

Preface: Asking Better Questions

In 1995, when I was first hired at the Indian Health Board of Minneapolis, fresh out of my psychology internship, our then-Medical Director, pediatrician Dr. Lydia Caros, asked me to conduct psychological evaluations on several of her patients that she had been tracking. These children had been exposed to alcohol in utero, and she was concerned that they might have a relatively unknown disorder called Fetal Alcohol Syndrome, or FAS¹, which could cause learning and behavior problems that would last throughout their lives. These children needed both medical and psychological testing to make an accurate diagnosis, and if they had this disorder, the best course of action was early interventions.

Such interventions might take the form of referrals for occupational therapy, speech/language services, or for any other developmental problem the child might have. However, other interventions would have to encourage caregivers and others to interact in new and different ways with their FASD child. Essentially, a child with FASD requires that caregivers and others think differently about how to interact with the child in order to promote success. The FASD child's brain damage obliges a different sort of expectations for what that child can do and how it can be done.

Diane Malbin, a social worker and tireless advocate for FASD, calls this approach "trying differently," and it involves advice such as providing simple, concrete instructions to the child or giving frequent reminders. Dr. Caros knew that these types of interventions were just as important to ameliorate our patients' problems and give them their best shot at overcoming potential disabilities and avoiding even worse problems in their future.

¹ Over the years, the nomenclature has changed and been refined. Nowadays, the spectrum of prenatal alcohol exposure disorders is more commonly referred to as Fetal Alcohol Spectrum Disorders, or FASD.

Dr. Caros was no stranger to early interventions regarding public health problems. Early in her career, she had almost single-handedly created awareness of and pushed for statewide interventions aimed at children with lead poisoning throughout Minnesota and especially in the Phillips neighborhood of Minneapolis, where our clinic is located. With her public health mindset and devoted commitment toward reducing health disparities for our primarily American Indian patients, Dr. Caros was discerning another serious public health crisis that many of our patients unknowingly faced—prenatal alcohol exposure and probable FAS.

I must admit that she had to make a hard sell to me. At the time, I had only a passing knowledge of FAS, and I preferred practicing psychotherapy over the more time-intensive skills involved in conducting psychological tests, despite my training in assessment and having previously worked on a multidisciplinary assessment team during my internship. Dr. Caros correctly pointed out, however, that many of my psychotherapy clients could very well have prenatal alcohol exposure, and that it would behoove me to be knowledgeable of FAS and the problems that it creates so that I would be a better psychologist for them. Partly because she was right, but partly because I was eager to justify the chance my new employer took with me, I reluctantly agreed.

In the mid-1990s, the only trainings I knew about for FAS evaluations were held at the University of Washington, and our non-profit clinic could not afford to send me, so I read over every article, both professional and popular press, that Dr. Caros sent my way. She also knew the importance of understanding state-of-the-art methods for conceptualizing and testing FAS and, accordingly, introduced me to the "Four-Digit Code Diagnostic Manual," a fairly daunting but well-researched multidisciplinary FAS diagnostic system developed by Drs. Clarren Sterling, Ann Streissguth, and Susan Astley, pioneers in the FAS field at the

University of Washington. After several months of self-study and consultation, I was ready to conduct my first FAS Evaluation in 1996.

For our first case, we tested a five-year-old boy who clearly had behavioral, cognitive, language, and sensorimotor problems. He also had mild facial characteristics associated with FAS and a verified prenatal alcohol exposure that involved numerous binge-drinking episodes throughout the pregnancy. Dr. Caros and I diagnosed him with "Fetal Alcohol Effects/Static Encephalopathy," which meant that he met only three of the four criteria for an FAS diagnosis, but he clearly had functional problems that stemmed from the non-progressive brain damage resulting from his alcohol exposure. Fortunately, this boy's caregiver was well-educated generally, well-informed about FAS in particular, and a talented advocate for his special needs. She was able to incorporate the "thinking differently" interventions that we recommended. Many of the children we later tested were not so lucky.

Caregivers for the patients in our FAS tracking system included some biological mothers, but many were grandparents or relatives, foster parents, or adoptive parents. They typically understood the importance of early diagnosis and intervention and agreed to the evaluations, but they were too often unable to fully grasp all the complexities of FAS or follow through with the interventions that their diagnosed children required on a consistent basis, especially those that required "thinking differently." We worked hard to make our FAS reports understandable and useful, but the gaps between what we recommended and what interventions those children were able to receive remained frighteningly wide.

To help close this gap and raise more awareness regarding FAS, Dr. Caros and I have both lectured on the topic quite a bit. Over the years, participants in my trainings seemed to understand the importance of diagnosis and interventions, but in my experience, when it comes right down to it, adequate interventions were often carried out "hit or miss"

at best and rarely used in a consistent, competent way. Over the years, I refined my lectures on how the brain works and developed visual aids illustrating the garbled system of neural circuits in brains exposed to prenatal alcohol. Again, participants showed increased understanding and gave positive feedback about the simple, concrete methods of explaining FAS, but consistent interventions still remained elusive. It seemed hard to impossible for people to "think differently" on a consistent basis. Clearly, a better system of educating caregivers and professionals was needed.

During a conference workshop in 2005, I quite unexpectedly hit upon the idea of using a metaphor which would improve people's understanding of what it is like to live with FAS (called FASD by then). Most participants in that lecture I gave were very experienced foster parents and advocates and had worked with many FASD children. Their questions for me were challenging and inspiring, and someone finally asked a question I had never thoughtfully asked myself, "What is the best way to explain FASD to a child?"

Usually, the question is "How *should* you explain FASD?" but now it felt like the bar had been raised from "the standard way" to "the best way" of explaining FASD. The standard explanation is usually some version of "Sometimes moms drink when they're having a baby, and the baby grows up to be a very special kid, but sometimes the kid has a hard time doing certain things in the same way other kids do... maybe the kid needs things to be extra quiet or needs extra time and hints to get schoolwork done. This is called a disability, which means that sometimes we'll need to figure out new ways to help you get the things done that you want to do." However, this group had reframed the question, and they wanted the best. It required me to think differently and also to articulate it. So I gave them the best kind of explanation for children that I know of—concrete, easily grasped, and immediately usable.

I sketched them my "cartoon" of brain structure and development, which I had drawn for numerous clients to show concretely how alcohol mangles a child's neural circuits and impairs brain functioning, manifesting the unpredictable and challenging behaviors. As with my clients, the participants quickly grasped the concept and wanted more. Riding this wave of giving the "best" explanation, I wanted to add another facet to this information that would stick with people in their minds and also help them better follow through with good interventions. I knew that providing consistently creative and competent interventions is the key to helping those with FASD have a smoother ride through life, and that is when it hit me—the "wheels" that FASD people use to ride through life have chunks missing, which is why they get stuck at certain places and times in their life journey!

This seemed like a powerful metaphor to me, and I already knew that metaphors are useful in promoting change and new behaviors in psychotherapy. A metaphor is easy to remember, and it provides a certain perspective, or lens, with which to view the world. A new lens provides new information and new understanding, in much the same way the lecture participants had asked me a "new" question. The Wheel of Functioning™ metaphor to understand FASD and achieve consistently creative and competent intervention is my attempt to contribute another perspective, possibly new information, and an easy-to-use framework for caregivers and professionals working with those affected by FASD. It helps promote "thinking differently." Those conference participants, and others after them, have found this idea useful, and I hope you will, too.

As a final point, I would like to state that this book may not be the "best" answer to the question, "How can we best serve those with FASD?" and it certainly is not the only answer, but I think it is a *better* answer than I used to give—not because I was suddenly inspired or smart, but because someone asked me a better question that opened up my

curiosity and creativity, which led me to develop a better roadmap for those traveling on a journey with FASD. Curiosity and creativity are qualities that everybody can use. It does not take a medical degree or doctorate in psychology to ask questions that lead you to better, more creative answers. You can do it any time—even right now—and that is my challenge to you as you read this book, to ask yourself "How can I better help a person with FASD navigate through their life's journey?" It's time to think differently.