

Catching a snowflake

A photo story of Asperger's Syndrome



Willie Rates at home, wearing his favorite hat

BY LEAH NASH
CONTRIBUTING PHOTOJOURNALIST

When you ask 11-year-old Willie Rates about life with Asperger's, he seems comfortable with his place in the world, both figuratively and literally.

"Well, you're indeed not usual, which I'm perfectly OK with," he tells me. "It's like I'm Portland unusual, or Los Angeles unusual."

A lover of ancient Egypt and Rome, dinosaurs and Playmobil figures, Willie will tell you that first and foremost he is a filmmaker, with 123 movies to his credit.

He lives in Southeast Portland with his mother Tobi, father Dale, and his 7-year-old brother Jacob, who is also on the autism spectrum. First tested for autism at age 4, Willie's path to a diagnosis hasn't been a straightforward one, "First we were told, 'we don't know what, but there is something going on there,'" says Dale, a musician. "And that turned into autism and that sort of started becoming Asperger's and then it became, 'who knows, he might just be a really unique guy.'"

After finding their way to the word Asperger's, both parents have mixed feelings about the planned elimination of the diagnosis by the American psychiatric industry (See accompanying sidebar, this page). His mother Tobi is a self-described "recovering" attorney who was recently named the executive director of the Autism Society of Oregon.

"My reaction is that it makes sense clinically, because right now the definition is so convoluted and ridiculous," Tobi says. "My concern is that it is a lot easier to hear a word like Asperger's than autism, and that if you have people who resist getting a diagnosis and getting support and treatment because they don't want to acknowledge

Regional Arts & Culture Council

This is the first in a special series on five individuals with Asperger's Syndrome as told through the lens of photographer Leah Nash. The project was made possible in partnership with the Regional Arts & Culture Council in an effort to chronicle the diversity of this complex diagnosis of autism, illustrating the challenges and beauty of an unconventional life.

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their autism, that's what I'm concerned about."

"It's just the way a word (autistic) can be taken," says Dale. "Language all too often conjures up images that may or may not really be true and so there's a lot of fear out there."

Regardless of the terms, Tobi offers advice for any parent dealing with a child who has been given a diagnosis.

"The main thing is, it's still your child. Nothing's changed. It's a challenge to deal with, but the main thing about any kid on the autism spectrum, or any person, really, is that everyone's different. It manifests differently. The saying is, and it's really true, 'If you've met one autistic person, you've met one autistic person.' So our experience isn't going to be the same as anyone else's. These are great kids – fun, interesting, wonderful, quirky, creative..." she pauses and smiles, "...and sometimes incredibly annoying, children!"

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From November 18th until December 23rd, Street Roots will run a weekly photographic series documenting the lives of five people with Asperger's Syndrome, a form of high-functioning autism.

Autism is the fastest growing disability in the U.S. with an economic impact of more than \$90 billion. The Center for Disease Control reports that now one in 110 children are being classified with autism spectrum disorders, compared to one in 10,000 in the 1970s, and according to the Autism Society of Oregon, our state has one of the highest rates of autistic diagnosis in the country.

First documented in 1944, many with Asperger's Syndrome can be quite gifted, but are often socially awkward and unable to make friends. Frequently misunderstood, those affected live in a world of missed social cues and difficult exchanges. Called "little professors" by their namesake, Hans Asperger, who noted their talent of acquiring expertise in specific topics. Those with the syndrome usually want to fit in and have interactions; they simply don't know how.

The objective of this series is to explore the diversity and complexity that exists across this spectrum, for it is often said that people with autism are like snowflakes – no two alike. This work is especially relevant given controversial revisions proposing to do away with the Asperger's diagnosis altogether in the Diagnostic and Statistical Manual of Mental Disorders (DSM), the diagnostic encyclopedia of American psychiatry.

As history changes, a record must be kept, these stories must be told. Through the support of Street Roots and the Regional Arts & Culture Council, the goal of this series is to encourage viewers to question their perceptions of both Asperger's and autism and challenge themselves to gain a deeper understanding of the people behind the label. Each week we will profile a different person affected by Asperger's Syndrome. This series can be found in the next three editions of Street Roots, with two additional people featured online with audio interviews and a photographic slideshows at streetroots.wordpress.com. Next week, online, we will feature the story and narrative of 22-year-old Anna Bauer, a young woman with unusual interests.

Please join us as we give a voice to those that often have none.

Leah Nash is a documentary photographer based in Portland. More of her work can be found at www.LeahNash.com.

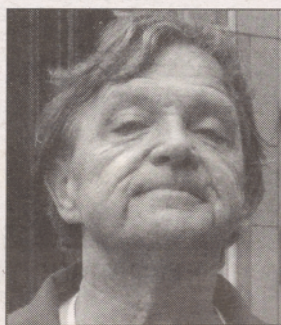
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