

Can't, Not Won't: A Christian Response to Fetal Alcohol Spectrum Disorder (FASD)

Reviewed by Cindy Warner Baker

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that describes a range of life-long cognitive, physical, behavioral and mental disabilities that can result when a mother drinks alcohol, which passes to the fetus. In *Can't, Not Won't*, we are introduced to two families living with FASD and their church communities. Facts of FASD are introduced, but the main purpose of the film is to increase viewers' understanding of the impact of FASD on affected individuals and families, and to explore how the church can respond in helpful and supportive ways. The appendices of the included study guide provide information on symptoms and secondary disabilities, as well as print, video, and web resources.

The personal stories of two families are woven throughout the video, and are powerful in their directness and honesty. As the mother of a young adult with FASD, I connected with the sharings of other parents in a similar situation. Their honest recounting of both the struggles and their commitment to what is positive in their son illustrate the complex challenges facing individuals and families. The reflections of pastors and other church leaders provide a basis for thoughtful discussion among congregations seeking to grow in their outreach and support of families living with FASD.

Can't, Not Won't: A Christian Response to Fetal Alcohol Spectrum Disorder

45 min., available in both VHS and DVD. Study guide included.

Copies available for purchase for US \$23.00 postage paid through ADNet or through Mennonite Central Committee (MCC). See contact information on p. 3. Although we encourage purchase as a way to support such endeavors, a copy in each format can be made available for loan as well.

For a more extensive review and discussion of issues related to FASD, see ADNet Online's Fetal Alcohol page at http://www.adnetonline.org/Information/Topics/Fetal_Alcohol or call 1-877-214-9838 (toll free) to request a copy. A free packet with more articles and information on FASD is also available.

And now, for the longer review....

First, I need to confess that this video was very difficult for me to watch. It was not a pleasant experience, and I would have been just as happy to turn it off after the first few minutes. Instead, I watched it five times, often stopping to jot down notes, and just as often to talk back to the presenters, wash the dishes, move the laundry ahead, or get a tissue and wipe away tears. I could only take so much at a time. It was a long, painful process.

I kept asking myself, "Why?" Why was I getting so emotional, so angry and frustrated and sad? What about the video evoked such strong, visceral responses in me? It wasn't that the video is poorly done, or biased, or negative in its perspective. It isn't. Given its short length and the complexity of the issues, *Can't, Not Won't* is a remarkably balanced, thoughtful presentation. In forty-five minutes you can only meet a few individuals and families, only hear from a few professionals, only see what a couple of congregations are doing to respond to the needs of the families within their circle of care. Given those limitations, the video takes an honest, thoughtful look at the practical, social, spiritual, and theological ramifications of living with the effects of fetal alcohol exposure. There are few such resources available anywhere, and I am profoundly

grateful to Irma Janzen, MCC Canada, and all those who gave their time and resources to the production of this video and study guide.

So what was my problem? Why, when I turned off the TV for the last time, was I still restless, still angry? With whom was I angry, anyway? That was the question that caught me up short. Because I *was* angry, and deeply so. Even now, two months later and finally tackling the job of writing this longer review, I can feel myself getting tense, indignant, and moving again toward the hard knot of anger that resides within me.

I am angry at the disorder. (How's that for futility?) I am angry at something that I don't fully understand and cannot change, something that affects every aspect of my life and has become as much a part of my reality as the air I breathe or the food I eat. I am angry that I can't change it, can't fix it, can't make my children's lives any easier. And unlike many other disabilities that come into our lives and the lives of our children, fetal alcohol disorders are caused by human choice. One human being, through her behavior, causes another to live with profound life-long disabilities and challenges. I have to admit it; I am angry about that as well.

However, I know the birthmother of my children, and it's not as simple as blaming her. Yes, she provided the direct cause of their disabilities, but she herself lives with multiple challenges. While I firmly believe that she bears some measure of responsibility, I cannot find it in my heart to be angry with her. I am angry about what she did, and the effects it has on my children—that I acknowledge freely. But when I think about her, the life she lives, the pain and loss, and the bleakness of her existence, I feel sadness, not anger. She made some terrible, terrible choices, but within her own limitations, she also tried to make some good ones. I pray for her often; she lives with the consequences of this disorder as much as we do.

In wrestling with the anger within me, which asserts itself when life is especially challenging for one of our children, or when I listen to the pain of other parents who don't know what else to do to try to reach their affected teenager, I realize that I am wrestling with profoundly spiritual issues.

God created each of us as free individuals, free to make choices, to choose wisely or foolishly. This gift of freedom comes at a price, and sometimes it is other people who pay the price for our choices. Individuals who live with FASD and their families don't have to be told that there is sin and evil in the world. We live with it. We live the reality that this is a broken and fallen world.

When my daughter is evicted for going too many months without paying rent, and loses her job for not showing up on time once too often and cries out, "Why does this always happen to me?" I know the sadness of brokenness. It's happened before; it will happen again, because the areas of her brain that connect cause and effect are permanently damaged. We can try to encourage her, try to help her make better choices, but there really is a kind of mental blindness operating within her. Whatever looks good or fun or interesting at the moment is the only thing she can see. Choices are often made without much reflection or consideration.

We have come to realize that we cannot rescue her, and we know that similar scenarios will probably occur many, many times in her life. Change comes slowly and unevenly for her. So we love her, encourage her, and allow her room to experience the consequences of her choices. Our daughter is not "successful" in the same ways that other young adults in their mid-twenties are. She doesn't hold a steady job, can't manage money very wisely, and gave birth to two children before marrying and then divorcing their father. But she loves and cares for her sons, and we are proud of her for that. It is not what we would have chosen for her, but there are

good things happening in her life, if we can remember to appreciate small steps of growth wherever they may be found.

But back to the video...

I appreciated the honest expressions of anger and pain that are found in the video, because they are part of the reality of living with FASD. I especially resonated with Karen, the adoptive mother of Ron, a young man living with FASD. At one point she reflects on her anger...

I was angry at everything; we were all angry at everything. And because we were angry, we isolated ourselves. Church, school, community—we were just angry. And I guess we were just angry, period, because this is not the way we expected life to be. We have this beautiful boy that we adopted as a beautiful baby, and he has so many positive qualities—why is everybody concentrating on the negative? Because then we have to concentrate on the negative because we have to try to correct this and it's not correcting, so are we doing something wrong? And of course then when that was backed up by people saying, "This kid just needs a good kick in the pants," or "this kid needs more discipline," or "this kid needs this," or "this kid needs that," that it just erodes your sense of self-esteem as a parent, too.

One of the big challenges of FASD is that it can be so hidden. It masquerades as "poor parenting," "lack of reasonable limits within the home," "spoiled child," "rigid parenting," and many other such hurtful assessments. Professionals who are not aware of possible FASD in a child or youth, or who are not willing to accept the significance of fetal alcohol exposure on a child's emotional, behavioral, and cognitive development can add to the damage, rather than help. Friends, family, even strangers in the grocery store often cause further pain in their attempts to be helpful.

Canada is ahead of the U.S. in naming, understanding, and offering services to individuals and families living with FASD. Even in Canada, however, it is much easier to get a diagnosis and appropriate services if the individual has fetal alcohol syndrome—with the facial features and other physical characteristics that make diagnosis more clear-cut. Without the full-blown syndrome, diagnosis cannot be made without documented evidence of maternal prenatal drinking. Since this requires acknowledgment of responsibility on the part of the mother, it is understandably rare. Unfortunately, the most challenging aspects of FASD are not the cognitive disabilities, but the behavioral issues—lack of impulse control, inability to understand cause and effect, and social disabilities. Parents are left struggling to understand if what is happening is caused by FASD, or if maybe what everyone says is true—they really are ineffective, poor parents. The lack of ability to get a firm diagnosis makes everything that much harder.

But the diagnosis itself is hard to live with, and harder still to speak. I find it hard to talk with my own children about, because in naming it, I am in essence acknowledging, "Your mother did this to you. She didn't do it intentionally or willfully, she didn't mean to cause you harm. But the reason you live with these challenges is because your mother drank, and the alcohol affected your brain development." So much regret, so much "would-that-it-had-not-been-so!" in the very name—fetal alcohol spectrum disorder.

Can't, Not Won't takes a good, though brief, look at the challenges that face individuals and families. A broad range of resources and strategies can be found at the following websites:

- National Organization on Fetal Alcohol Syndrome (<http://www.nofas.org>)
- FAS Community Resource Center (<http://www.come-over.to/FASCRC>)

Can't, Not Won't also addresses the role of congregations in welcoming, accepting and nurturing those who live with FASD. The congregations shown in the video are learning how to adapt their expectations and their teaching styles to accommodate different ways of understanding and having a relationship with God.

Much of what they have learned in their journeys with individuals and families with FASD could also hold true in relating with youth with ADHD and other disabilities or mental illnesses. One Sunday school teacher observes, "If you've told a child a thousand times and they still do not understand, then maybe it's not the child who's the slow learner." Making Sunday school lessons visual as well as auditory, allowing for movement, and learning to be sensitive to those for whom noise and excitement can be overwhelming are techniques that can benefit all youth, not just those with specific disabilities.

In addition to ADNet's FASD web pages (see below), further exploration of how the church can nurture and support individuals and families living with FASD can be found at the FASD resource homepage (<http://www.mcc.org/themes/04-05-fasd/index.html>) of MCC Canada. The links to stories, articles and resources contain a wealth of good information for pastors and congregations.

The greatest gift that the church has to offer individuals and families who live with FASD is respect. Respect is the acknowledgement that we are all children of God, all made in the image of God. Each of us is unique, and we each are unique mixtures of strength and sin, gift and need. A congregation that is willing to walk the journey, and learn the new and sometimes exhausting terrain of life with FASD, will also be blessed by the gifts that each individual has to offer.

The challenge that *Can't, Not Won't* offers to the Mennonite Church is my challenge as well.

- Be ready to see Jesus in each person, no matter who they are.
- Be ready to learn and grow in how you care for each other.
- Be ready to be stretched and sometimes torn, but also to be blessed.

Individuals and families who live with FASD desperately need the acceptance, nurture, and care the church can offer, and the church desperately needs the courage, enduring hope, and love we can offer. It is a long, hard journey, and God is glorified when we learn to walk it together.

This article can be found online with links on the ADNet Online website at http://www.adnetonline.org/Information/Topics/Fetal_Alcohol/FASD_Video



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