#### INTEGRATED SERVICES FOR AUTISM AND NEURODEVELOPMENTAL DISORDERS

## ISAND helped give my son a future — and hope to our family

By Shane Nixon

Our son Liam was diagnosed with autism when he was just 18 months old. My wife Gail and I honestly didn't really know anything about autism. After doing some homework, we began to realize the seriousness of the diagnosis.

The days, weeks and months that followed were the most heartbreaking, gut wrenching, emotionally draining, and tear-soaked times of our lives. We had been told that our amazing and beautiful baby boy was severely and profoundly autistic. He wasn't even two years old!

Imagine having to grieve the loss of the dreams and aspirations you have for your child. We struggled to accept that Liam may never go to high school, university, get married, have kids or a family of his own, hold a job, or even



Shane and Gail with their sons Liam (left) and Declan

live independently. To this day, Gail and I shed tears worrying about Liam's future. Fortunately, the universe led us to ISAND as one of our therapeutic choices for Liam. Their staff and services have been nothing short of amazing. Between ISAND and a couple of other providers, Liam's progress has been incredible! When our little boy started therapy he spoke less than a handful of words and didn't recognize or acknowledge the people or world around. Today, Liam loves being social, can communicate as well as any other child his age, and loves the people and world around him! He's such an amazing little man and we are beyond proud of the work he has put in and

how well it's paid off. He inspires us every day and fills our life with such joy. We are committed ISAND supporters. Why? The answer is simple. The ISAND team has helped give Liam a future and hope to us at the same time. Every day our hope grows and every day there is a much higher probability that Liam will be able to go to university, find a job, get married, and live independently.

Gail and I believe that ISAND changes the lives of our children for the better every single day. By supporting the amazing work they do, we can be a part of giving other children a future and hope to their families.

#### **Gratefully looking forward to the future!**

We hope this summer was a time of rejuvenation and rest for you and your family.

For many people, fall represents a new beginning. It's the same at ISAND too. We're excited by our plans to launch some enhanced programs and services later this year and we continue to explore how we can serve more families with our integrated and interdisciplinary services. This work has been helped by the many comments and suggestions received from families through our recent client survey and

from our committed and talented team of professionals.

In addition to our dedicated volunteer Board of Directors, we are establishing a volunteer Clinical Advisory Board to support and inform our clinical framework. We look forward to be being able to share more with you in the coming months.

We remain grateful to our wonderful team, our donors and volunteers – and, most of all, the families we are privileged to serve, who remain at the centre of all we do.



Dr. Wendy Roberts
Clinical Director

**David Gray** Executive Director

## Preschool pilot program set to launch

Do you have or know a child who could benefit from extra support as they transition to junior kindergarten? Let's Get Ready, ISAND's new preschool pilot program, is now available to support young clients and their parents and is currently enrolling children for an October start date.

The daily structure for Let's Get Ready is similar to that of a classroom. Children attend Monday to Friday from 12:30 - 2:30 p.m. for a sixmonth period. With a ratio of one teacher to a maximum of four children, the small group setting provides an

introduction to learning as a member of a group. The curriculum focuses on learning classroom routines, social communication and play, early literacy and numeracy, self help and independence, self-regulation and fine and gross motor skills. Children are welcome to participate for one or two six-month cycles.

Please contact Cheryl Libman, BA, B.Ed., M.Ed., Reg. OCT., ESDM (Cert.) Program Coordinator and Lead Teacher Therapist at cheryl.libman@isand.ca for more information and/or to arrange an enrollment consultation.





#### **Good times at ISAND Family Fun Day**

Our Family Fun Day on Sunday, August 13, 2017 was a wonderful opportunity for ISAND families to come together to enjoy a day of games, crafts, delicious food, friendship and more. Many thanks to our fantastic team of volunteers! A very special thanks to Lynn Braybon of Scholar's Choice, DJ Trevor of Interactive Entertainment, Peter Kerasiotis of Astoria Shish Kebob House and Ann Doucette of Variety Village who helped make the day possible.

## **Support** rooted in desire to improve lives





Before ISAND was established, Autism Speaks Canada and KRG Children's Charitable Foundation funded a study led by Dr. Wendy Roberts to examine autism services in Ontario. The study revealed significant gaps and identified a desperate need for integrated, coordinated and comprehensive services. Subsequent support from these two organizations, as well as additional donors, founding Board members and referring partners, enabled the creation of ISAND in 2013.

Since then, Autism Speaks Canada and KRG Children's Charitable Foundation have continued to provide generous and strategic funding for ISAND.

"Their support has been absolutely vital," says Wendy, ISAND's Clinical Director. "It has enabled us to create a unique organization, build an outstanding team, and break new ground in the delivery of autism services."

Jill Farber, Executive Director of Autism Speaks Canada, is not surprised by ISAND's continued progress. "The approach to integrated services, as well

as the organization's collective passion and vision to realize their mission. has helped propel ISAND's success since the beginning," Jill says. "Supporting ISAND has been a natural fit for us. Their vision and mission closely align with our own. We both seek to improve the lives of people living with Autism Spectrum Disorder."

"I was struck by the goal of caring for the whole person, across the spectrum and along the life span, all under one roof. We were inspired to help bring their vision to reality."

Steven Wise, founder of KRG Children's Charitable Foundation. adds, "The clinical experts at ISAND recognized an enormous void. I was struck by the goal of caring for the whole person, across the spectrum and along the life span, all under one roof. We were inspired to help bring their vision to reality."

Autism Speaks Canada, KRG Children's Charitable Foundation and Steven Wise's ongoing commitment and support are enabling ISAND to further develop and strengthen its services and programs for families living with autism and other neurodevelopmental disorders. Together, they have provided more than \$500,000 in funding to ISAND, as well as support for collaborative services and programs that serve the autism community in which ISAND participates.

"We are deeply grateful for the funding from Autism Speaks Canada, KRG Children's Charitable Foundation and Steven Wise," says ISAND's Executive Director David Gray. "ISAND does not receive funding from government, United Way, or any other ongoing source. As a nonprofit organization, we rely on gifts such as these to support our programs and services for the families we are privileged to serve. We look forward to our continued work together."

Photo: ISAND's vision to improve lives inspires Steven Wise of KRG Children's Charitable Foundation and Jill Farber of Autism Speaks Canada.





Featuring wisdom and insight from people who receive services and support from ISAND. In this issue, questions are answered by Karen Bojti, mother of 7-year-old Charlie.

#### What brought you to **ISAND?**

Our son Charlie was diagnosed with autism when he was 3 years and 8 months old. My husband Tony and I knew that something was wrong but not that autism was the problem. Once we had Charlie's diagnosis we knew we were in for a big project but had no idea of how challenging Charlie's life was going to be. All of my assumptions about child development and meeting benchmarks had to be thrown out. There were long periods of panic that were hard to shake. I was anxious, terrified and lonely. I didn't have anything in common with other mothers (of neurotypical children). I felt invisible.

Our pediatrician told us about ISAND, which had started up the previous year. Our heads were spinning and

we needed help wading through the various options for Charlie. We knew that early intervention was vital. As Charlie wasn't yet speaking, we felt speech-language therapy was the most important place to begin. He started therapy at ISAND the summer before he began junior kindergarten.

#### What did the ISAND team do to help you and your family?

When we came to ISAND we were overwhelmed and Tony's health was not good. But seeing how well Charlie responded to Shelley Mitchell (his speech-language therapist) gave us hope. Shelley brought me into the world of autism one step at a time, at a pace I could handle. At every therapy session there are two clients: Charlie and me! I am free to observe, take notes and videos of Charlie's therapy

sessions. I learned by example how to help Charlie communicate and play with him in a way that is satisfying for all of us. As a result, we have fun as a loving family who knows how to have a great time together.

#### How has life changed for you and your family?

ISAND has had a huge impact on our entire family. Shelley has been an advisor and sounding board and has been with us every step of the way to explain what is going on with Charlie. I learned that if I slowed down and really observed Charlie, I would be able to connect with him. He still has very limited verbal abilities, sensitivity to sound, and anxiety. I am a bit more relaxed now. We are certain that putting Charlie in ISAND's expert hands has completely changed the trajectory of his life.

#### What advice do you have for others in a similar situation?

Be gentle with yourself and give yourself space to learn! When raising a child with special needs you need to let go of expectations that you didn't even know you had, even the simplest ones. Your relationship with your child will be different than what you ever anticipated. It's a life-long journey and you must make peace with it.

#### What would you like others to know about you and your family?

I wish people understood that we are just a little family in a big world. We want Charlie to have access to everything that other children do. We don't consider this special treatment. People don't realize that when my child is excluded from activities that are affordable and available, he is missing out on opportunities to practice and learn. I think if people knew and understood more they would be able to include children like Charlie. Right now we're just not part of the picture, but we need the village too.

#### What are your hopes for the future?

I am hoping that as Charlie matures his anxiety will decrease and that autism will not be a big boulder that he will continuously have to climb over. Tony and I hope that we will have less stress and anxiety and a more peaceful life.



#### Is there anything else you would like to share with us?

Sometimes if we can't find what we need we must create our own opportunities. I wanted Charlie to have a social life so I began a play date initiative with families of other special needs children in my community. We started with six families and have grown to about 150 families, teachers and therapists in four years.

# Psychologists: Vital members of integrated team

Did you know that ISAND's six psychologists provide assessment and psychotherapy services for children, youth and young adults with a suspected or confirmed developmental difference? ISAND psychologists have experience in the full spectrum of developmental differences and age ranges from infancy to early adulthood. They have strong research backgrounds in autism and have worked in a variety of settings, including hospitals, mental heath agencies and schools.

"The psychology team at ISAND has experience in both child development and mental health," explains clinical

psychologist, Dr. Vicki Rombough. "As well, our psychologists have extensive experience working within multidisciplinary teams. This has given each one a thorough knowledge of every aspect of Autism Spectrum Disorder and informs their assessments, consultations, intervention planning and recommendations."

ISAND psychologists offer developmental, psycho-educational and socio-emotional assessments. They use gold standard tools for autism assessments, including the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2) and the Autism Diagnostic Interview (ADI-R).

ISAND psychologists also provide evidence-informed psychotherapies for children, youth and young adults with a developmental difference, as well as their siblings and families. These include Cognitive-Behavioural Therapy (CBT) and/or mindfulnessbased therapies that are modified to address the unique learning needs and strengths of each client and to best support their families.

If you would like to learn more or schedule a consultation with an ISAND psychologist, please contact Beth Goswell, Clinical Services and Intake Coordinator at 416-224-5959 or beth.goswell@isand.ca.





Amanda Cox

'Will using non-speaking forms of communication slow down my child's ability to eventually talk?"

Response provided by Amanda Cox, Speech-Language Pathologist, Reg. CASLPO

Non-speaking forms of communication are referred to as Augmentative and Alternative Communication (AAC). These forms of communication either augment and support speech abilities or replace speech if speech is not possible. Sometimes parents, teachers and professionals are concerned that introducing AAC will further delay speech development. While this is an understandable and common concern, recent research demonstrates that introducing AAC does not prevent children from learning to talk. In some cases, children actually make gains in their speech production and overall communication.

Available evidence shows that AAC may improve spoken language by increasing interaction, improving language skills, and providing verbal models for speech. It also reduces challenging behaviours and frustration

by giving children a way to effectively communicate their message when their speech is not understood.

Often, parents and others are concerned that children will choose to use AAC rather than speech. However, this is not supported by research. Children will use the quickest, most effective and accessible way to communicate. As speech is the most efficient form of communication, a child will generally not choose their AAC instead of speech if they are able to verbally communicate.

There are many different AAC options available which include both aided and unaided AAC. Unaided AAC refers to communication strategies that use our own body. These include eye gaze, facial expression, gesture/ signing, body language and tone of voice. Aided AAC involves an external system that can be either high- or low-technology based. Low technology aids include PECS (Picture Exchange Communication System), PODD (Pragmatic Organisation Dynamic Display), visual schedules, communication boards, real objects and photographs. High technology

aids include the use of computers, iPads or speech generating devices. It is important to note that if an AAC option is recommended for your child it does not mean we are giving up on speech. Even as adults we use a variety of options to communicate and we do not solely rely on speech. For example, we use gestures to emphasize our message, point to things we want, and use visual organizers to help us plan our day. When we travel to places with languages other than our own, we use a range of AAC options to help us communicate. These options may include using a gesture of eating food or drinking to help find a restaurant or looking for universal visuals to find the airport or a washroom.

The overall aim of AAC is to provide children with a way to communicate successfully and meaningfully with others, and provide more opportunities to participate in everyday environments. There is no 'one size fits all' when it comes to AAC. Please speak to your child's Speech-Language Pathologist to discuss the most appropriate AAC option.



### Supporting families is Beth's passion

Talking to and supporting ISAND families is the favourite part of Beth Goswell's job. As Clinical Services and Intake Coordinator, Beth handles initial intake calls, coordinates all clinical appointments, explains available services to families, and so much more.

Beth was drawn to ISAND in 2016 after holding a variety of positions including as an educational assistant,

ABA therapist and, while living in the UK, as a registered nurse and midwife.

"The thing I love about ISAND is that families can come to one single location to get the multiple professional services they need," Beth says. "As a parent of a child on the autism spectrum, I understand some of the challenges families face. In this role, I have a wonderful opportunity to help them on their journey."

## Social Peers Program fosters social, communication and play skills

For children who have difficulty playing and interacting with others or making friends, ISAND's Social Peers Program can provide some much-needed help.

Often, young people with Autism Spectrum Disorder lack some of the social communication skills that support developing and maintaining friendships. However, with the right support, these skills can be learned.

During ISAND's 12-week Social Peers Program, children, youth and young adults receive personal coaching and support within a social setting. Participants are grouped in twos or threes based on their needs and complementary strengths. Each one is given the opportunity to both learn and practise the social skills needed to successfully interact with others.



"One of the great strengths of our program is that children are supported by an interdisciplinary clinical team," says Ali Dussault, Clinical Services Manager. "Sessions may include a speech-language pathologist, occupational therapist, behaviour analyst, early childhood educator or a communication disorders assistant. Each clinician will bring their own perspective on what is happening and can offer suggestions to assist the child."

For the best learning opportunity possible, participants must be carefully matched according to age, needs, and strengths. Sometimes, the right match cannot be made and a child will need to wait until the following 12-week care cycle or until an appropriate match can been confirmed. "Moving ahead without the right match isn't in the best interest of the client," says Ali. "In the long run, it's better to wait, as hard as that can be."

As children are learning social skills in the program, parents also receive coaching to build skills and access tools to help them support their children. In the process, they learn that they are not alone and have the opportunity to connect with other parents who have shared experiences. Often, friendships develop between parents too!

## **Cousin inspires a career**

When Jenny Lall-Budhu was in university she accompanied her cousin to a speech pathology appointment. Jenny had never heard of speechlanguage pathology and knew nothing about the field. But that visit inspired her to pursue a career in speechlanguage pathology, helping her fulfill a life-long dream of supporting children.

Jenny went on to earn a Master of Science degree in Clinical Communication Studies and then worked for more than 22 years in preschool speech and language services in both clinical and management roles. She joined ISAND in 2016 as a senior speech-language pathologist.

"I came to ISAND because of their unique approach to helping families," Jenny recalls. "Families are in the driver's seat. They tell us what they need and that's where we start."

Jenny works primarily with preschool children and their parents. Through coaching, she helps parents understand their child's unique abilities and equips them with a variety of tools and techniques they can use at home.

"Sometimes parents need support in readjusting their goals so they can have meaningful and nurturing interactions with their children," says Jenny. "I'm passionate about helping parents create relationships with their children through play and communication.



It's inspiring to see their confidence arow."

Having an integrated team at ISAND also means that Jenny can involve colleagues from other clinical disciplines when needed.

"The entire team is committed to doing what's best for the child and family, based on where they are at in their journey," Jenny says.



#### **Get Active 4 Autism!**

Join us on **Sunday, October 22nd** for #GetActive4Autism, an exclusive fundraising event to support ISAND autism services for young adults. Collect pledges and come enjoy an afternoon workout with some of Toronto's top fitness instructors!

Proceeds from Get Active 4 Autism will help fund a pilot project at ISAND to develop a much-needed Transition to Adulthood program for young adults with autism. These wonderful young people, who have much to offer, deserve the opportunity to acquire independent living and vocational skills and become productive and contributing members of their communities.

Learn more and sign up at isand.ca/getactive4autism.

The Elpida Autism Foundation PRESENTS



A gala fundraising evening in support of ISAND.

**Friday, November 3, 2017**Parkview Manor, Toronto

For more information, please visit **www.elpidagala.com** 



## Solah's sweet initiative

Earlier this year, Solah Brownrigg Ho-Sang, a bright, engaging grade 12 student with Asperger's Syndrome, organized a bake sale at her school, Vaughan Road Academy, to raise funds to benefit ISAND's clients and their families. ISAND's Administrative Lead, Leah Miltchin, had the opportunity to attend the bake sale on April 25, 2017 and meet Solah. The sale was a sweet success, raising over \$82.10 from the school's small but enthusiastic student body and staff. Thank you, Solah, for your passion for inspiring individuals with ASD to reach their potential!

#### Your support makes a difference.

Donations from generous supporters enables ISAND to provide professional care to even more families living with autism. Please consider making a gift today! **www.isand.ca/donate**. To explore giving opportunities tailored to your unique philanthropy goals, please contact David Gray, Executive Director, at 416-224-5959 or david.gray@isand.ca



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