Supporting children affected by pre-natal substance use

A conversation with Deborah Kacki

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Based on an interview conducted by Margaret Leslie of Breaking the Cycle (Toronto)

Our mandate

There were a number of agencies, daycares and schools in Winnipeg that were concerned about the number of children with alcohol-related disabilities. They didn't know how to go about meeting the needs of these children. They thought that they should have extra supports in the community for families, daycares and schools.

Four agencies, the Mount Carmel Clinic; Pregnancy Distress Services; New Directions for Children, Youth and Families; and Winnipeg Child and Family Services, obtained CAPC funding and created the Interagency Fetal Alcohol Syndrome Program. The Program's mandate is to provide home-based services for families with alcohol-affected children aged 0 to 6. Supports are also provided in schools and daycare centres.

We don't require a diagnosis, only confirmation that a child has been prenatally exposed to alcohol and/or drugs. This is essential for getting assistance to families as early as possible. When the family decides to pursue a diagnosis, the project supports them through that process.

Occasionally families flip-flop on whether there was drinking during pregnancy. When they get to the diagnostic clinic and the child is diagnosed with an alcohol-related disability, there is a huge support piece that is needed for the family. There is so much stigma and shame attached to drinking during pregnancy, and society can be really ugly in pointing the finger at women.

Having someone to lean on or someone to give you a ride over to the diagnostic clinic and support you through it makes it a little easier.

Helping the family

Our primary service is home-based counselling for families. We provide education about the effects of alcohol and help people to make a shift in their thinking from seeing this child as willfully disobedient or willfully misbehaving to seeing that this child has a brain that works differently, and these are the implications.

Intervention starts with the family's presenting problem. They usually come with a particular issue, such as that the child isn't eating or isn't sleeping, or they heard that they could get information, or they're struggling with the school or daycare. So, if the family is concerned that the child is not sleeping at night, we examine bedtime routines and assess the stimuli in the child's bedroom.

There's a part of the counselling service that we call consultation, and it involves advocating for the family with the larger community. For instance, when the family is in a panic because they're not getting money for this or that from welfare, we write letters of support, and we go with them to appointments. Usu-

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ally the initial issue that they come in with is the tip of the iceberg. Sometimes they only want to deal with that and then they're on their way, and that's just fine. The voluntary aspect of the program – that you can come and go as you please – is important.

We start by identifying the key information they need and we provide it over time. People need time to think about new information and to make it fit for them. We support them in the really practical stuff that takes up their days. They're trying to understand about the effects of alcohol on their child, but they may also need groceries and may have two other small children at home, or have just run out of diapers. It's very nice that we're sending the sensory integration facilitator to help them, but what are they going to do without milk and diapers?

We help people access food banks and find out where the bargains are, and we provide transportation, which is a huge need. So, it's very practical, and the counselling and educational components can have many flavours. It may be written information, or tapes and videos that we'll sit and watch, and discuss with the family. Sometimes it's just using that teachable moment, when mom sees you reading a book to the child while you're waiting at the doctor's office, and she says, "Hey, I can read books to my child." You're passing on a lot of information about child development in indirect ways.

We make a number of referrals, depending on the need identified by the parent. Families can access Children's Special Services, which provides them with essential support such as respite. However, not all children with alcohol-affected disabilities are eligible. They need to have a Developmental Quotient of 65 or lower to qualify for this service. It is these systemic barriers that provide endless frustration for families. However, that same service is provided for children with autism. Change will happen for this population as well, but the wheels grind slowly.

In addition to the Program Counsellors, we have a Sensory Integration Facilitator who is an Occupational Therapist. She works with the family to modify the sensory environment for the child. The family has to make a paradigm shift from seeing the child as behaviourally challenged to seeing that the child has organic brain differences, and is having difficulty making sense of information.

We have a mandate to work with at-risk parents and families around life skill issues. That's extremely helpful, because then it's one person who is a direct contact for a whole gamut of services. The child is the main focus, but it's the growth of the family and the understanding of the family that's a big prerequisite.

The fact that we could potentially be involved for six years with a family is an advantage in helping the family care for an alcohol-affected child. There are a lot of stages that families go through in six years. If the same person is involved with the family over time, that's even better because there are so many trust issues. Once you've been able to make a connection and develop a trusting relationship with someone, there is a lot of learning they can do around healthy relationships.

Support at school

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Our educational consultant does some work with the families. However, her primary focus is the schools, and support for teachers and other people working with children in the school system. She helps them make shifts in their approach, to adapt the school environment, and to develop their curriculum.

The school system has teachers with a 1:30 or 1:28 ratio. When you throw one or more children with special needs into the mix, it's really difficult to meet the needs of all children.

An FAS diagnosis is not usually enough to get the one-to-one support needed for a child. If the child doesn't have the behavioural issues and isn't acting out, if it's this child who just doesn't get it, but sits quietly in the classroom, you don't get the funding for one-to-one support.

Help at the daycare

In the Manitoba daycare system, it's very difficult to find and keep qualified early childhood educators. The level of education for qualification is very high; however, the salaries are not commensurate with the years of study. Fewer people are choosing early childhood education as a career. The Manitoba Child Care Association continues to work politically to try to get that changed, but it's a really slow process. Meanwhile, there's a shortage of qualified people.

We advocate for the children through direct consultation with daycares and schools. We help them to adapt the environment – things like redefining the boundaries of activity areas or creating bunny holes or calming spaces – all kinds of ideas that help them to better address the needs of the kids in their daycare. Many are very open to it. We *build* those relationships. We'll say, "We can come and do a presentation for your staff, free of charge. We'll do a whole educational piece on FAS for you." We'll gear it specifically to the daycare.

We wrote a manual, "Living and Working with Fetal Alcohol Syndrome/ Effects", and there's a chapter on daycare that I did because I'm really familiar with daycare (I was a director at one point). I realized that creating great daycare for children who are alcohol-affected is really creating great daycare for all children. Early childhood educators make environments predictable for children, they create boundaries to activity areas, so kids aren't going to be running back and forth through the library area. They erect barriers to define the activity areas.

Most early childhood educators "get it" right away. Some are very open to it, but there are some people who just can't make the shift to seeing the child as having a disability and I kind of blame our tendency to think everything children do is a purposeful act that needs to have consequence. That's such a limited way of seeing children. Our first tendency is to create a consequence as opposed to nurturing, to think what else might be happening here. Sometimes it takes people a long time to grapple with this. The opportunity and advantage we have is that we can keep going back on a consultative basis when people are struggling.

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Using functional assessment

When we were developing our project, we grappled with the issue of assessment. Often when people are intervening with children who are developmentally handicapped or developmentally delayed, they do a very child-focused developmental assessment. The goals for the child are triggered by that developmental assessment. We found that to be a hurdle that we had to get around.

We decided not to do developmental assessments because we found they got in the way in these situations. We know that the developmental assessment will only reflect how the child is performing on that particular day, and will also reflect all the distractions and interruptions that might happen during the assessment process. It doesn't really give you a lot of information about how that child functions from day to day.

We decided to do functional assessment instead of developmental assessment. We look at how the child functions within the larger environment and then adapt the environment. Yes, you do need to know about how that child interacts socially, about their gross motor skills and some of their cognitive skills, but you can learn so much more through observation, and you get a lot more information when you're watching them in a larger situation.

We created our own tools that are about environments. We ask questions about what's happening in this environment, what the physical environment

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looks like, what the expectations are of the people in this environment, what are their rules and how does that fit for this particular child. We have an assessment for early childhood educators and one for the home environment. It's something that we do initially, and it's a starting point for looking at improving environments.

This is especially useful when I go into a daycare and look at the daycare environment. I look at their scheduling and their routine practices. We can do a sensory assessment, which is very helpful in developing intervention strategies, for instance in helping the child to eat.

When they tell me that the child cannot sit and eat at lunchtime and I come and observe, I'll see that the shelf of small toys that's sitting right beside the child's chair is a complete and total distraction. So, for intervention purposes, we can talk about, "maybe if that was turned around or if that was covered, the child will be less distracted … much more functional".

Prevention and outreach

We do work with prenatal groups. It's a preventive focus, but it also profiles our program with women who may be using in their pregnancies. We don't just walk in and say, "This is what FAS is. This is what our program is about." It's a much more sensitive approach, I think, where we talk about why a woman might drink during her pregnancy. It's very supportive and it's very non-judging. It's saying, "If you're drinking during your pregnancy, there are probably some really good reasons why. Nobody is here to judge you. And if we can support you, here we are."

One other thing we do is phone consultation. We just call it our general consultation role. I get a lot of phone calls from people with older children because there aren't a lot of services for them here. I may get a call from a parent with a 20 year old, who says, "My child has had 30 jobs and hasn't kept one of them for any length of time", or, "I've just heard about this issue, and I think there may be some alcohol difficulties here because I know her birth mother drank." It's amazing. We've had so many calls from grandparents, and extended family. We provide referrals to services that might support them, or just provide them with information. I think they hear about us from all kinds of different places. We have brochures in various community organizations. We don't ask callers how they heard about us. Often people won't even identify themselves. It's all very private and confidential.

There is a Provincial Coalition on Alcohol and Pregnancy that has representation from just about every area – health, education, addictions, justice, family support, and daycare. It's great because there is a lot of exchange of information and there are new people attending the coalition meetings all the time. This helps with coordination of services.

There have been lots of barriers to service delivery, but I don't think they're unusual. They represent people who are not aware of how to approach the issue, who may be frustrated and have money issues, funding issues, personnel issues.

We are seeing change over time in family, school and daycare systems. It helps to see that all systems go through various stages as they contemplate change. We're prepared to hang around long enough to see it happen. ☐

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