completely

## Trainee Research Report cont...

understood. Future research should examine these variables more thoroughly.

Our research team will be continuing this project over the next year and will be interviewing parents of children with and without developmental delays. We hope to gain more information about the experiences of all families during the transition to school, so that we gain a clearer understanding of the experiences of families of children with special needs.

In conclusion, this project provides some information about the experiences of children with autism and other disabilities and their families as the child transitions into school. We have learned that there is considerable variability in the experiences of these families. As well, the findings suggest that further research is needed to provide a better understanding of the changes that take place during the transition to school and the predictors of successful transition.

However, it seems as though parental involvement in support groups should be encouraged. It is expected that with further research we may be able to provide further recommendations that may be beneficial for families of children with intellectual disabilities attending school for the first time.

This project was funded by the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID), which includes partners from across South Eastern Ontario as well as collaborators from other areas. The community partners are primarily developmental service sector agencies across the six county catchment area and the primary researchers are based at Queen's University in Kingston. The complete list of researchers and partners can be found on our website ([www.seocura.org](http://www.seocura.org)). Our vision is to augment the quality of life for individuals with intellectual disabilities and their families through enhanced inclusion, sense of belonging and support. Our

goals are that research findings be used to inform policies and practices of service providers and government ministries and that the partnering experience inform future research areas and approaches.

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We would like to thank the staff at the community agencies involved in recruitment for their ideas and assistance. We would also like to thank the families who participated for sharing their experiences with us.

**The views expressed in this study report are not necessarily the views of all SEO CURA in ID partners, researchers, collaborators or members or the Social Sciences and Humanities Research Council of Canada which funded the study.**