

FASD

growing into, not out of a lifelong disability

Second Chances for Everyone — Meet Chancer

By Donnie Kanter Winokur

Everyone said, “Don’t worry, he will outgrow that.” Your gut told you otherwise. Family members consoled you, “Oh, every boy acts like this at 4!” That’s not what you thought.

Friends offered, “That’s nothing! You should see my son.” While said with good intent, you are left feeling dismissed, unheard and invalidated, as well as still worried and no diagnosis in sight.

What’s going on?

Babies exposed to alcohol while in their mother’s womb may be born with fetal alcohol spectrum disorder, or FASD. FASDs are considered medical conditions, as well as developmental disabilities. Similar to the autism spectrum, FASDs range from mild to severe in their impact on an individual and family’s life. The effects are lifelong and may include physical, mental, behavioral and learning disabilities. Ninety percent of fetal alcohol-affected kids look just like your neighbor’s kids, until you spend time with them.

FASDs are “hidden” disabilities. The prevalence of FASD is nearly 1 out of 100 live births in the United States. Yet this serious disability is greatly misdiagnosed and only rarely recog-

nized for what it is. FASDs are often accompanied by other disorders, such as:

- Attention Deficit Hyperactive Disorder
- Obsessive-Compulsive Disorder
- Sensory Integration Disorder
- Oppositional Defiance Disorder

Average or above IQ disguises impaired intellectual disability, creating false impressions of capability. Because FASD is so unfamiliar, many kids go undiagnosed when early intervention can be so helpful.

The cultural stigma attached to alcohol prevents many doctors from informing their patients about the risks of drinking while pregnant. There is no known safe amount, time, or kind of alcohol that can be consumed during pregnancy. Although this disability is not curable, it is 100 percent preventable if a pregnant woman does not drink alcohol.

As a mom of a child with FASD, I advocate for my son every day. Through him, every aspect of our life is shaped with unique questions. We struggle to find answers.

What helps? Some people think that labels signify worth or value, and don’t want one attached to their children. Parents worry that their child will “stick out.” FASDs are an exception to most rules — even in the world of developmental disability. In my mind, as

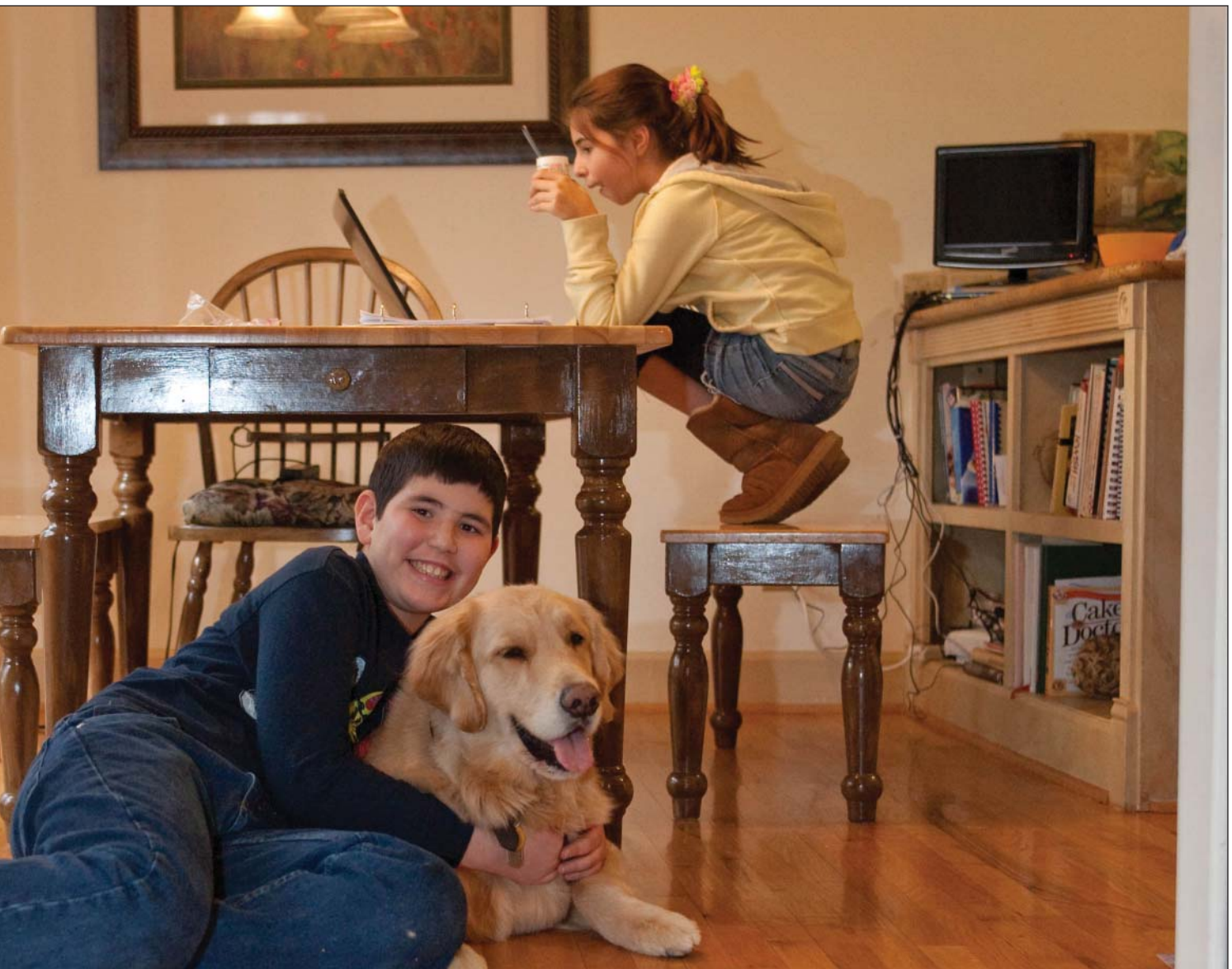


with apparel, a label of FASD tells others that my child needs to be “handled with care.”

Without the appropriate label, our kids are given plenty of others:

- Lazy
- Defiant
- Dumb
- Difficult

Because of cognitive impairment and an inability to understand cause and effect, our children can be dangerously vulnerable. Inclusion and mainstreaming may pres-



HUGGING his service dog, Chancer, is Iyal Winokur, while Iyal's sister, Morasha works on homework. Morasha, author of "My Invisible World" won 2010 Reader Views' Best Children's Book. Left, Iyal and Chancer work together. Since coming to their home, Chancer has helped Iyal overcome challenges caused by Fetal Alcohol Spectrum Disorder.



SERVICE DOG CHANCER has I made in impact on the Winokur family, helping Iyal, right, overcome some challenges of living with the effects of Fetal Alcohol Spectrum Disorder. Morasha, left, wrote the book, "My Invisible World" about dealing with her brother's disabilities.

ent unintended challenges. The need for an "external brain" to help guide those living with FASDs becomes paramount.

Sharing the truth allows others to support my son and strengthen his self-esteem. You can only empower your children when you are comfortable with your own reality.

There is never any shame in telling the truth. And that...lasts a lifetime.

Eventually our life became limited to what we could do as a family due to our son being easily overwhelmed or frustrated. And this influenced everyone until in 2008, an irresistible, rambunctious service dog named Chancer changed all that.

In all my research with interventions for FASDs I had not found any literature regarding assistance dogs trained for this disability.

As I learned how service dogs were taught to help children with autism, the more excited I became about the possibility of a dog learning to assist Iyal. My research landed me at 4 Paws for Ability. This service dog agency was the first to train dogs to assist children with autism among other disorders. Within 10 months we were blessed with an 85-pound, pure bred Golden Retriever — a best friend for Iyal.

Changes occurred in our household immediately.

"We noticed Iyal spending up to 30 minutes just lying on top of Chancer hanging out," says Iyal's dad. "Iyal will have his head on top of Chancer and the two of them will be quiet together. This is huge! Before having Chancer, when Iyal didn't know what to do with himself; while waiting for the next activity, he would run around the house out of control

and get increasingly irritated. Iyal was unable to stay calm by himself."

Similar to the ways in which a service dog assists an individual with autism, FASD service dogs provide support in a variety of environments, which result in improved communication and social skills.

The term "social lubrication" was developed by researchers, R. A. Mugford and I.G. McComiskey to describe the phenomenon where the presence of animals increased social interaction between people. Chancer helps to minimize social inappropriateness while boosting Iyal's self-confidence.

Perhaps the most profound unexpected change after obtaining Chancer was an emergence of language. Within two weeks after our training at 4 Paws, we noticed that Iyal began using multisyllabic words in

complex sentences. This was a significant difference in the way Iyal communicated prior to having Chancer. In addition, to using more sophisticated language, his words showed self-reflective thinking: a different sense of self emerged.

Iyal wanted Chancer to go with us everywhere. He is so proud of Chancer and tells other kids immediately that Chancer is his working dog. Other significant benefits that Chancer helped to develop in Iyal were:

- an advancement in abstract and concrete thinking
- improvement in focus
- an increase in the length of attention span

“We could never have anticipated this sort of transformation for Iyal.”

Enter the sister. Being the sibling of a child with special needs has unique challenges that often go unrecognized and unseen, especially when the disability itself is invisible. Our 11-year-old daughter, Morasha, wrote and published “My Invisible World: Life with my

brother, his disability and his service dog,” in 2009. Her book exposes those challenges to middle school students. It is a gentle, honest book that describes what many families face daily behind closed doors. While Chancer opens doors of acceptance and understand-

to national experts on the unique benefits of providing service dogs for children with FASDs and other developmental disabilities. Winokur has been a unique presence in Atlanta’s communications arena for more than 25 years, as a speaker, and award-winning producer,

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ing for Iyal, Morasha’s book introduces and affirms the realities of living with a brother who says unexpected things and behaves in surprising ways. Most of all, it sends a clear message that a sibling’s gifts can be revealed in the least likely places.

As a direct result of obtaining the first FASD Assistance Dog in North America for her son in early 2008, Donnie Kanter Winokur presents

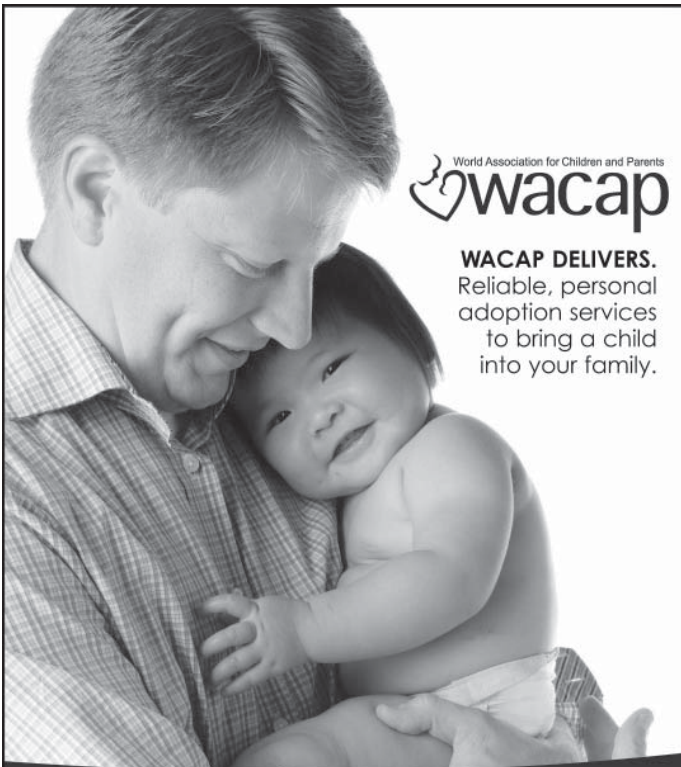
creative director and writer. This experience provides a creative insight into her work as a change-agent in the world of public health. She has now turned her focus to help raise awareness and prevent the devastating disorder that affects her son, her family and every community. To meet the Winokur family, visit www.TheChancerChronicles.com and to learn more about service dogs for persons with FASD, visit www.4pawsforability.org/FASDdogs.html.



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