



Anishinabek G7 FASD: Celebrating the Journey

Workshop Summaries and Speaker Biographies

Tuesday November 4, 2014

7:30 am CONTINENTAL BREAKFAST and REGISTRATION

8:30 am Welcoming Remarks- Stan Wesley
Opening Prayer-

8:45 am Opening welcome

9:15 am Opening Panel Presentation

RJ Formanek

Having obtained a diagnosis later in life has given RJ Formanek a number of unique insights about living with FASD and it is these nuggets of information learned along the way that he tries to share with others in the hope of fostering a better understanding. He shares stories of his own struggles and relates how his own brain dysfunction affected different areas of his life.

Born in 1961, RJ was the child of a young mother who was not able to care for the child herself so he spent the next 15 years in and out of foster care and family care situations.

Since FASD was not recognized at that time he dealt with the effects of prenatal alcohol exposure on his own and relates stories of how, if things had been recognized earlier steps could have been taken to make life much easier. He is often able to express feelings and concepts that help caregivers and parents understand how brain damage can affect every aspect of a person's life. Experience can be a great teacher.

RJ now runs one of the largest Facebook groups for people living with FASD, called "Flying With Broken Wings" and has enlisted others living with FASD to help administer the group and help others understand more about the challenges and rewards of living with FASD.

He recently completed the FASD Certificate Program offered by the Anishinabek Educational Institute, in Nipissing and is keen to take this new knowledge out to others who may need it.

Currently, RJ is involved in a brand new FASD Day venture, in conjunction with Jodee Kulp they have launched a new awareness campaign called "Red Shoes Rock". This is a fun, exciting way to start the conversation about FASD, by wearing red shoes. This campaign has been picked up and endorsed by NOFAS in the United States and is growing day by day.

When it comes to living with FASD, RJ is all about building on the positives and moving forward in whatever way suits that individual person. Understanding the spirit of the person and their needs and desires is only the beginning of a journey that can be both wonderful and intense for all involved. Knowing that people living with FASD want to help themselves, and honouring that fact can change the outcome incredibly, if given the chance.

It's all about thinking differently, and it is that concept Mr. Formanek shares with all.

Amy Assinewai

Amy is a band member of the Wikwemikong Unceded Indian Reserve No. 26. Born to the parents of Richard Assinewai and Winnifred Peltier, she is the second oldest of their four children. She is the mother to four daughters who helped facilitate her personal growth, development and educational endeavors. She is graduate of the Native Community Worker Program – Traditional Aboriginal Healing Methods and Post-Graduate of the Fetal Alcohol Spectrum Disorder Certificate Program delivered through the Anishinabek Educational Institute, St. Clair College and Sault College.

Amy currently works as an Addiction Services Initiative Caseworker which has enabled her to work diligently to assist community members address personal wellness/personal well-being by assisting community members to Naakezhegehn – stoke their internal fires within.

Julian Assinewai is a band member of the Wikwemikong Unceded Indian Reserve No. 26. He is the youngest of four children born to the parents of Richard Assinewai and Winnifred Peltier. Julian is a father to three children who motivate him in his own personal recovery to wellness. The reality of self-diagnosed FASD, mental health issues and hardships, family dysfunction and his own personal journey requires attentive listening, open minds and kind hearts.

10:15 am NUTRITION BREAK

10:30 am – 12 pm Keynote Address

Dr. Chudley

Dr. Chudley is Medical Director of the Genetics and Metabolism Program with the Winnipeg Regional Health Authority and is a Professor in the Departments of Pediatrics and Child Health, Biochemistry and Medical Genetics, University of Manitoba. He has been a member of MICH since its inception. MICH, and CHF has supported Dr. Chudley's research for the past 30 years.

His clinical and research interests are in the areas of dysmorphology; the recognition, delineation and prevention of birth defects, including fetal alcohol syndrome and fetal solvent exposure; the causes of mental retardation, developmental disabilities and autism spectrum disorders; prenatal diagnosis; gene mapping and gene discovery. His recent interests are in the genetic and epigenetic contributions to Fetal Alcohol Spectrum Disorder (FASD). He has been a consultant to the Manitoba, Alberta and Canadian governments and internationally (New Zealand, France) on issues related to FASD and he is a former member of Health Canada's National Advisory Committee on FASD.

12 pm – 1 pm LUNCH

1 pm – 2:30 pm & 2:45 pm – 4:15 pm

Concurrent Workshops Series A & B

Workshops will be run twice. (1 pm -2:30 pm & 2:45 pm – 4:15 pm). Attendees will be able to attend one workshop in each time slot. Pre-registration for workshops is not necessary.

1A/B ***Creating Successful Accommodations for People with FASD***

This session explores the Neurobehavioural Model, in the support of people with FASD. This model establishes a research-based-framework for understanding the meaning of behaviors differently, and provides a structure for operationalizing this understanding and developing effective accommodation approaches. Linking brain function with behavior redefines the meaning of behaviors, the nature of problems, and redefines solutions. It results in increased understanding of the individual, deeper relationships and less conflict and/or stress.

Nancy Hall

Nancy Hall has had almost thirty years' experience working in the non-profit sector for the improvement of services for people with disabilities. Her academic background is in Child and Youth Care as well as Clinical Behavioural Sciences. In addition, she has obtained a mastery certificate in the Neurobehavioural Model of accommodation for the successful support of individuals with Fetal Alcohol Spectrum Disorder, under the mentorship of FASD expert, Diane Malvin MSW, founder of FASCETS, in Portland, Oregon. Historically, Nancy worked as a residential coordinator and case manager for fifteen years with people impacted by developmental disabilities, mental health issues and/or physical barriers. In addition, Nancy also has extensive experience as a behavioural consultant, as well as, providing training to staff in the safe management of aggressive behaviours.

Over the past ten years, Nancy has worked as a community development facilitator, educator and consultant, to nurture and enhance community potential to better meet the needs of people impacted by Fetal Alcohol Spectrum Disorder (FASD) and Dual Diagnosis. For eight years, she sat as a member of the FASD Ontario Network of Expertise (FASD ONE). Nancy has also presented on FASD at multiple local, provincial, national and international conferences including NADD, AIDD, HSJCC, OADD and the Ontario Health and Well Being Conference. Nancy co-authored a research paper on Effective Service provision for people impacted by FASD, in 2009. The practices revealed, in this compelling research, are now considered emerging best practice, with new research validating these findings in Grey-Bruce Ontario.

2A/B *Imagine Yourself What To Do and How to Deal With Life's BIG Scary Stuff*

"Imagine Yourself" is used by children, youth, adults & families, students & teachers, social workers, health and mental health care professionals & communities.

The outcome of the program is to learn how to build our capacity to better manage behavior through skills & awareness. To assist parents, professionals and volunteers help all ages help themselves.

How?

- a) Learn a simplified common language. Helping us talk about our energy (Feelings and Behaviour) in a safe manner starting with those with comprehension ages 36 months and up.
- b) Understand a very simple model ages 3 and up can understand.
- c) Understand how to best use the audio & video support programs.
- d) Practice the key skills.
- e) Understand and start to use a Positive Asset Approach for all ages and abilities.

Michael Ballard

Michael H. Ballard specializes in building resiliency by helping groups and people of all ages learn how to deal with change and adversity in the fast pace of modern life with its overwhelming situations and stresses, through Resiliency for Life™ (RFL). Michael has delivered breakthrough solutions for over 207 organizations across North America and around the world from the beaches of Bermuda to the skyscrapers of Singapore, dedicating his life to helping others prepare for, or recover from, life's challenges. Michael delivers actionable solutions that reflect the depth of his experience, applying a practical yet science-based approach to instill a courageous point of view. His goal is to help people get back up and "dust themselves off" after an upset, develop and deepen their resiliency and out-perform their former selves. He knows what's possible. He's lived it. Despite his multiple battles with cancer, and a near death experience due to a failed medical procedure, Michael still reached sales success placing 7th out of 78 professionals in a year when he was off work for four months. Michael knows exactly what it takes to be resilient.

3A/B *The Critical Link Between Memory and Learning*

Memory and learning are inseparable. When individuals have a difficult time storing, recalling and holding information in working memory, frustration can result and academic success will often be compromised.

What may appear to be non-compliance, may in fact be a reflection of memory weaknesses. Students with memory weaknesses may have a hard time keeping up with the pace in a classroom. Information may be presented at a rate that is too fast for them to efficiently process. This often leads to frustration both in school and in their everyday lives. Frustration resulting from memory weaknesses is unfortunately the reality for many individuals with FASD.

This presentation will provide participants with a basic understanding of the memory process and behaviours related to and reflecting weaknesses in this area. Practical strategies will be discussed to support memory, decrease frustration at home and at school, and increase student engagement within a learning environment.

Danielle Reynolds

Danielle has worked as a Speech-Language Pathologist (SLP), in an educational setting, for 25 years. In her role as an SLP, she assessed memory as well as speech and language abilities of numerous students with a diagnosis of FASD. She has provided consultation to schools around the unique needs of these students. For the past 5 years, she has conducted numerous in-services on FASD, and, for the past 10 years she has provided in-service on the topics of memory, auditory processing and language issues.

Since 2010 she has been a member of the Niagara FASD Coalition and has also been a member of FASD ONE - Education Action Group, since 2012.

2:30 pm NUTRITION BREAK

2:45 pm – 4:15 pm **Concurrent Workshop Series B**- see above for topics

4:15pm – 4:30 pm Closing

Wednesday November 5, 2014

7:30 am – 8:30 am CONTINENTAL BREAKFAST

8:30 am Welcoming Remarks- Stan Wesley

Opening Prayer-

9 am Plenary Presentation: *LiveAbilities – Staying Safe in a Medical Health Crisis*

Liz and Jodee Kulp

Jodee and Liz Kulp share their new Health Care triage kit to help families guide medical personnel and their loved one during a medical crisis. Liz hopes these new ideas will help other adults remain safe while in the care of health professionals.

10:15 am NUTRITION BREAK

10:30 am – 12 pm Keynote Address: *Life with FASD*

Morgan Fawcett

Morgan is the Founder and Spokesperson of One Heart Creations, a not-for-profit meant to increase awareness for Fetal Alcohol Spectrum Disorders (FASD). Morgan and his Grandparents began to raise awareness for FASD when he was 14 years of age and they've travelled extensively over the years. Morgan incorporates his Native American Flute playing into his programs to provide support for his message. He currently released three CDs (Ancestral Memories, Tears of Our Fathers, and Legacy). Morgan was inducted into the NOFAS Tom and Linda Daschle FASD Hall of Fame, selected as a Champion of Change for President Obama's Winning the Future Initiative, participated in a the White House Internship as well as an Internship with Senator Mark Begich.

12 pm LUNCH

1 pm – 2:30 pm & 2:45 PM – 4:15 PM Concurrent Workshop Series C and D

Workshops will be run twice. (1 pm -2:30 pm & 2:45 pm – 4:15 pm). Attendees will be able to attend one workshop in each time slot. Pre-registration for workshops is not necessary.

1C/D *The Talk: Why, When and How to Talk About FASD to Someone Who Has It*

How do we talk about a preventable disability that impacts all aspects of life with someone who has it? It is hard but not impossible. Those with FASD often experience depression and anxiety. Knowing why the world is difficult for them to navigate can ease some of these negative responses and encourage them to engage in positive interdependent relationships. Personal advocacy skills can be enhanced building the potential of safer community engagement. Knowledge can provide an opportunity to talk about the challenges they face and help caregivers and others to support them more effectively.

This workshop will explore some example of how to engage in the topic, recognizing the need for creative, individualized approaches that leverage strengths and minimize blame and stigma. The value of this conversation is considered in context of age, development and readiness – including the emotional readiness of the caregiver.

Often the positive qualities of individuals who have the disability are overwhelmed by stigma or are clouded by the history of adverse outcomes. Adverse outcomes are often the result of systemic ignorance, the marginalization of vulnerable women, and a reluctance to talk about alcohol's impact on pregnancy or women's substance use. FASD is preventable and complex disability but those living with FASD can be contributing, loving and engaging members of their family and community. Getting comfortable talking about it is an important step forward.

Sheila Burns

Sheila is a specialist in FASD and a strong advocate for improving the way the disability is understood. She promotes a holistic and collaborative approach toward FASD prevention, diagnosis and intervention and focuses on capacity-building within the existing system of care where individuals with FASD live, learn and work. She frames behaviour in context of disability to help caregivers and their support teams provide stable and nurturing environments that contribute to successful outcomes. Sheila has held leadership roles on FASD Ontario Network of Expertise and was a Law Foundation of Ontario Community Leadership in Justice Fellow.

2C/D *How to Facilitate Interdependence, Insulation and Enhance Relationships for People Living with FASD and Their Families*

Caregivers of individuals living with an FASD often struggle with the demands of supporting their loved one while navigating systems that can unintentionally compound stress. We will look at a tendency to view “bad parenting” as the cause of undesirable outcomes and how this can undermine commitment and effective parenting. We will examine strategies that build strong relationships and reinforce healthy interdependence and insulation for individuals living with and FASD.

Debbie Michaud

Debbie is a foster and adoptive parent. She is a supervisor at a child welfare organization. She is an instructor for the FASD Certificate program at Sault College. She has a Master’s Degree in Social Work from Laurentian University. She helped develop the FASD Community Action Partnership in Sioux Lookout Ontario. She is a member of the Algoma FASD Committee and the North Western Ontario Network on FASD. She recently published an article in the Journal of Development Disabilities titled “The Complexities of Caring for Individuals with FASD” and presented at the International Conference on FASD in Vancouver in 2014.

Rhonda Konrad

Rhonda is a foster parent as well as a family home provider through Community Living Dryden Sioux Lookout. She is a resource worker at a child welfare organization. She has a Masters in Social Work Degree from Laurentian University. She was involved in the Photo voice project: “Picture This” life as a parent of children with FASD. She has a great deal of personal and professional experience supporting individuals with FASD with expertise in the area of facilitating transitions to adulthood. She has been involved in service consultation and training throughout the district and is the chair of the Prevention Pillar for the Sioux Lookout Community Action Partnership on FASD.

3C/D *LiveAbilities – Braids to Healthy Interdependence*

Liz & Jodee Kulp

Jodee and Liz Kulp share the ups and downs of navigating Liz’s adult transition years of 18-23. Together, the Kulp’s celebrate their journey into adulthood. For Liz this meant climbing over barriers and tackling obstacles with love, laughter and living. Included in the workshop are Braided Cord strategies developed to help other young people and their caregivers create a path of safety during this tumultuous time for many.

2:30 pm NUTRITION BREAK

2:45 pm – 4:15 pm **Concurrent Workshop Series D-** see above for topics

4:15 pm – 4:30 pm Closing

6 pm – 7:30 **Evening Coffee House for families and individuals living with FASD**

Come and showcase your talents, and enjoy the talents of those around you.

Thursday November 6, 2014

7:30 AM CONTINENTAL BREAKFAST

8:30 AM Welcoming Remarks- Stan Wesley

Opening Prayer-

9 am Keynote Address *FASD: It’s What’s Behind the Face that Matters – The Effects of Prenatal Alcohol on Brain and Behavior* Edward P. Riley, San Diego State University, San Diego, California, USA

Fetal alcohol syndrome (FAS) is a major public health issue that has lifelong consequences for society and the functioning of the individual. FAS was described independently in France in 1968 and in the United States in 1973, and is currently estimated to affect between 2 and 5 of every 1000 births in the western world. To receive a diagnosis of FAS, an individual must present with a specific pattern of dysmorphic facial features, growth deficiency, and central nervous system dysfunction. However, FAS

is only one of several possible outcomes of heavy prenatal alcohol exposure. The term fetal alcohol spectrum disorders (FASD) has been adopted to acknowledge that effects from prenatal alcohol exposure can range from FAS to subtle behavioral effects, growth deficits, or isolated physical anomalies. The introduction to this presentation will provide an overview of FASD, including a brief history, methods of diagnosis, and potential mechanisms of damage. The majority of the presentation, however, will focus on the changes in brain structure and function and the effects on behavioral and cognitive development. Prenatal alcohol exposure has regional effects on brain structures, with some structures, such as the frontal lobes and corpus callosum being more effected than others. Functional imaging studies demonstrate over activation in several brain areas while performing tasks with demands on frontal lobe functioning. Changes in white matter integrity have also been found. Behaviorally, individuals with histories of heavy prenatal alcohol exposure often have executive functioning deficits, attentional problems, specific learning and memory deficits, and motor problems. A relationship between affected brain alterations and the behavioral problems will be made. The presentation will end with strategies for dealing with FASD, including possible interventions.

Edward P. Riley (Ph.D., 1974, Tulane University) is a Distinguished Professor of Psychology and Director of the Center for Behavioral Teratology at San Diego State University. He has authored close to 300 scientific papers and reviews, primarily on the effects of prenatal alcohol exposure. He also served as Chair of the U.S. National Task Force on FAS/FAE from 2000-2004 at the request of the US Secretary of Health. He is a Past-President of the Research Society on Alcohol (RSA), The Fetal Alcohol Study Group of the RSA, the Behavioral Teratology Society, and the International Society for Biomedical Research on Alcoholism. He previously served as a member of the US National Institute on Alcohol Abuse and Alcoholism Council and on the Behavioral and Social Advisory Council of the ABMRF/The Foundation for Alcohol Research. He serves on the Expert Panel for the US Substance Abuse and Mental Health Service Administration's FASD Center for Excellence and previously served as Chair of this advisory group. He has received numerous awards for his scholarship and contributions to the alcohol field, including the RSA Distinguished Researcher Award, the National Organization on Fetal Alcohol Syndrome Research Recognition Award, and most recently the Frank Seixas Award from the RSA. His work on FASD has been funded continually since 1978 by the National Institute on Alcohol Abuse and Alcoholism. He currently directs the Collaborative Initiative on FASD, an international, multisite consortium funded by NIAAA.

10:15 am NUTRITION BREAK

10:30 am – 12 pm Closing Panel Presentation

James Gideon

James recently received his FASD Diagnosis of ARND (Alcohol Related Neurodevelopmental Disorder). He has also recently been diagnosed with ADHD.

He has been employed with John Howard Society of Sudbury for 4 years, and is a Program Coordinator for the Extra Judicial Sanctions Program (Diversion Program) for youth ages 12-17, who are in conflict with the law. It is a second chance program. He also works with youth who are in conflict with the law living with a FASD and other diagnoses such as ADHD, ODD, etc.

James is the recipient of the first: Kim Meawasige Memorial Award which he received March 2013. He also received his FASD College Certificate from Anishinabek Educational Institute in Nipissing; James is a Native Youth Worker, and a Life Skills Coach and is also Coordinator for the Equine Assisted Life Coaching Program at John Howard Society of Sudbury.

Tanya Northcott

Tanya is an inspirational speaker on the subject of FASD. She has recently graduated from the Lethbridge College of Alberta as a Certified FASD Educator. Also, Tanya is experienced in living with ARND/FASD, and she is a dedicated FASD Peer Advocate.

Tanya has been a Guest Speaker at many FASD Conferences in and around Ottawa, Ontario, over the past seven years and she was recently a Guest Speaker at the "2013 National FASD Conference" in St. John's, NL. Furthermore, Tanya is a member of the FASD Coalition of Ottawa, a supporter of the CHEO FASD Support Group and the Wabano Centre for Aboriginal Health FASD Support Group. With a unique perspective on the subject of living with FASD, Tanya shares inspirational hope for those living with FASD and for those who love and care for those living with FASD.

Tanya is of Ojibway and West Coast Native descent. She was adopted by a Newfoundland couple and raised in St. John's, Newfoundland. She is an accomplished artist specializing in soapstone sculptures, an award winning photographer and a part-time federal employee.

Liz Kulp's journey into teen life and adulthood was rough, taking her through violence and addictions that almost cost her life – hear her story, understand her needs as a child, teen, young adult and now adult woman. Learn how FASD has challenged her life - Liz is vibrant and speaks her truth. Ms. Kulp is the award winning author of *Best I Can Be Living with FASD* and *Braided Cord: Tough Times In and Out*.

Jodee Kulp is the Executive Director of Better Endings New Beginnings and runs Live Abilities a program that takes the 'dis out and embraces hidden challenges. She is an international FASD advocate, US certified Parent Support Provider and licensed direct service provider for couples living with the challenges of FASD. She is also the award winning author or co-author of 12 books to help caregivers and persons living, loving and laughing with FASD.

12 pm LUNCH

1 pm – 2 pm Closing Keynote *Preparing for a Full Body Diagnosis*

Myles Himmelreich

Myles resides in Calgary, Alberta, and lives with Fetal Alcohol Spectrum Disorder (FASD). Myles offers insight into his experiences that include both the challenges and successes that he has faced. Myles has spoken to national and international audiences, motivating and captivating them, with his personal journey through life that includes his dealings with FASD.

2 pm – 2:30 pm Closing Remarks, Door Prizes, Closing Prayer
