



pafc

PACIFIC AUTISM FAMILY CENTRE

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BUILDING POTENTIAL FOR A BRIGHTER FUTURE

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Copy written by Kristen Ross



PACIFIC AUTISM FAMILY CENTRE

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AT FIRST, WE DIDN'T WANT TO BUY INTO THE
DIAGNOSIS. PEOPLE SAID, 'OH, HE'S JUST A LITTLE
SLOW.' BUT YOU QUICKLY REALIZE THE MAGNITUDE
OF WHAT YOU'RE FACING, AND THEN YOU NEED
SOMEWHERE TO TURN...YOU DON'T KNOW WHERE
TO FIND THE RESOURCES.

— John, Parent





ASD affects boys
more than 5 times
as often as girls.

.....

1 IN 42
BOYS
HAVE ASD.

1 ILLUMINATING THE DARKNESS

Over a century ago, the term “autism” was coined by psychiatrist Eugen Bleuler to describe schizophrenic patients who had severely withdrawn into their own world.

In the 1940’s, psychiatrists Leo Kanner in America and Hans Asperger in Austria noted similar behavioural “disturbances” in case studies of children. They included crippling anxiety, an inability to connect with others, and a tendency to withdraw from the world. It was these children who became our first real accounts of autism.

Since then, we’ve certainly advanced at detecting autism, yet definitive causes remain a mystery. From one in 2,000 children diagnosed in the 1970’s, the Centre for Disease Control and Prevention reports that one in 66 children can now expect a diagnosis of autism. That makes 67,000 people with autism in BC alone according to the Ministry of Children and Families in BC. Autism strikes consistently around the globe, and in all socioeconomic, racial, and ethnic groups equally. Autism is not partial.

There are few conditions as complex or misunderstood as Autism Spectrum Disorder (ASD). A developmental disorder, ASD is usually discovered in early childhood when a child either doesn’t respond to social cues, or fails to begin speaking. One mother described the early warning signs her son exhibited. “He

“**EVEN THE MOST AFFLUENT, KNOWLEDGEABLE AND SAVVY PARENTS CAN END UP INSULAR, EXHAUSTED, DESPERATE, AND ISOLATED FROM THE WORLD. BUT FOR FAMILIES WITHOUT RESOURCES...THE SITUATION CAN BE EVEN MORE CHALLENGING.**”

— Sharon Baxter, Applied Behavioral Analysis Specialist

didn’t like making eye contact, but would often stare for hours at a single object. We tried everything to coax words out of him, but nothing worked. He’s five now and still doesn’t speak.”

There was a time early on when many people believed that ASD was a psychological condition. Today, we know it’s a neurological disorder affecting the brain in four primary areas: language and communication, social skills, sensory systems, and behaviour. But every person with ASD will experience their symptoms to varying degrees, often in wildly different severities. This enormous range is why it became known as a “spectrum disorder.”

While it’s possible that someone on the higher functioning end of the spectrum could go on to earn a PhD, others remain non-verbal, at risk for self-injury, and need 24-hour care. Wherever they exist along the spectrum, all will need intervention, therapy, and support, many throughout their lives.

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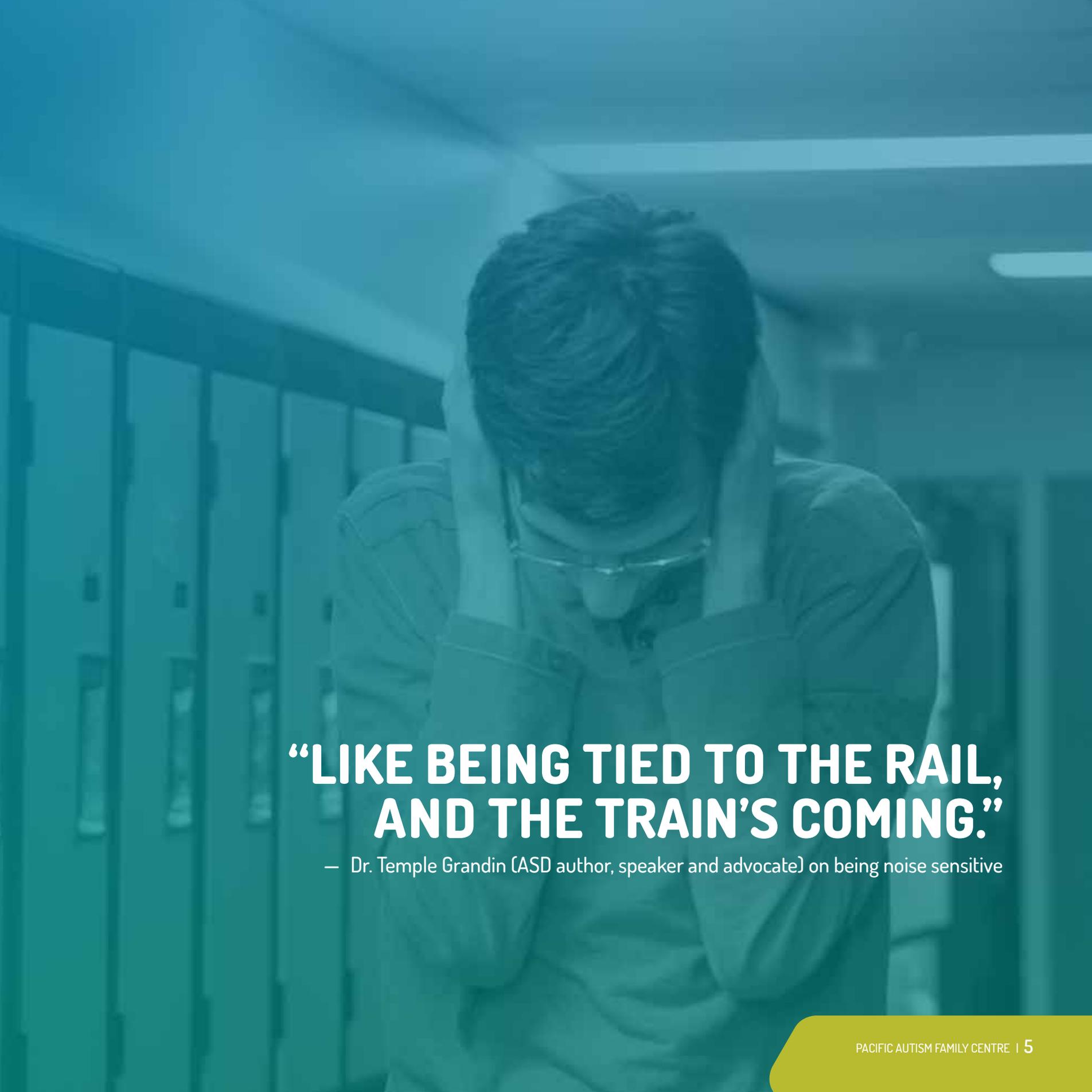
To appreciate the scope of how many people are affected, directly and indirectly, we must first look at the families caring for family members living with ASD.

Families with children with ASD suffer the burden of a condition that is both misunderstood, and for which there are precious few resources to help them. It is not uncommon for families to lose everything they own in search of treatment. Recently, a University of Calgary study calculated the lifetime costs for care and lost productivity will exceed \$5.5 million per child. These are the things we can calculate – but there are plenty of other costs the numbers can't capture.

Emotionally, the strain of looking after a child with ASD can be agonizing. The lack of adequate care usually means that the parents are primary caregivers, and play the role of both parent and therapist. Many parents burn out under the strain and marriages often break up. Those with other children struggle to provide them with a normal life when most of their attention is saturated by the child with ASD. But what about the child who is trapped inside a mind affected by autism?

**PEOPLE WITH AUTISM
MAY EXPERIENCE MILD
TO DEBILITATING SENSORY
HYPERSENSITIVITY.**

MANY HAVE PROFOUND SKIN SENSITIVITY; OTHERS FIND SOUNDS, TOUCH, TASTE, SMELLS, LIGHTS, OR EVEN COLOURS PAINFUL. IT'S AS IF ALL THEIR SENSES HAVE BEEN DIALED UP TO MAXIMUM CAPACITY.

A photograph of a person in a locker room, covering their ears with their hands. The image is overlaid with a teal color filter. The person is wearing a light-colored shirt and glasses. The background shows rows of lockers and a hallway.

**“LIKE BEING TIED TO THE RAIL,
AND THE TRAIN’S COMING.”**

— Dr. Temple Grandin (ASD author, speaker and advocate) on being noise sensitive



PEOPLE WITH ASD MAY BE
“DIFFERENT” FROM THE NORM,
BUT THEIR UNIQUE WAY OF
EXPRESSING THEMSELVES IS
A DIRECT EXTENSION OF THE
HUMAN MIND AND SPIRIT.

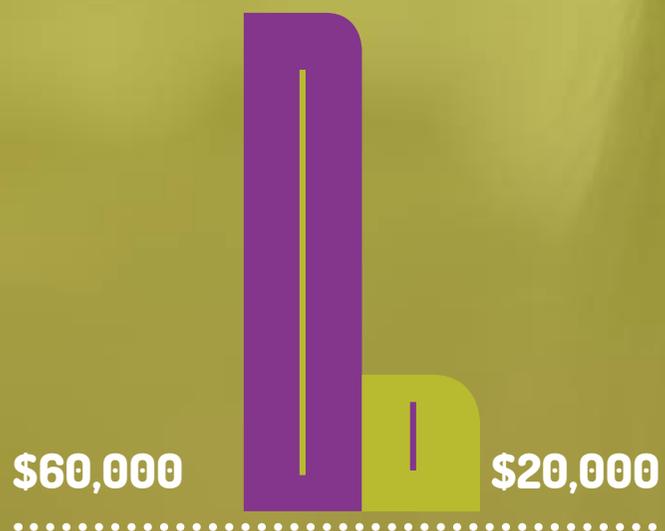
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The child with ASD with few resources grows up to be an adult with even fewer choices. Without proper behavioural therapy, the dream of getting an education, holding down a job, or simply having a close friend becomes a distant fantasy. They are ostracized and cut off from a world they already struggle to understand, and society loses as well.

People with ASD who go without therapy are at high risk of becoming homeless or entering the penal system, and their socially naïve tendencies make them vulnerable targets. But perhaps most of all, we stand to inhibit or lose the potential achievements and contributions of our future citizenry. We must abandon the notion that because people with ASD think differently, they have nothing to contribute. Individuals with autism have been shown to be highly creative, and in the case of higher functioning ASD, of above average intelligence. People with ASD may be “different” from the norm, but their unique way of expressing themselves is a direct extension of the human mind and spirit.

FINANCIAL NEED COMPARED TO GOVERNMENT SUPPORT

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THE STATUS QUO IS A DISASTER

.....
In the case of ASD, half the battle is often getting the diagnosis to begin with.

Sometimes that means the child was misdiagnosed, but more often than not it's due to a system plagued with obstacles and delays. In BC, most communities don't have adequate resources to provide an autism diagnosis. This means many families must travel, sometimes great distances, to find medical help. When they do, assessment appointments can take months, even years to book in advance. The average provincial wait lists for diagnosis in BC can be up to nine – 12 months. There is no "central station" to turn to for guidance navigating the system. Many children fall through the cracks, and therefore lose the benefits of early intervention. One parent described the process like falling down a rabbit hole with no way out.

The BC government provides all children with ASD foundational services and funding. Families of children under age six have access to \$22,000 per year, and families of children ages six through 18 have access to \$6,000 annually for out of school services. This number may seem big, but a comprehensive early intervention program can cost as much as \$60,000 per year. More shocking still is that designing the treatment program is left completely up to the parents. Most parents are completely bewildered on where to even start designing a therapy program for their child. Most cobble together a program based on whatever "research" they've done independently. Many families have already lost all or a significant portion of their resources trying to deal with this. They simply can't afford effective treatment.

“
THE DIFFERENCE BETWEEN THE AUTISM SERVICES NEEDED AND THOSE AVAILABLE IS LIKE... WALKING INTO A CAR SHOWROOM WITH \$30,000 TO BUY A CAR, AND BEING SHOWN TO THE PARTS DEPARTMENT WITH \$10,000 AND BEING TOLD TO DESIGN AND BUILD YOUR CAR.”

— **Chris McIntosh**, Adult with Asperger's & PAFC Steering Committee member

.....

While there are many people with ASD who go on to enjoy successful lives and careers, those on the more severe end of the spectrum are at even greater risk after age 19.

The help stops there and they hit the wall in BC. There is virtually no support for them to get into post-secondary education or the workforce. Once again, families are left to their own devices and do their best to care for an adult who is incapable of being independent. Without financial or emotional assistance, this responsibility usually remains solely the parents'. There is no organized relief.

With the meteoric rise of ASD in the last 35 years, society will not have the luxury of turning a blind eye for much longer. There are simply too many people who need proper care to ignore. What is perhaps most tragic about the situation is that many treatments for autism do exist; we just don't have the facilities or the manpower to provide them, especially in a province as geographically large as BC. One of the most concrete examples is the drought of specialists trained in Applied Behavioral Analysis, largely accepted as the most successful type of autism therapy. Today, there are more than 8,500 children needing services in BC and only a few hundred properly qualified specialists trying to serve them.

“
YOU FEEL SO HELPLESS — IT'S REALLY, REALLY LONELY. OUR SON WAS VERY ANXIOUS...JUST INCONSOLABLY MELTED DOWN ALL THE TIME — THEY JUST CAN'T FUNCTION AND REASON THE WAY OTHER KIDS DO. A LOT OF THESE KIDS NEVER HAVE A REAL FRIEND AND ARE THE BUTT OF JUDGEMENT ALL THEIR LIVES. **WHAT HAPPENS WHEN THEY'RE OUT THERE IN THE WORLD AS ADULTS AND NO ONE IS THERE TO PROTECT THEM?**

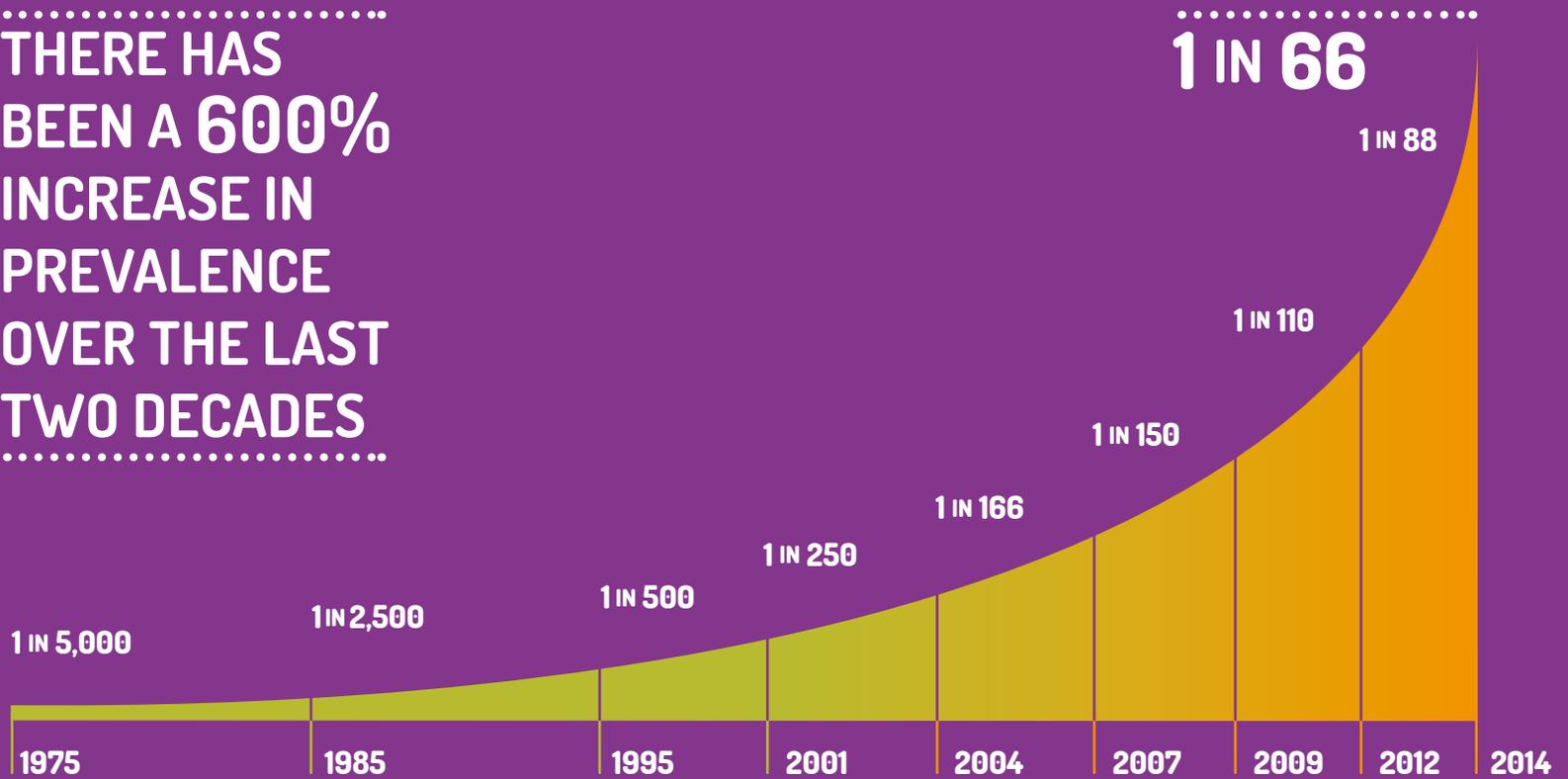
— William, Parent ”





“ NUMBER OF PEOPLE WITH ASD RISING. NUMBER OF SPECIALISTS TRAINING TO HELP GOING DOWN. ”

.....
THERE HAS BEEN A 600% INCREASE IN PREVALENCE OVER THE LAST TWO DECADES
.....





3 AN AMAZING CHANGE IS STARTING TO HAPPEN RIGHT HERE IN BC.

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Many great achievements were born of necessity. The Pacific Autism Family Centre (PAFC) has recognized the tremendous need for a facility of its kind in BC, and is acting quickly to make it a reality.

In the last few years, BC has quietly begun to emerge as a hub for research and innovation in autism. An existing network of innovative programs for children with special needs, and a highly talented pool of researchers and practitioners provide solid legs for a centre like this to be built on. PAFC recognizes the necessity of comprehensive treatment programs for ASD. This point cannot be stressed enough. Every person is unique, and therefore every treatment must be

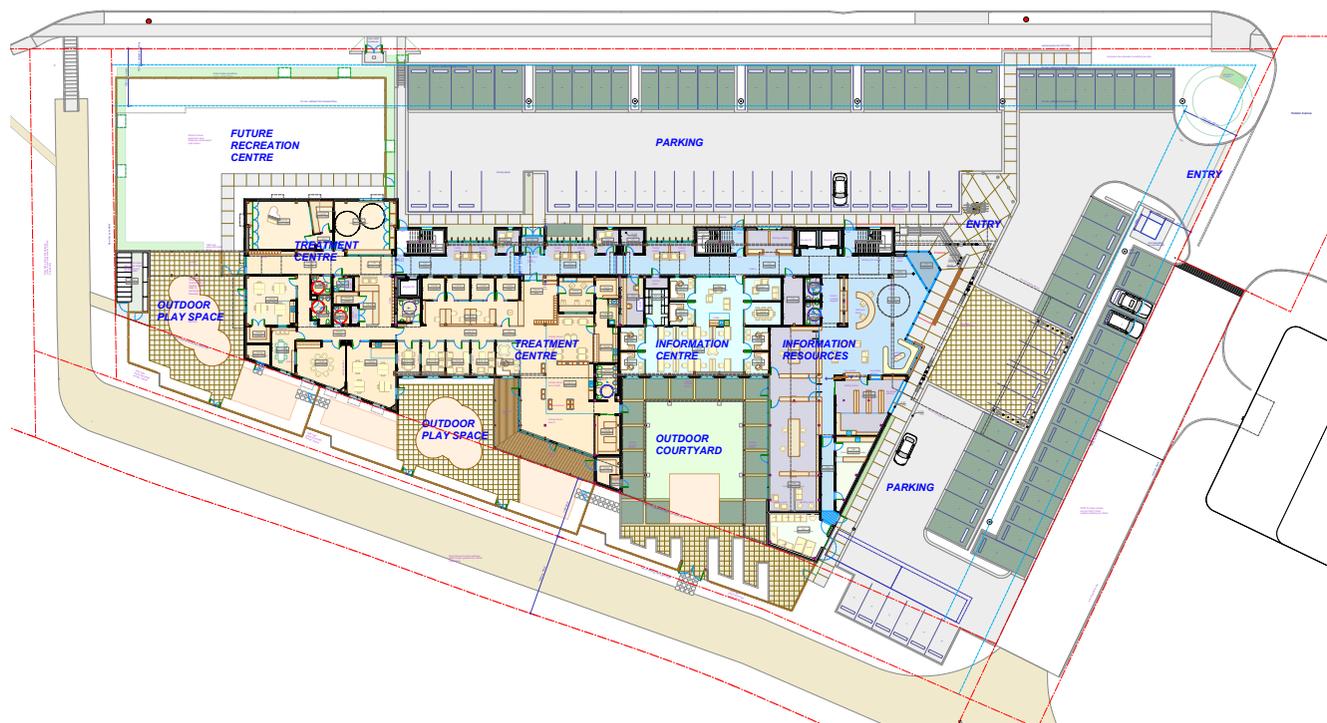
BECAUSE AUTISM IS SUCH A COMPLEX DISORDER...IT'S NOT SOMETHING THAT CAN BE ADDRESSED WITHIN THE SINGULAR SILOS OF MEDICINE, EDUCATION, RESEARCH, PSYCHOLOGY, OR SOCIAL WORK. THAT'S WHY GOVERNMENTS FACE SUCH CHALLENGES CONCEPTUALIZING HOW TO DEVELOP AN EFFECTIVE AND INTEGRATED SYSTEM TO TREAT AND MANAGE IT.

equally unique. This “central station” will integrate, provide, and build capacity for a wide range of medical and social supports, home therapy, schooling, psychological counselling, emotional support programs, diet, and nutrition, as the fundamental building blocks of this multidisciplinary resource centre for families. The centre will collaborate, work with, learn from, and support agencies providing services to those impacted by autism. It will work to turn a fractured system of services into a cohesive network of support throughout the province. It will ensure treatments that we know are effective move from labs to the homes of ordinary families at an affordable cost.





PACIFIC AUTISM FAMILY CENTRE

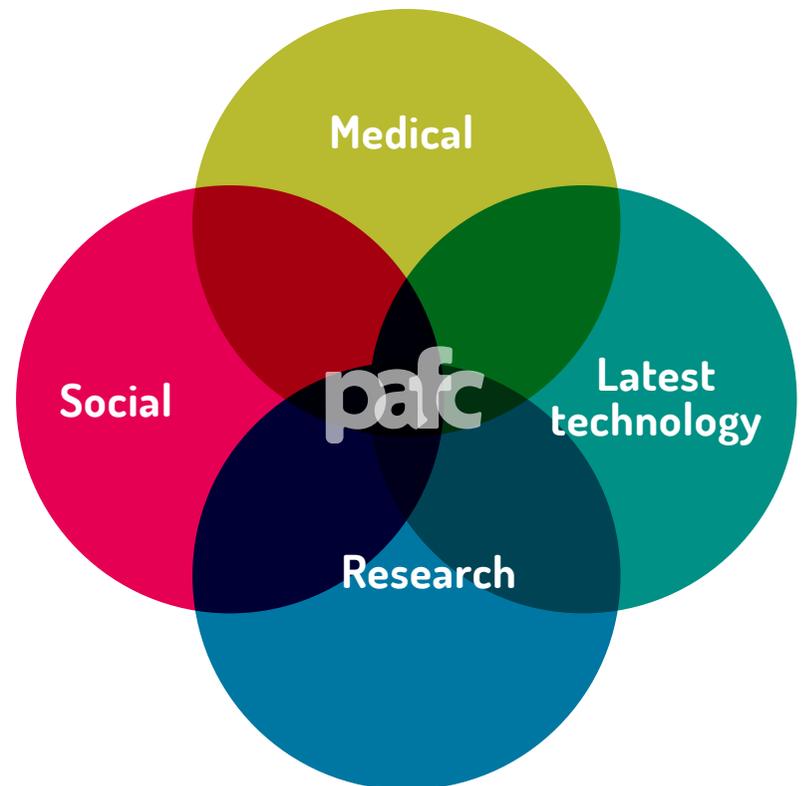


4 A NEW FRONTIER, RIGHT HERE, RIGHT NOW.

In addition to the medical and social programs PAFC plans to foster, the centre will be truly interdisciplinary.

Providing a strong platform for the latest technology, research, information sharing, and outreach, PAFC will support visionary research on the frontiers of modern ASD science. It will attract some of the top researchers and practitioners in the field; the best and the brightest working side-by-side in advances in genetics, neuroscience, earlier diagnosis, brain plasticity, and intervention.

The BC government has recognized PAFC with a \$20 million contribution, funding the Pacific Autism Centre in Richmond, BC and spoke centres around the province. PAFC is poised to become a global model for how communities everywhere will one day think about, manage, and address the ASD crisis.



A scientist in a white lab coat is working in a laboratory, holding a test tube. The background shows laboratory equipment and shelves. The image has a yellowish tint.

**PAFC WILL BE A HOME FOR
FAMILIES, RESEARCHERS,
FUNDRAISERS, TEACHERS,
MEDICAL STUDENTS,
GOVERNMENTS, EDUCATION
ASSISTANTS, SOCIAL
WORKERS, PSYCHOLOGISTS,
AND PEOPLE ON THE SPECTRUM TO
GAIN A SENSE THAT NEW SOLUTIONS
ARE WITHIN OUR GRASP.**

“
PAFC WILL BE A KIND
OF ‘MAYO CLINIC’ FOR
RESEARCHERS.
IT WILL BE A PLACE WHERE
RESEARCHERS AND CLINICIANS
HAVE THE OPPORTUNITY TO COME
TOGETHER...AND SHARE THEIR
FINDINGS ON A DAILY BASIS WITH
INDIVIDUALS AND FAMILIES...AS
WELL AS HAVING ACCESS TO THE
INFORMAL KNOWLEDGE NETWORKS
THAT COME FROM BEING IN TOUCH
WITH OTHER FAMILIES IN SIMILAR
CIRCUMSTANCES. ”

— **Dr. Suzanne Lewis**, Senior Clinician Scientist,
CFRI & Director of the Autism Spectrum Interdisciplinary
Research (ASPIRE) Program







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**TO SAY THIS IS A LEGACY
OPPORTUNITY IS AN
UNDERSTATEMENT.**

**THIS IS WHERE HISTORY OF AUTISM SPECTRUM
DISORDER WILL BE REWRITTEN.**

.....

5 WRITING THE NEXT CHAPTER

Just fifty or sixty years ago, a diagnosis of autism often meant being institutionalized.

To think of how much the world lost by writing these people off – the potential they may have reached with proper intervention and treatment. We can't rewrite that story, but we can begin the next chapter.

Early intervention has the most success, but learning is a continuum for people wherever they are along the spectrum. Research has moved from psychology to neurology and genetics, and neuroimaging advances in recent years have made fundamental strides in our understanding of ASD. With intervention and treatment, we now can help all people with ASD reach their individual potential – whether that be graduating high school, learning to be verbal, or earning a PhD. We want tangible results that better lives.

The sea change begins with you. We do not know why the number of people in BC affected is so large, but we do know it has spurred a rejection of the virtually random ways of helping families through it.

The need for a new centre was identified here and the movement to make it real has picked up momentum and support from government, the medical profession, families that have been personally impacted, and visionary individuals who know that this is the time to make real

progress in prevention, treatment, and ongoing elevation of skills and quality of life for people along the spectrum.

Here's where you come in. With the construction of the new centre comes opportunities for naming of the new hub and spokes, specific facilities within it, and programs that will run in it. Although based in Richmond, the new centre will be a hub, with spokes evolving across the province and perhaps across the country over time.

WE NEED YOUR VISION, DRIVE, AND RESOURCES TO MAKE IT HAPPEN AS SOON AS POSSIBLE.

TO SAY THIS IS A LEGACY OPPORTUNITY IS AN UNDERSTATEMENT. THIS IS WHERE THE HISTORY OF AUTISM SPECTRUM DISORDER WILL BE REWRITTEN.



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