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MCAP*news*

www.capmanitoba.ca

Sharing ideas, information, resources, struggles & successes

HAPPENINGS

Celebrating Strengths Through Storytelling:

Highlighting supports and services for people with disabilities

by Carie McIntosh, Opaskwayak Health Authority

Big Daddy Tazz

Community members, professionals and parents were treated to an hour of comedy with Big Daddy Tazz at a conference on Opaskwayak Cree Nation (OCN). Big Daddy Tazz was the keynote speaker at the Opaskwayak Health Authority's (OHA) "Celebrating Strengths through Storytelling: Highlighting Supports and Services for People with Disabilities" on March 27. Big Daddy Tazz's message was one of hope and healing—he believes that by talking about mental illness we can break through the stigma and move on to acceptance. Through humor and personal stories, Big Daddy Tazz was able to connect to the audience and share his message of empowerment and inspiration.

Susana Scott presented on behalf of Brematson and Associates, a Winnipeg-based business that assists people in accessing government benefits such as the Disability Tax Credit, the CPP-Disability Benefit, the Child Disability Benefit and the Registered Disability Savings Plan. Susana is the parent of a child with Spina Bifida so she was able to speak with the parents in the audience about their frustrations in accessing government supports.

Lesley and Darren from Special Olympics Manitoba shared a presentation about the benefits of sport for all people. Special Olympics currently has swimming available to athletes in The Pas/OCN, but they are looking to expand to

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VOLUME 9
NUMBER 1

MCAP News is a semi-annual publication of Manitoba Coalition on Alcohol and Pregnancy (MCAP). Its mandate is to disseminate current information about FASD, a disability affecting those who have been exposed to alcohol in utero.

MCAP provides a forum for service providers, families and agency representatives throughout Manitoba with an interest in FASD to share ideas, information, resources, struggles and successes. MCAP facilitates this through regular meetings, special events, the MCAP website and this published newsletter. MCAP receives funding support from Healthy Child Manitoba. MCAP meets every third Monday of the month from 10 a.m. to 12 p.m. at the Healthy Child Manitoba Office. Teleconference available.

Contact kerrihiebert@mts.net for more information.

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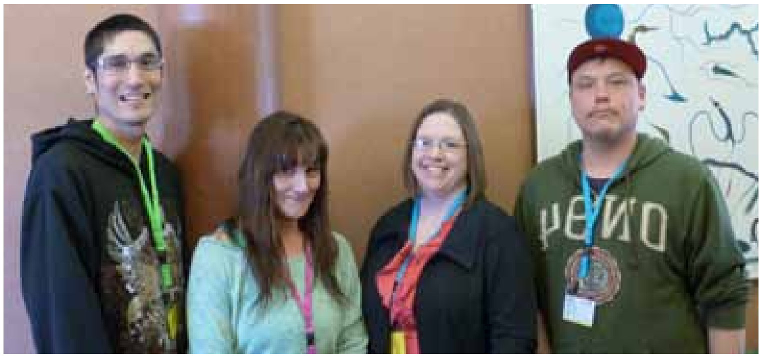


Russ, LeAnne, Carie and Ryan

different sports. Special O has training available for coaches and lots of support for our Northern athletes.

In a moving presentation about her three sons, Melanie Young shared her family's journey in the world of Autism/Asperger Syndrome. Melanie shared examples of how the three boys are similar in some ways and how the sensory world affects them in different ways. Melanie's son had a great time in the mini "Flying Buffalo Teepee" while he was at the conference with his mom! Imagine his surprise when he won it at the end of the day!

Day One wrapped up with a Visions and Voices presentation from Winnipeg. Russ and Ryan shared their story with us after airing a 5 minute video about their life. Both presenters were diagnosed with FASD, one as a child and one while in custody. LeAnne was their driver for the long trip to OCN and back. The audience members asked questions and the guys were genuinely happy to answer them!

Day Two featured personal stories of people with disabilities starting with a video produced by the research of Dr Roberta Woodgate "Understanding the Disability Trajectory of First Nations Families of Children with Disabilities: Advancing Jordan's Principle."

Next on the agenda was the Parent Panel where three local parents shared strengths, stress and service needs. The audience heard from Donna Janzen about the Disability Tax Credit, CPP-Disability, and the Registered Disability Savings Plan. Chantell Barker showed the premiere of the hip hop video produced to promote the Culturally Appropriate Program (CAP) from Manitoba Justice and described the program modules.

The conference concluded on March 28th with a Roundtable discussion about what to include next time and how to engage the community. Many heartfelt thanks to Chief and Council, OHA Board, Beatrice Wilson Health Centre staff and volunteers who made the event possible. Looking forward to the next learning event! For more information about the conference speakers, please contact Carie (OHA Disability Research Advocate) at 204-627-7458.

Healthy Child Manitoba Office Welcomes New Member to the FASD Team

by Ken Lamoureux, Program and Policy Consultant, Healthy Child Manitoba Office

New Staff Member

The staff at the Healthy Child Manitoba Office (HCMO) is excited to welcome a new member to the FASD team.

Oluwatomi (Tomi) Adelani is the new FASD evaluations co-ordinator, filling in for Kathy Andrew while she is on maternity leave. Tomi spent her practicum for her masters in Public Health with the HCMO last year, and was later contracted to work with Kathy on the evaluation of new FASD programs. Tomi previously worked in a global health organization that focuses on improving women's health.

Tomi is actively involved in co-ordinating the first phase of the evaluation of the provincial FASD strategy, which will include diagnostic and support services for individuals and families affected by FASD. Tomi also provides support for the evaluation of other FASD programs, such as Project CHOICES, the Manitoba Key Worker Program and Starfish.

FASD Updates

The FASD team at the HCMO has been busy working on several projects and training events over the past six months.

On Feb. 25, HCMO once again partnered with the Manitoba FASD Family Network to host an event in Winnipeg for youth with FASD in grades 7–12. The event, Incredible Me! Living with FASD, featured Myles Himmelreich, a motivational speaker from Calgary, AB.

Myles presented to approximately 65 youth, who attended with their caregivers or education support persons. Myles shared his inspiring story of what it is like to live with FASD, and left the youth with the hopeful message that they should embrace who they are and focus on their strengths.

The audience then had the opportunity to hear from Jaysun McLean, the event's emcee, who is a motivational speaker for Manitoba's Visions and Voices Speakers' Bureau. Jaysun shared some of his own experiences of living with FASD.

Thank you to everyone involved in making this event such a success. HCMO also partnered with The Pas and Area FASD Committee and the Flin Flon/Creighton FASD Committee to co-ordinate two training events in Opaskwayak Cree Nation (OCN), MB on Feb. 26.

The first event, You Are Not Alone, brought together caregivers, service providers, and some individuals with FASD. Myles Himmelreich shared his inspiring story and gave examples of the supports he needs to be successful. The second event was Myles' Incredible Me! Living with FASD presentation for local youth. Thank you to everyone from The Pas and Area FASD Committee and the Flin Flon/Creighton FASD Committee for helping to plan two very successful events.

In March, the HCMO updated its FASD Services in Manitoba resource list. Hard copies of the new resource list can be ordered at no cost by contacting the HCMO at 204-945-2266 or toll-free at 1-888-848-0140. An electronic copy is also available on the HCMO's website at gov.mb.ca/healthychild/fasd/fasdresources_en.pdf.

For the second year in a row, the HCMO partnered with staff from the Community Service Delivery division within the Department of Family Services to provide FASD training to community organizations. The one-day event on April 17 offered training to staff from Children's disABILITY Services, Employment and Income Assistance, Community Living disABILITY Services, and Early Learning and Child Care. Participants were given an opportunity to develop a better understanding of FASD, the unique challenges that people with FASD face, the complex issues surrounding FASD prevention, and Manitoba's FASD strategy.

The HCMO also planned the 2014 Canada Northwest FASD Partnership (CNFASDP) conference. The conference, Living Well: FASD and Mental Health, is set to take place Nov. 5–7, 2014 at the RBC Convention Centre in Winnipeg, Man. Early bird registration will take place in mid-June. Additional conference information, such as registration instructions and fees, keynote speakers, agenda, and more, can be found on the conference's website at plannersplus.ca/livingwell2014

Starting the Discussion on Male Perspectives of Drinking During Pregnancy

by Julie Strome

Recognition of the negative effects of drinking alcohol during pregnancy goes back to biblical times. What is also interesting is that even in these times men were seen as key contributors to pregnancy outcomes. Plato had it right when he recommended that newly married 'couples' forgo alcohol, "...that the child that is begotten may be sprung from the loins of sober parents" (427-347 B.C.). At some point in history we stepped away from this mentality and put the focus (and the stigma) predominantly on women. Once again we are trying to move away from a focus on women's drinking and instead understand the related social and health issues that contribute to FASD.

That being said, the partners of pregnant women have a huge impact on pregnancy outcomes. More often than not, women who are drinking throughout their pregnancies are drinking with their partners. With this, men who drink heavily are unlikely able to provide the necessary care and emotional support for their pregnant partners (FASD the Basics, 2014). Knowing this, it then becomes apparent that we need to educate ourselves and the public on men's perceptions of alcohol use in pregnancy and how this plays a role in how supportive they are of alcohol free pregnancies.

There has been limited research on this topic up until now as the previous focus has been on women. Regardless, there is some research coming out of South Africa that is inclusive of male perspectives on this topic. One study looked at male and female perspectives on whether or not women should drink alcohol during pregnancy. It also looked at whether or not they believed that alcohol use during pregnancy could harm the baby. They achieved these results by conducting surveys in popular drinking establishments.

Their findings showed that approximately 40% of men with pregnant partners did not see drinking during pregnancy as problematic. With this, 50% of men with pregnant partners did not feel that drinking during pregnancy could harm the baby. These results were congruent with the perspectives of pregnant women in these establishments (Eaton et al., 2014).

The high rates of FASD in South Africa prove that these perspectives are resulting in serious consequences. I am unsure how this translates into the Canadian context as research on the topic has yet to be done. What I surmise, however, is that there is a correlation between pregnant women's perspectives on drinking during pregnancy and those perspectives of their partners. Therefore, targeting the partners of women with the FASD prevention message is paramount to addressing the related health and social issues that contribute to FASD.

Citations:

Eaton, L., Pitpitan, E., Kalichman, S., Sikkema, J., Skinner, D. & Cain, D. (2014) 'Beliefs about fetal alcohol spectrum disorder among men and women at alcohol serving establishments in South Africa', The American Journal of Drug and Alcohol Abuse 40(2), pp. 87-94.

FASD: The Basics Presentation (2014). Available from edmontonfetalalcoholnetwork.org/prevention-conversation/fasdthe-basics (Accessed on 2 April 2014).

The MCAP newsletter committee was recently made aware of a great newsletter called *FASD Frontline*, which contains articles that inform and provide support to frontline workers and caregivers, and is produced by the Edmonton and Area Fetal Alcohol Network (EFAN).

The following poem and article are reprinted with the permission of EFAN. To learn more about this group, contact *fasdsolutions@hotmail.com*. You can also check out the May 24 edition of *FASD Frontline* at edmontonfetalalcoholnetwork.org for information about the role men play in FASD prevention.

YOU ARE AWESOME

By Ariadne Brill, posiitiveparentingconnection.net

Yes. You. You really are.
You matter more than you know.
You are more amazing than you think.
More capable than you believe.
You can love more than you can imagine.
You can make a difference.
You can be fierce to protect those you love.
You can make mistakes, get up and try again.
You can learn and grow.
Remember you don't have to do it all alone.
You can be warm, kind and loving.
You can be happy, sad, angry, worried.
Or any other thing you need to be.
It doesn't change a thing
if you are flawed or scared.
Be confident. Be Brave.
Be YOU because
You Are Awesome

The Power of Partnership

by Devon Ungurain

My name is Devon Ungurain and I am one of the FASD diagnostic co-ordinators working in the region. There are many things I love about my job, as it has a wealth of diversity that makes it more than interesting. I want to share with you two areas of my job that are quite different, but certainly connect with one another.

One of my favourite quotes is "keep life simple." Sometimes, those seemingly simple things in my job, like organizing speakers to attend a community event, can grow to something that moves peoples' hearts and lives. That is what I live for.

This past January, we had the opportunity to have Visions and Voices present at our FASD coalition's monthly meeting, held at the Wings of Power Resource Centre in Pine Falls, Man. Chris, an adult diagnosed with FASD, attends the community centre for job placement and support.

He lives in the residential home affiliated with Wings of Power. He has encountered many struggles in his life, including being born to a mother with addictions, growing up in the foster care system, and living with the lifelong challenges of FASD.

On this day, it was the first time in Chris' life that he heard three adults with FASD tell their stories and express the challenges and strengths they had in their lives. This moved Chris to share some of his own story. Chris opened up about his disability and shared what his life has been like living with FASD. His story, in turn, moved every person in attendance.

Chris' words were kind and did not place blame. He spoke clearly about having an attitude of perseverance and faith, and liking himself for who he is. It was enough to touch the hearts of everyone in the room that day. It's human connection—like the one Chris made with the speakers from Visions and Voices—that helped Chris open up about his disability.

From the onset of my job, there was a vision to develop partnerships within the region to provide assessment and diagnosis of children within or near their communities. I am so pleased to say that partnerships have been established with Sunrise School Division and Children's Therapy Initiative.

Our first local FASD clinic was held in Pine Falls on Oct. 3, 2013, with our second clinic taking place on May 8, 2014 in Oakbank, Man. The next clinic is set for Oct. 30, 2014 in Pine Falls. We anticipate having these clinics twice per year.

There are many formalities and processes, along with detailed planning and organization, that are required to host these clinics, but there is a strong human element that impacts the children, the families, and the professionals involved.

Many of the children that come for assessments are already involved in clinical services at their schools, and many of them have already built relationships with professionals in the school system. These relationships are fundamental to support the child and the family going through the assessment. Feedback from these clinics indicates that our assessments are highly respected and an integral part of the multi-disciplinary approach to FASD assessment. Without the work of community service providers, the vision to provide local FASD assessments would never be possible.

It's people like Chris that help bring community members together. It's those kind-hearted souls all over this region, and especially in our partnerships, that make a lasting impact on the lives of many children, their families, and their communities. The more understanding that a person with FASD has of his or her disability, as well as the understanding that professionals in his or her life and the surrounding community has, the better off we are as a society in understanding his or her diverse needs.

To me, people with FASD are among the unsung heroes in this world. They shine brightly in their strengths, despite living daily with the challenges of FASD. The words of Myles Himmelreich, a motivational speaker with FASD, are a constant echo in my memory—and those words are, "I've renamed FASD to faith, ability, strength, and determination."
Reprinted with permission

Christopher Martin
For more on Chris's story, search online for IJC's Just News, Volume 1, Issue 4.

The Starfish Project

by Catarina Witt and Lorraine Brake

The Starfish Project is an addictions services project for youth living with FASD who are involved with the justice system and experience problematic substance abuse.

The Addictions Foundation of Manitoba (AFM) offers this program in partnership with Manitoba Youth Corrections and Healthy Child Manitoba with three-year pilot project funding through the federal Youth Justice Fund.

The Starfish Project is open to youth who meet the following criteria:

- have a diagnosis under the FASD umbrella;
- are involved in Manitoba Youth Corrections (residing at the Manitoba Youth Centre, the Agassiz Youth Centre, or on probation);
- experience problematic substance abuse;
- live in Winnipeg, Portage la Prairie, or surrounding areas.

The Starfish Project is a voluntary program that includes one-on-one counselling, small group sessions, mentoring supports, and recreation and leisure activities. Participation involves one to four sessions a week initially, moving to less frequent sessions as participants progress through the program.

The Starfish Project supports ongoing participation by providing transportation, appointment reminders (via text or phone), non-traditional meeting places and times, and inclusion of support persons.

The name for the program, The Starfish Project, was chosen to reflect the uniqueness and worthiness of each individual with FASD. The Starfish Project's programming enables staff to tailor program components and the level of involvement to each participant. Some youth may be in and out of custody and on probation during their time with The Starfish Project, so programming is designed to move with each participant through the different systems as his or her needs change.

Referrals to the program can be made by child and family services workers, social workers, probation officers, youth corrections staff, and as recommendations by the court. Youth with FASD who are sentenced to probation with the condition of attending AFM for assessment/treatment could be diverted to The Starfish Project as another option to the regular AFM intake.

The goals of The Starfish Project are to support participants in experiencing success in meeting their goals, reduce recidivism, and increase participants' quality of life.

For more information or to contact AFM, visit afm.mb.ca/programs-and-services/for-youth/fasd-addictions-services-starfish.

FASD: Trying Differently Rather Than Harder

by Carla Champagne, FASD Diagnostic Coordinator, Brandon

On Nov. 19, 2013, the Brandon and Area FASD Committee welcomed speaker Diane Malbin, who has a master's degree in social work and authored the book Trying Differently Rather than Harder.

The crowd of more than 200 included parents, foster parents, school staff, frontline workers, therapists, and representatives from community support services. Attendees came from as far north as Thompson, MB, and as far south-east as Steinbach, MB, with a large population travelling from Winnipeg to hear Diane's message.

The day began with a warm video welcome from the Honourable Kevin Chief, Minister of Children and Youth Opportunities, as well as kind words from Her Worship, Mayor Shari Decter Hirst. Diane's presentation introduced a neurobehavioural framework, and she spoke about the importance of linking brain function with behaviour. FASD is often an invisible physical disability that requires accommodations and support, just like many other physical disabilities. Understanding that FASD is a brain-based disability will help one further understand that in many situations, the individual with FASD can't achieve the assigned task, rather than won't.

Developing a level of understanding around the individual's disability can help to avoid secondary behaviours, which are present when there is a poor fit between the individual and their environment. Secondary behaviours can include symptoms such as fatigue, anxiety, loneliness, withdrawal from peers, and depression, to name a few. Diane provided attendees with great examples that used many personal stories, as she is a mother of two adult children who have FASD. FASD is the leading cause of intellectual disabilities in the Western world. Diane noted that approximately 80 per cent of the population drinks alcohol and between 50 to 75 per cent of pregnancies are unplanned. A staggering 16 to 35 per cent of all pregnancies are considered "at risk."

Diane spoke in detail about the purpose of using a functional neurobehavioural assessment, and encouraged attendees to use this approach when dealing with challenging situations and behaviours. A functional neurobehavioural assessment looks at the individual and assesses how they are functioning developmentally. Once we understand the developmental level of the individual, we can create a good fit between the individual and his or her environment, which will prevent secondary disabilities or defensive behaviours.

Diane encouraged service providers to rethink their model of delivery, as many systems use a cognitive behavioural approach. This approach assumes that an individual's brain can learn from his or her mistakes by processing the outcome and reviewing behaviours to make effective changes the next time the same situation arises. It ignores the idea of brain function and the ability of the individual to follow the model. Diane suggested that service providers recognize the brain function of the individual, and then provide appropriate accommodations to help resolve the secondary behaviours that have developed from trying harder, rather than differently. We need to adjust our expectations to create a better fit between expectation and ability, resulting in less stress and strain on the individual and his or her relationships.

Diane's extensive knowledge, personal experience, and open mind made for a valuable learning experience for those in attendance. The Brandon and Area FASD Committee members organized the conference with a goal of spreading awareness and understanding of FASD, and I feel that goal was achieved. I would like to thank the committee members for their hard work and dedication to making this day a success.

On behalf of the committee, I would also like to thank our guest of honour, Diane Malbin, Mayor Shari Decter Hirst, Minister Kevin Chief, and all of our valuable participants for making this day a huge success.

You Are Not Alone Comes to The Pas

by members of The Pas and Area FASD committee and Flin Flon/Creighton FASD committee

On Feb. 26, Healthy Child Manitoba joined forces with The Pas and Area FASD committee and the Flin Flon/Creighton FASD committee to host a one-day event for caregivers and those who work with children and youth who have FASD.

The event kicked off with a videotaped welcome message from Kevin Chief, Children and Youth Opportunities minister. Conference attendees then had a discussion about what is available within and outside school systems for children with a FASD diagnosis. The crowd had many questions for Linda Markus, Kelsey School Division representative, and Marni Streit, occupational therapist. The audience was encouraged to think about and answer the question, "What do we need to see in schools that would help our children with FASD thrive?"

Following came a presentation by Myles Himmelreich, motivational speaker, who talked about his struggles and successes throughout his life with FASD. Myles shared how a perceived disability transformed into "ability." His engaging manner, combined with his firsthand knowledge of FASD, enlightened and entertained the audience.

One audience member volunteered for a hands-on activity that demonstrated how a brain affected by FASD filters sensory input. Using various props such as flashing light glasses, oversized "Mickey Mouse" gloves, and a squiggly pen, the activity revealed how difficult it can be to concentrate as your senses become increasingly overwhelmed.

The afternoon started with a short presentation by Marian Paul, who spoke about living with and caring for a child diagnosed with FASD. She spoke words of encouragement and reminded caregivers to also care for themselves.

Then, the audience broke into small groups to discuss and brainstorm ideas to provide care for one's own self while caring for others with high needs. When coming together later as a large group, various ideas and suggestions were discussed. The final hour of the day was reserved for two speakers from Visions and Voices, who told their stories of hope, struggles, and accomplishments while living with FASD. A video vignette introduced both speakers' life experiences. Their powerful stories concluded that with support and encouragement, FASD is a part of their lives, yet it does not overtake their lives. The silence in the room spoke volumes as audience members related and connected with their own stories.

Afterward, the audience's questions and comments strengthened the perspective that there are many people who care about children and youth with FASD, and truly want to learn how to help them succeed.

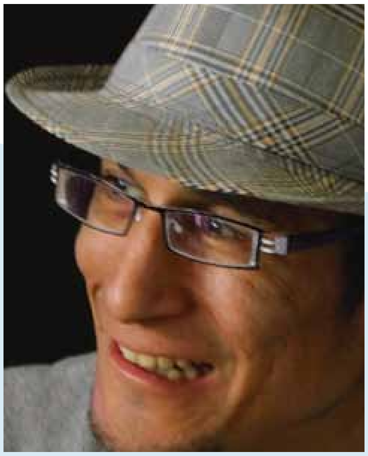
Myles Himmelreich returned to spread his positive message later in the evening, holding a session geared toward youth. Myles used humour and personal reflection to demonstrate his natural ability to relate to different age groups.

The diagnosis of FASD may seem daunting to both youth and adults, yet the message implied by Myles and the Visions and Voices speakers is that people are not defined by their diagnosis. With support and understanding, the stigma of FASD can be reduced and transformed into an optimistic message for future generations.

Thank you to all the presenters for sharing their knowledge during this successful event. In addition, thank you to the Kikiwak Inn, Healthy Child Manitoba, The Pas FASD committee, and the Flin Flon/Creighton FASD committee for all their efforts in making this conference a reality. The conference reflected how caregivers and those who work with children and youth with FASD are not alone.

Visions and Voices: Introducing Russ

by LeAnne Price



Visions and Voices speaker, Russ shares how living with FASD makes every day a challenge.

Russ has given presentations on FASD since 1998 and has been with Visions and Voices since it began in 2010. One of the many gifts that Russ possesses is his ability to be a public presenter. He captures audiences' attention with his stories of living with FASD.

It was between the ages of seven and 12 that Russ was told of his FASD diagnosis by his adoptive mom. As a child, Russ struggled in school. There were no school supports to help with the daily challenges that individuals with FASD face. Russ has difficulty with focus and memory, which also contributed to his poor school experience. He would often not be able to recall what had been taught the previous day. The lack of support and understanding led to Russ's frequent school suspensions.

Many people with FASD exhibit impulsive behaviour. Russ is aware of his impulsiveness, but awareness doesn't eliminate the behaviour. Russ speaks of his impulsiveness hampering his ability to regularly attend work. He explains in his presentation how on his way to the bus, he becomes distracted by "whatever or whoever" he comes across, and impulse takes over. Support workers assist Russ by transporting him to and from work. Russ has found a great amount of support and understanding at his place of employment, the Manitoba First Nations Education Resource Centre.

Russ also speaks about his difficulty making decisions. "It's like looking down a hallway and all the doors (decisions or choices) are grey," he explains. "To you, the bad ones would maybe look red so you don't go through (those) doors. To me, they are all the same—not good or bad."

With the support of Touchstone FASD program, Russ has an understanding network of people to suggest positive, alternative choices. Living independently can be difficult for anyone. With the challenges of FASD, it is understandably more difficult. Russ lives in a duplex on his own, with a support person from the Next Door Neighbour program living on the upstairs floor of the same duplex. This gives Russ the ability to quickly and easily access help or a distraction, if needed.

Russ is a proud father of two girls. He understands that positive supports help him achieve and maintain a positive life. Sharing his story as a Visions and Voices presenter helps to provide Russ with an added sense of meaning and purpose to his life.

Visions and Voices: Introducing Marnie Anderson

by Emma Puttaert, Spectrum Connections, and LeAnne Price, Visions and Voices, Touchstone FASD

Marnie Anderson is the newest addition to the Visions and Voices team. Our program members at Spectrum Connections have had the pleasure of working with Marnie for four years, and we have been asked to share what we know of Marnie's story with you.

Marnie is a 25-year-old aboriginal female, born in Winnipeg, MB. Marnie was adopted by the Anderson family at birth, and has remained living with her family to the present. Marnie's family members are excellent supports. Marnie reports that she didn't understand the reasons for her frustration, her temper, and her difficulty maintaining relationships, until junior high. At the age of 15, Marnie was diagnosed with alcohol-related neurodevelopmental disorder, which provided some explanation for the struggles she experienced at home and in school.

Marnie completed high school successfully, going on to complete the veterinary office assistant course at Robertson College in 2010. Marnie continues to work on her wellness in order to achieve full-time employment in the veterinary field. Some days are better than others.

Marnie is very passionate about FASD prevention and is excited for the opportunity to spread awareness through Visions and Voices. I would encourage you to obtain a copy of the next MCAP newsletter, as Marnie plans to share her story in her own words in the upcoming edition.

Visions and Voices is very excited to welcome Marnie to the team, as the addition of a new presenter gives the program another valuable perspective on the unique experience of living with FASD. It also increases our ability to provide knowledge and awareness about FASD.

As the costs of obtaining a new presenter are not within our usual operational budget, we are currently working on fundraising the additional $2,000 needed for the production of Marnie's presentation DVD. The DVD serves as an introduction to the presenter and helps him or her focus on the presentation.

Our hope is to have Marnie's DVD completed within the next few months. Visions and Voices is currently fundraising by selling Kicking Horse coffee, steeped tea, and Bothwell cheese. For more information or to place an order, please call 204-899-3556 or email *lprice.fasd@initiativesjc.org*. We would gratefully welcome your donation to assist with Marnie's project.

Highlights from the 6th Biennial Conference on Adolescents and Adults with FASD

by Ken Lamoureux, Program and Policy Consultant, Healthy Child Manitoba Office

In April, I had the opportunity to attend the sixth National Biennial Conference on Adolescents and Adults with FASD in Vancouver, B.C. With Changing the Conversation as its theme, the conference brought together individuals with FASD, caregivers, researchers, and service providers from across Canada and the U.S. to discuss the importance of addressing systemic barriers to ethical service provision for adolescents and adults with FASD.

Participants heard from many excellent speakers, such as Dr. Peter Choate, who used examples from his work to show that individuals with FASD can be successful parents when provided with the right supports. He also discussed how some of the words commonly used to describe individuals with FASD, for example, suffering or victim, can cause people to develop a negative view towards FASD and prevent them from focusing on an individual's strengths. This message was shared by all of the individuals with FASD who provided short keynote presentations throughout the conference. Rather than focusing on the terminology used to describe their disability, they spoke about their strengths to let the audience know they are proud of who they are.

During one of the plenary sessions, individuals with FASD shared stories of how they are able to live successfully. They left the audience with the message to never give up on an individual, because sometimes all it takes for them to experience success is to have one caring person be there for them.

Dr. Mansfield Mela shared findings from a study that looked at best-practice approaches to help offenders diagnosed with mental illness and FASD within the community. His presentation showed that one of the best approaches to help individuals experience success when they transition back into the community is to make sure all of the systems involved are working together.

Dr. Edward Riley's presentation asked the question, "Do we really know what happens when children with FASD become adults?" Dr. Riley explained that a person's brain develops well into adulthood, but the majority of FASD research is done during childhood and adolescence. Dr. Riley recognized the importance of early intervention, but he believes that more research with adults is needed in order to gain a better understanding of how to support individuals with FASD across the lifespan.

As they do at every National Biennial Conference on Adolescents and Adults with FASD, the closing ceremonies included the presentation of the Starfish Awards. These awards are given to people who have made significant contributions to FASD awareness. This year's service provider award was given to Cory La Berge, Manitoba's deputy children's advocate.

BEST PRACTICES

Attachment and the Child With FASD

by Lois Hunt, on behalf of Portage & Area FASD Coalition

Left to right: Barry Rud, Kristen Zwarich, Lois Hunt, Tracey Miller, Gerard Allard, Jamie Pelletier, Sheila Mitchell, Nancy Neufeld

On May 8, 2014, the Portage and Area FASD Coalition presented a day-long workshop called, Attachment and the Child with FASD. It was held at the McKenzie United Church in Portage La Prairie.

The workshop was facilitated Tracey Miller and Gerard Allard of T and G Training. Tracey is a social worker with many years of experience, and is also an attachment therapist and trainer. Gerard is a retired police officer with 25 years of policing experience, who has also worked as a trainer.

Approximately 60 participants, including education and healthcare professionals, foster parents, and social workers, learned about FASD environmental realities and symptoms, struggles, and solutions. Participants also learned about brain development and attachment issues, and how to apply the "circle of security" to understanding FASD behaviour. Evaluations completed by participants indicated that the day was enjoyable and informative. Tracey and Gerard were well-informed presenters, and participants requested further workshops presented by them.

HAT'S OFF

A round of applause and a thank you go out to the MCAP website and Speakers Bureau sub-committees. Your hard work is benefitting us all. Great job!

Also, hats off and a "great job" go to Dorothy Schwab, FASD educator for the Manitoba FASD Centre, and her team, for their hard work in planning and delivering the very successful spring sessions of Building Circles of Support. Thanks for all of the great lessons!

If you know someone who deserves recognition or a thank you for something they have done, send a little write-up to the MCAP newsletter committee at *ctower@nrha.ca* or *MCAPNews@mts.net* and we'll be sure to include it in our next edition.

WIRED

Online Safety

During the Feb. 28 MCAP information session, Parenting Teens and Tweens in the Digital World, the audience was informed of several helpful websites. These include:

- protectchildren.ca - the Canadian Centre for Child Protection;
- cybertip.ca - Canada's national tipline for reporting online sexual exploitation of children
- missingkids.ca - resource for missing children
- zoeandmolly.ca - Grades 3-4 resource
- smartstrongsafe.ca - Grades 5-6 resource
- thedoorthatsnotlocked.ca - parent resource
- weneedhelpnow.ca - junior high resource

If you live or work with kids who use the Internet or social media, these sites may be very useful to you.

Male Support

CanFASD has developed another great resource for the prevention of FASD. Alcohol, Pregnancy, and Prevention of Fetal Alcohol Spectrum Disorder—What men can do to help contains 12 tips on how men can promote a healthy pregnancy and help make a difference. Check it out at *fasdprevention.wordpress.com*.

MCAP Launches New Website

by Jennifer Sanderson, New Directions

The MCAP website has been refreshed and has a brand-new look. A big thank you to the hardworking MCAP team and of course, our website designer. On our site, you will find information about our info series, membership, a new Found in Manitoba resources section, and more.

Another new section to look for on our website is the Speakers Bureau. The Speakers Bureau will be a Manitoba-based resource that assists with finding a speaker for presentations. It will consist of speakers' names with contact information, condensed biographies, audience demographics each speaker can present to, and presentation topics. Soon, finding a presenter will be just a click away! Look us up online at *capmanitoba.ca*.

RESOURCES

Book Review

I Am a Man Who Cries by Micheal D. Mann

Micheal D. Mann was born in 1982. He met his foster mother and adopted her and soon after, he found a dad, who he and his mom adopted too. It's here that the adventures described in this book began.

From the life of a foster child, to that of a young man with disability struggling to find his own way in this world, he met many obstacles, including living on the streets and dealing with drugs and alcohol.

Seldom are we offered an insider's view of a complicated diagnosis such as FASD. Incredibly gifted, Micheal has a way with words that will leave readers deeply affected. Micheal says he's "written the book to open doors, open people's minds, open people's hearts."

It can be found on the website *mingamarketplace.com* along with many other great resources.

Another Great Resource

The British Columbia Centre for Excellence on Women's Health has sponsored a website entitled "Coalescing on Women and Substance Use-Linking Research, Practice and Policy". This site includes six posters with supporting documentation targeting service providers on the topic of alcohol and pregnancy. It provides information on why girls and women drink during pregnancy, partner support, treatment and care for women who use substances, pregnancy alcohol and trauma informed care, alcohol contraception and preconception, and the meaning of 'safest not to drink during pregnancy'. *coalescing-vc.org/virtualLearning/section6/default.htm*

Patient Advocate Form Now Available

The Patient Advisory Committee of the Manitoba Institute for Patient Safety (MIPS) has developed a Patient Advocate form for people who wish to appoint a person(s) to speak up and act on their behalf.

A patient advocate is a person chosen to support an individual and act on their behalf in talking with the health care team such as the family, doctor, nurse.

Why do people need advocates?
Some people are:
Unable or have trouble stating their feelings and concerns.
Afraid to speak out.
Unclear about what is being said or what is happening to them.
Too ill to speak up.

More information and access to the Patient Advocate form can be found at *mbips.ca*.

Are you having trouble finding the answers to your questions about FASD?

Do you have information about FASD that you would like to share with a wider audience?

Are you interested in advertising an upcoming event that you or your agency is hosting?

Contact the MCAP newsletter committee and we'll make sure your information is shared and your questions are answered.

Newsletters go out in the spring and fall each year. To submit your questions, articles, or information, contact Colleen at *ctower@nrha.ca*.

MCAP Q & A

In the last edition of the MCAP newsletter, readers were asked to send in questions about FASD that they would like to have answered by a FASD expert. The following question was submitted:

"I am working with a mom who has to take the bus home from daycare with her three-year-old daughter. During the 15-minute ride, it is impossible to keep her seated. The bus driver has gotten angry with them more than once because the daughter is swinging from the bars or screaming all the way home. What can she do?" Below are the responses from service providers and caregivers.

The MCAP newsletter contacted service providers and caregivers looking for an answer to this question and these were the responses:

Lia Braun, independent FASD consultant

Lia Braun, independent FASD consultant, suggests for the mother to sit in the seat closest to the aisle and put the child next to the window. The mother could blow up a dollar store beach ring for the child to sit on and play "What's out the window?" to distract and engage her daughter.

The mother could also pack a "toolbox" for every outing, including items such as:

- healthy snacks (using several separate containers for things that take longer to eat, such as Cheerios, grapes, cut-up carrots or cucumber, or a mandarin orange that the child could peel herself) and water in a sippy cup;
- appropriate books that the mother could read, sing, look at, and discuss (a good way to learn and reinforce numbers and colours, too);
- interactive toys, such as dolls, animals, and cars, which the mother could use to engage the child ("Hello, what kind of animal are you?" "Will you be my friend?" "Do you like bus rides?" "What do you see out the window?");
- sensory tools, such as squishy balls or toys, a piece of fur to stroke, a stretchy or bendable toy, something that opens and closes or fits inside something else, or bubble wrap to pop.

The trick is to engage with the child and keep her interested and occupied. If the mother expects to give the child something that will keep her entertained on her own, or simply tells her to be "quiet" or "good" or to "sit still," then she may have difficulties. However, if the mother sings and plays with her daughter or feeds her a snack on the way home, then the bus ride can be a special time for mom and daughter and will be much more enjoyable for everyone else, too.

The mother could also take the opportunity to give the bus driver a pamphlet on FASD. She could explain that her daughter has a neurological disability and she is trying hard to improve her behaviour, and she hopes the bus driver will try to be more understanding.

Marsi Rock, FASD specialist, Southern First Nations Network of Care

Marsi Rock, FASD specialist for Southern First Nations Network of Care, suggests for the mother to break the challenge into small steps so her daughter knows what to expect and feels more comfortable taking the bus.

Marsi's tips for developing steps, routine, structure, and consistency when taking the bus are as follows:

- Remember that the child has difficulty sitting still, not that she refuses to sit still.
- Develop the steps in a way that encourages the child to sit still on the bus, without simply telling her over and over.
- Develop the steps in a way that considers the child may be over stimulated in a very noisy and distracting environment. For example, one step may involve the mother saying, "Now that we are in our seats, it's time to put on your head phones." This example illustrates a way that steps can be developed into a routine, while also addressing the background noises and distractions that may be making the child uncomfortable and/or over stimulated.
- It may be helpful to put the steps and directions into song form. For example, the mother may sing, "Now that we are sitting on the bus and have your headphones on, it's time to look at your picture book."
- The mother could also take pictures of the child doing each step, so she can show the pictures to the child on future bus trips. This activity will create even more structure, routine, and consistency, which will further help the child learn what to expect.
- If the mother is comfortable doing so, she could discreetly let the bus driver know that her child has special needs, is developmentally delayed, or has FASD, and that she is attempting to meet her needs and would appreciate his understanding. This approach will hopefully minimize the bus driver's anger.

Betty Wiebe-Hosein, program counsellor, New Directions

Betty Wiebe-Hosein, program counsellor at New Directions, says this would be a challenging situation for any parent and child. “Staying seated or contained in a situation where they need to wait is pretty tough for most three-year-olds. When there are sensory differences or hyperactivity, it is even more challenging for the child—and mom.”

Betty recommends preparing ahead of time to make the bus ride easier. Using a social story at home that describes what is expected when riding the bus can help prepare a child for the experience.

Incorporate photos of the child and lots of positive language in the social story, Betty suggests. For example, “Lucy waves at the bus driver and sees all the people sitting on the seats,” or “Lucy likes to sit beside mommy.”

Read the social story when the child is comfortable at home, and not just before going on the bus. Making the social story a part of the child’s nighttime routine is a good idea, and avoid talking about any misbehaviour when reading it.

Other ways to prepare ahead of time include making sure the child has used the washroom before leaving, and dressing her for the weather. Easy-to-remove layers can be helpful, as overheating on the bus is enough to agitate anyone. Finally, remind the child just before she gets on the bus, “We are going on the bus. We need to sit and use our inside voice.”

Adapting the environment is another suggestion Betty makes. “On the bus, the environment mom has control over is the space between the seats where they are sitting, and we can do a lot in this little space.”

Allow the child to sit next to the window with mom in the aisle seat, as this defines the child’s space. Sitting at the front of the bus is another idea, which may help determine if the child’s agitation is related to being carsick.

“After daycare is often a hungry time, so providing a snack and water to drink on the way home can distract and meet a physical need,” Betty adds.

Betty also recommends bringing along a tool kit of activities. “A busy bag of activities can make the trip seem much shorter for both daughter and mother,” she says. “This bag of special activities should be kept for the bus only. This makes it a special time and the activities will stay fresh and hold the child’s interest for a longer period.”

Some of the items Betty suggests packing in a “bus toolkit” include:

- picture books or a story book the child can “read” to mom, or a photo album to share together;
- contained activities, such as a sticker book, lacing cards (yarn through the holes), interactive books, or a small Etch-a-Sketch;
- interactive cards.

Regarding the interactive cards, Betty says, “I have made sets of 15 two-by-two inch laminated picture cards on a ring, that the child can go through and name the objects. Another set of picture cards had common sights she would see on the way home and it was a game to find the sights pictured on the cards.”

These card sets can also tie in with Betty’s next solution, which is to provide for movement. “My favourite card set allowed for movement while seated on the bus,” she says. “I used animal pictures and a phrase to direct the child to ‘wiggle your nose like a bunny,’ ‘wag your tail like a dog,’ and ‘raise your trunk like an elephant.’ Mom would provide direction so that the child learned the activities and kept the actions contained.”

A kaleidoscope or small binoculars to check things out is fun, as are hand games or finger plays with rhyming verses.

Throughout these activities, the mother’s participation can be key to having the child “buy in.” The mother and child should take turns with each activity, with the mother showing interest in the child’s responses and letting her know she delights in her.

“If it is important to mom, then she will think it is interesting, too,” says Betty.

The mother should be prepared that each activity will only occupy her child for a few minutes, so it’s a good idea to bring many activities along. From day to day, the activities will need to be rotated, and adding some new, creative activities will keep things fresh.

Ideas for creating tools to help children stay organized while on the bus (or in other situations where they need to wait) are as endless as our imaginations. The Internet is full of pictures that can be used, and Betty particularly likes using the website Pinterest (pinterest.com/kaylyn914/kids-busy-bag-and-quiet-bag-ideas). With some of these activities, the child can help in the creating process, which will make it even more meaningful to her.

Thanks to our reader for the great question and to Lia, Marsi, and Betty for their informative and helpful suggestions!

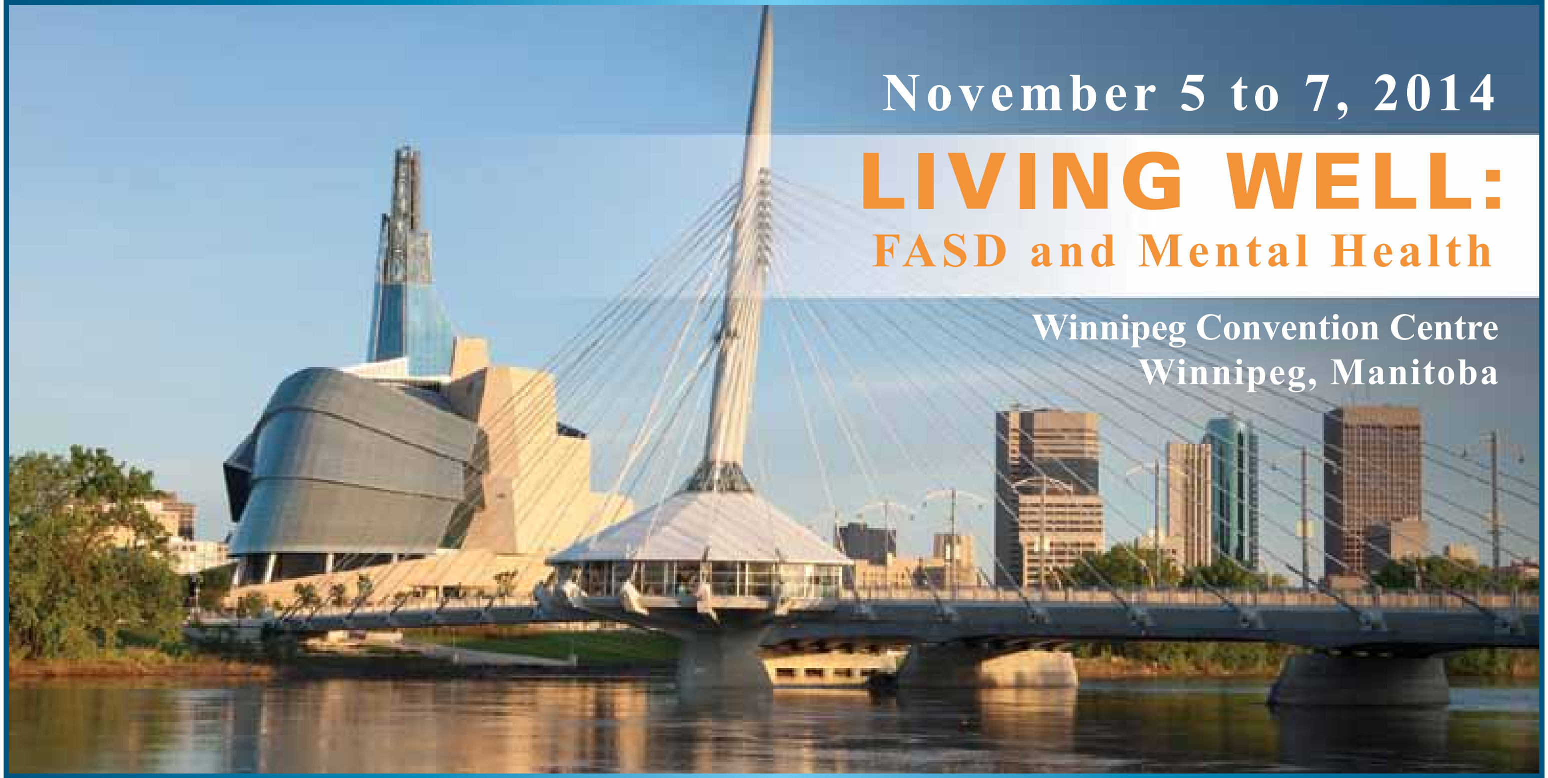
International FASD Day Call for Proposals

The Manitoba Coalition on Alcohol and Pregnancy (MCAP) is a provincial organization committed to reducing the incidence of alcohol and drug use during pregnancy, and ensuring the best possible outcomes for people living with Fetal Alcohol Spectrum Disorder (FASD).

This year, MCAP is providing an opportunity for up to 12 FASD coalitions or community groups in Manitoba to access one-time funding of $500 to help raise awareness about FASD on International FASD Day. Since 1999, people around the world have marked Sept. 9 as a day to raise awareness about the danger of drinking during pregnancy and the impact of FASD on individuals and families.

In lieu of a formal evaluation report, grant recipients must submit a short article with photographs of their International FASD Day event or project for inclusion in the MCAP newsletter by Sept. 23, 2014. Articles and requests for further information can be directed to Kerri Hiebert at kerrihiebert@mymts.net.

SAVE THE DATE



November 5 to 7, 2014

LIVING WELL:

FASD and Mental Health

Winnipeg Convention Centre
Winnipeg, Manitoba

The *Living Well: FASD and Mental Health* Conference, will delve into the interconnection between Mental Health and Fetal Alcohol Spectrum Disorder spanning the areas of prevention, intervention, support, evaluation and research.

Topics will include:

- Mental health and substance use for pregnant and parenting women
- Mental wellness for those living with FASD
- Case management for individuals living with FASD and mental health co-morbidities
- Diagnosing FASD and co-occurring mental health disorders
- Emotional wellbeing for caregivers of individuals living with FASD

You will receive program and registration updates as soon as they become available!

A Canada Northwest FASD Partnership Conference
Hosted by Healthy Child Manitoba

Canada Northwest FASD Partnership

Healthy Child Manitoba
Putting children and families first

Manitoba

Hope to see you in Winnipeg next November!

Manitoba Coalition on Alcohol and Pregnancy (MCAP) – Membership Form

Thank you for your interest in the Manitoba Coalition on Alcohol and Pregnancy (MCAP). MCAP membership is open to all Manitobans with an interest in fetal alcohol spectrum disorder (FASD). MCAP will facilitate representation from across the province through the use of teleconferencing technology. Anyone may attend a MCAP meeting, however only voting members may participate in making decisions for MCAP. There are no membership fees or dues. Members must complete and submit annually a membership form confirming their intention. The type of membership chosen reflects the level of commitment to MCAP. Voting members are encouraged to attend meetings regularly to ensure quorum can be established at each meeting. Voting members are asked to let the MCAP administrative co-ordinator know when they are unable to attend a meeting.

Name: ____ Date: ______________

Organization (if applicable): ____

Mailing address: ____

Tel: ________________ Fax: ______________ Email: ___________________________

Please indicate the type of member you wish to be:

☐ **Individual Voting Member:** An individual voting member is a person with an interest in FASD, who is not representing an organization. Voting members are committed to attending meetings on a regular basis and are engaged in MCAP activities.

☐ **Organizational Voting Member:** An organizational voting member is a person representing an organization. The membership will be held by the organization, which will appoint a representative to vote at MCAP meetings, participate in MCAP events and receive minutes and correspondence. Each organization will have one vote. An alternate may attend meetings to represent the organization. The organization is committed to providing a representative to attend meetings on a regular basis and engage in MCAP activities.

☐ **Individual Non-Voting Member:** An individual non-voting member is a person not representing an organization, interested in receiving the *MCAP News* and invitations to MCAP events but does not wish to participate in the operation of MCAP. Individual non-voting members are encouraged to attend MCAP meetings, however if they wish to participate in the administration of MCAP they must change their membership to a voting member.

☐ **Organizational Non-Voting Member:** An organizational non-voting member is an organization with an interest in receiving the FASD News and invitations to MCAP events but does not wish to participate in the operation of the MCAP. The organization will identify a contact person to receive information. The organization is encouraged to send a representative to attend MCAP meetings, however if they wish to participate in the administration of the MCAP they must change their membership to a voting member.

☐ **Ex officio non-voting member:** MCAP funders.

Please mail the completed form to:
Kerri Hiebert, MCAP Administrative Co-ordinator
299 Truro Street, Winnipeg, MB R3J 2A2