

Been There. Done That. Finally Getting it Right.

Developing Authentic Individual Education Plans for Students with Autism

Lessons from a Mother and Teacher

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To my students,

I dedicate this book to all my students with autism -you have been so patient with me as I continue to learn from you. I did not choose this journey and yet, my life is so rich and rewarding because each of you has journeyed with me and taught me more than I can ever teach you. I love each and every one of you.

To my family,

Karli, Kieran and Kaiya, each of you have lived with me being 'present but not really there' as the pages of this book unfolded. Thank you for reminding me to get my head out of the book! I love each of you beyond words; you give me purpose and joy. You are deeply loved and appreciated.

Kieran, you allow me to open your life and experiences up to the readers so that others may find hope and reassurance. You are a gift to our family and to the world. We love you.

My husband, Ivars, you are my partner and my best friend. You encourage me to be all that I can be and together we have made a difference. I love you.

Jenn
(aka: Mrs. K., and Mom)

Who is Jennifer Krumins?

Each child's birth changes the face of the world and brings with it new hope and a fresh beginning. Never could I have imagined what gifts my children would bring to my life: passion, clarity, and purpose. But life also has a way of delivering the greatest gifts wrapped in the disguise of grief. When our second child was diagnosed with severe autism our life as we knew it (and planned it) changed dramatically.

Our own son and the students that I have had the privilege of teaching have made me take a hard look at what I value and what I believe about purpose and fulfillment in life. They have collectively taught me that getting ahead doesn't bring happiness but looking into the eyes of a child that finally conquers a skill...now that is pure joy! My kids have taught me to really tune into my senses; truly feel the sun on my skin and the smell of a spring day. My kids have taught me to slow down and really look at even the most insignificant things in life and see their glory. I have learned that our productivity doesn't make us loveable; we already are. Our purpose in life isn't about financial gain and material prosperity; it is about accepting ourselves and being at peace with who we are; living our lives for the sake of bringing some peace and happiness to others. My kids with autism have taught me more than I could hope to teach them.

Raising a child with autism has taught my husband of 22 years and me the most important lessons in life: present difficulties are defined by our attitudes far more than by the challenging circumstances; stay optimistic, build relationships whenever possible and rely on your faith.

Riding the tidal wave of autism is a voyage of a life time but the rewards are profound and immeasurable. This is not to diminish in any way the heart - wrenching, exhaustive and heartbreaking nature of autism but we refused to look at it that way. Even through the tears, we knew that our son was here to teach us something. Individuals with autism have gifts that they bring to the world. Sadly, the world doesn't always recognize these treasures.

My husband and I have 3 children: two daughters aged 20 and 12 and our son who is 18 years old. Teaching in Ontario, Canada for 23 years has equipped me with vast experience in all kinds of learning differences and challenging learning difficulties. But none would compare with teaching my own son both in the general classroom (for two years) and in private therapy at home. It was these experiences that both drained me emotionally and inspired me professionally. Being the teacher and the mom brought me face to face with my own teaching philosophy and my teaching practices. Living on both sides of a child's education taught me many lessons in advocacy. The critical role of building relationships,

compromise and empathy became crystal clear as I sat in both the teacher and parent role.

I earned Masters of Education in Human Development and Applied Psychology at the Ontario Institute for Studies in Education. Raising a son with autism motivated me to obtain a Special Education Specialist and to train extensively at Queen's University in Kingston, Ontario and the Geneva Centre for Autism in Toronto, Ontario. I had the privilege of working in a private therapy program for my son under the guidance and direction of the Behaviour Institute in Hamilton, Ontario. But most importantly, I have been privileged to work with students with autism that have given me the best education imaginable.

I have been blessed with a family and a career that have enriched my life and made me who I am today. I want to share what I have learned and do my part to open the doors for students that have autism, their teachers and their parents. I want to facilitate collaboration, teamwork and mutual understanding in the education of our children. It is my belief that Autism has the potential to create more compassionate communities and families if we accept the challenge of working together to recognize the strengths, develop weaknesses and celebrate the diversity of autistic minds.

Welcome to the journey! You are not alone. ☺

Jenn

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Important: Read This First

It's only fair that I be honest right from the start. I don't enjoy creating individual education plans. I have a hard time deciding what goals to choose, especially when a student's needs are high. I want to do it all and be all I can for the student who needs me most. I hate how scripted and hemmed in I feel by IEPs - always striving to be clear and concise while incorporating the correct terminology and prescribed components. Frustration grips me at times when I am trying to transform ideas into meaningful SMART goals. Instinct about what I really want for a student clashes with the question of how I can put that knowledge into a well written goal and subsequent objectives. I especially hate trying to decide how I will measure the goal! I find writing individual education plans tiring and mind bending at times.

You might think that having researched IEPs for years, written books and consulted in the development of them, I would hold some perverse pleasure in the documents. No, quite the opposite; the more I learn, the more I confound my own ability to create a simple and authentic product. Lurking in the shadows of my awareness is the suspicion that no one will really even look at the IEP when it is complete. Does anyone actually pore over it and integrate its ideas into daily practice? I cringe considering the answer.

Despite my feelings, I must concede that the core of my beliefs as an educator center on individualizing education based on the unique qualities of each student. Long ago, the concept of cookie cutter teaching was replaced by reality. In addition, when I strip away all the reasons I entered the profession: my love for talking and for kids, the weird excitement I feel when I am in a teacher supply

store, the challenge of making tough concepts understandable and - the holidays, I am left with something big inside of me. Something that often gets obscured by the craziness of the daily demands.

In the essence of who I am there lies an unchanging, profound desire to make someone feel good about themselves. Twenty some years of teaching has not changed this deep drive within me. There is simply no better feeling in the world than to be a part of facilitating growth in an individual of any age. Even the crappiest of days can be transformed by one small moment when a student looks into my eyes and I witness the unmistakable glow that proclaims, "I get it!" This declaration reflects the deeper and unspoken thrill of the words, "I *am* smart!"

When we allow ourselves to dream with and for the child, we create far more than a legal document, but a roadmap of the best travel plans we can conceive.

So what does this have to do with an individual education plan? Everything. An IEP will only be as valuable to the degree that it reflects a genuine desire to help a child be his/her best self. Let's be clear, and maybe a little harsh: if you are going to view the IEP as a formal hoop completed with as little time, energy and enthusiasm as possible, in order to appease some external force, then I suggest the final product will indeed be quite uninspiring. It will be done. You will have fulfilled your duty. But, you will have missed an opportunity to transcend the drudgery.

An individual education plan gives us an occasion to use the gifts that brought us to a career in education: creating a vision for another person's life, thinking through the steps of getting there, and finally, crafting activities and strategies to facilitate growth towards the vision. Without meaning to diminish our role as teachers, many students will have the intellect and skills to achieve their goals with minimal direct intervention from us. But, as you are well aware, there are students who need our skills, our creativity and our compassion more than others in order to grow towards their potential.

IEPs can make a difference when they are viewed with a growth mindset: the core belief that intelligence and abilities can be developed (Dweck, 2007). Personal growth in ourselves and in our students is not only possible but expected. When we allow ourselves to dream with and for the child, we create far more than a legal document, but a roadmap of the best travel plans we can conceive. And we begin the journey one small step at a time.

The fact that you have chosen to read this book tells me that you and I share a passion for educating children and facilitating the growth of human potential. If by chance you were coerced into reading this, I am sorry. It will not be a gripping, page turner. But, if you can keep an open mind and hold a student you care about in your mind's eye, it just may help you to grow as an educator. My hope is that somehow through reading this book you will feel less alone, more competent and empowered to be the best educator you can be.



We should not live in the clouds, on a superficial level. We should dedicate ourselves to understanding our brothers and sisters.

Mother Teresa

Welcome to a New School Year!

It's the end of summer. For parents, students and teachers alike, this month brings with it the excitement of a new year and a fresh start as well as the anxiety and concern of the unknown. Parents may question: Who will be the teacher? Will he know and understand autism? Will my thoughts and concerns be heard and valued? Students may wonder: Will the teacher like me? Will I be able to succeed? And teachers may worry: Will I be able to reach this child? Will I have the support of the parent? Will I have a team to help me or will I be on my own? The angst of a new year is felt by everyone involved and sleepless nights are common as summer winds down!

But, on the other hand, there is a renewed hope for a new year. The success of a new year has everything to do with how each person involved approaches it. Parents, teachers and professionals have a fresh chance to embrace a team mentality. Together the team can raise the child to new heights when each person adopts a 'growth mindset' both for the student and the adults working for the student.

The road on this journey will be challenging: assumptions, strong emotions and miscommunications are to be expected. We, as teachers and parents, are going

to have to actively listen with the intent to understand, the ideas and perspectives of others. Parents bring a keen knowledge of their child, but, they are too often left on the sidelines - watching others plan for their child. Teachers bring years of experience teaching many children (sometimes thousands) as well as professional training in a variety of pedagogical approaches. We cannot discount their perspective.

If we want to implement a plan that will bring the student's Individual Education Plan to life every single day in the classroom, each one of us will need to use our skills as problem solvers, analyzers, organizers and team players! There is no place for personal agendas and ego. Educational planning for a child with Autism Spectrum Disorder must be authentic rather than generic; it must be ongoing rather than static; and it must reflect the individual's abilities and disabilities as well as the curriculum requirements. When we keep the plan individual, relevant and dynamic we are well on the way to making this school year a success!



Every child deserves a champion – an adult who will never give up on them, who understands the power of connection and insists that they become the best that they can possibly be.

Rita Pierson

What Does Autism Spectrum Disorder Look Like in the Classroom?

Autism is a life-long, complex developmental disorder resulting from neurological differences in the functioning of the brain. These differences have a profound impact on the way a child thinks, behaves, communicates, learns and relates to the people in his or her life and the environment. Each and every child presents a unique expression of symptoms that often change over time. Sometimes, symptoms will manifest differently on a given day! As non-medical as it sounds, some individuals seem to have days where they seem 'more autistic' than on other days! Every parent of a child with autism knows that some days their children are more "off" and harder to figure out than other days. To be fair, it is often *our* lack of organization or planning that creates a 'more autistic day!'"

To complicate matters further, individuals with autism often exhibit 'splinter skills:' a child may show above average intelligence in one area and below average in another domain. For example, a child might not respond when you ask his name

but he will count to a hundred with little difficulty. Or a student may be able to compute complex mathematical equations and yet struggle immensely with making a prediction in a narrative story.

Autism is not always visibly noticeable, especially in those individuals that have advanced language skills and a more social nature. Metaphorically, autism is much like an iceberg: some children will exhibit odd behaviour, difficulty with speech and/or social interactions, but, these are just the 'tip of the iceberg.' Issues with thinking, verbal/ non- verbal communication, executive function, anxiety and sensory integration often hide beneath the 'surface' but have the potential to wreak havoc on the individual's overt functioning. Sometimes it isn't until we ask the student to choose a topic to write about, work in a group or play with peers that autism becomes more glaring.

It is inaccurate to judge the severity of an individual's autism based on what we see or fail to see. Sometimes the most 'typical' looking kid lives with some very challenging and invisible autism traits. At the same time, a student may appear to be very 'low functioning' and yet harbor hidden capabilities. Appearances can be brutally deceiving when it comes to autism. The range in severity, complexity and the changing nature of autism makes parenting and teaching these individuals both exhilarating and perplexing!

Our own son is one of those kids whose looks are deceiving: A bright, articulate boy with a brain that is significantly impacted by autism. When people meet him, many assume he has a very mild case of autism. (For the record, never, never, say that to parent of a child with special needs!) He is sociable, affectionate, and articulate. But, Kieran's walk to school may serve to illustrate the impact of autistic thinking on a kid who is very intelligent and does not 'look' autistic.

One morning my husband agreed to allow our son, aged 10, to walk to school rather than take the school bus. The school was a 15 minute walk straight north on the same street so my husband agreed to forego the usual 'practice sessions' (priming) that Kieran would typically do before he performed a skill independently. A few minutes after Kieran left home, my husband left in his car to secretly 'shadow' Kieran's walk.

Much to his surprise, our boy was nowhere in sight! Stomach in his throat, Ivars began scouring the neighborhoods. Within a matter of minutes, Kieran was spotted - walking in a westward direction! Rolling down the car window and attempting to sound nonchalant, Ivars inquired as to where he was headed. Peering into the window with a perplexed look, Kieran gave a strikingly logical response: he was headed towards school, going exactly where the bus goes!

Ah, those are the moments when parents are once again reminded that autism has a sneaky way of influencing one's thought process! Our son's thinking was quite logical, but not very efficient. In fact, it may have added an hour or more to his 15 minute walk! Yes, even the most high- functioning, even-mannered individuals can be quite impacted in their thinking. Teachers need to be especially vigilant when assuming that a student is capable of higher level

thinking and age appropriate behaviour because that may not be the case and - it certainly is not the child's fault!



Autism: A Closer Look

Before we get into the 'nitty gritty' of what autism might look like in your classroom, I feel compelled to remind the reader that our kids with autism do not come to school to be cured. Autism is not a problem to be fixed. We are not called to be miracle workers or clinicians. Rather, our role is to identify and build on individual abilities and to teach skills that will facilitate autonomy, independence and self-esteem. Like all children, students with autism need their parents and teachers to teach them how to use their strengths in order to build bridges for their weaknesses and to grow to be more independent and autonomous. If we bring a deficit mentality of autism to our teaching we will certainly be overwhelmed in no time. If we are looking for a clear cut, 'one size fits all' educational solution for teaching a student with autism we might as well save our energy. Efforts we put into learning as much as possible about each individual child with autism and planning for that child based on his own interests, needs, and strengths will deliver more benefit for both teacher and student. Please don't ever forget that students with autism **will** progress when programs, resources and goals are matched to their unique needs and strengths.



Students with autism WILL progress when programs, resources and goals are matched to their unique needs and strengths.

The Diagnostic Definition of Autism

In spite of the complex nature of Autism, the Diagnostic Statistical Manual – V outlines two areas of impairment for the diagnosis of Autism Spectrum Disorder.

Our kids with autism do not come to school to be cured. Autism is not a problem to be fixed.

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

- Deficits in social-emotional reciprocity
- Deficits in nonverbal communicative behaviours used for social interaction
- Deficits in developing, maintaining, and understanding relationships

Specify current level of severity

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history

- Stereotyped or repetitive motor movements, use of objects, or speech

- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper- or hyperactivity to sensory input or unusual interests in sensory aspects of the environment

Specify current level of severity

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Severity Level:

Level 3

"Requiring very substantial support"

Level 2

"Requiring substantial support"

Level 1

"Requiring support"

DSM – V Diagnostic Criteria, Autism Speaks, retrieved on January 15, 2014 from <http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>

In its previous version, the Diagnostic Statistical Manual (DSM IV) outlined a triad of impairments for an Autism diagnosis: 1) Impairments in communication, 2) Impairments in social interactions and 3) Patterns of behaviour, interests and/or activities that are restricted, repetitive, or stereotypic.

The newest version - DSM V - describes the Autism diagnosis in two main areas: 1) deficits in social communication and social interaction and 2) restricted repetitive behaviours, interests, and activities. Under the DSM-V criteria, individuals with autism must show symptoms from early childhood, even if those symptoms are not recognized as ASD until later. Early identification is paramount and the latest version of the manual will hopefully help in that area. It will also acknowledge those individuals who meet the criteria for ASD at a later age.

Language and communication are so entrenched in social interactions that it seems reasonable to combine them into a single criteria. The decision to leave out a language delay, which was once a key feature of Autism, was largely due

to the fact that these delays are not observed in all individuals with autism. Secondly, language delays can also be a symptom of so many different disorders.

Diagnostic Criteria

Impairments in Social Communication

Students on the autism spectrum have difficulty with both expressive and receptive communication. Receptive language ability should never be assumed for our students. They may, in fact, understand more (or less) of what we communicate. A student with autism may seem to understand a communicative message, but, the proof is shown if their response or actions match what they 'understand.' Repeating back a message is not the equivalent of understanding. When a student repeats your instruction to get the text from the library and come back to class but subsequently sits at his desk, he has failed to understand the message.

Given that our students with autism will likely be able to process simple information quite well and that they can 'talk a good game' we can sometimes be fooled by what we think they understand. At the risk of repeating myself: parents and educators must be cautious. We tend to overestimate the amount of language the student understands. We also use reasoning to explain a point. The problem is that people with autism are far more impaired in language and higher level thinking, like reasoning, that we may realize.

Our most critical task as parents and educators is to find a way to give a voice to those persons who cannot speak

In the Cognition section of this book we will examine receptive understanding in greater detail but for now, it is important that educators are aware that our autistic students (including all levels of intelligence) will need more time to process what we say. They will need simple, direct instructions and visual support (words and/or pictures) to supplement what is verbal. Complex language, long winded explanations and negative directives such as, "Don't write in red pen," will only confuse and slow down information processing.

About 25% of individuals with autism are non-verbal. A few decades ago it was thought that about 50% of children with autism would remain non-verbal. What is critical for parents and teachers to understand is that non-verbal does not equal intellectual disability (NIH, 2010). The success stories of three non-verbal individuals testify to the value of never giving up on finding a voice for our kids with autism.

At the age of two, Carly Fleischmann was diagnosed with severe autism and an oral motor condition that prevented her from speaking. She was never expected to develop intellectually beyond the ability level of a small child. Years of intensive behavioural and communication therapy yielded modest results and it

would have been easy to assume that Carly had reached a ceiling in her communication ability. However, at the age of ten, she had a breakthrough. "While working with her devoted therapists Howie and Barb, Carly reached over to their laptop and typed in "HELP TEETH HURT," much to everyone's astonishment. This was the beginning of Carly's journey toward self-realization (carlys voice.com)." Carly lives in Toronto, goes to a mainstream high school, takes gifted classes and passionately advocates for those living with autism. She is the author of *Carly's Voice*.

Born with autism, Jenna Lumbard never developed speech nor could she always understand what was said. However, she became a voracious reader and in grade two, armed with a keyboard and the help of a facilitator, Jenna began to express ideas in poetry and short stories. Like Carly, Jenna wants to use her voice to inspire others to persevere and be the best they can be. Jenna has published, *Worried Wendy Goes to School*.

Diagnosed as "severe" or "low-functioning" autism, Tito Rajarshi Mukhopadhyay had almost no language skills when he was eleven years old. His vocalizations were approximations of words and he was completely dependent on his mother. She taught him to read and write by using an alphabet board. From the age of six years he had learned to write by himself using a pencil. From this humble beginning, Tito has a remarkable ability to use long words in complex sentences and to express philosophical thoughts about life in spite of being severely disabled. In fact, at twenty-five years old, Tito is the author of three books: *The Mind Tree*, *The Gold of the Sunbeams*, and *How Can I Talk If My Lips Don't Move?*

We can never give up in our quest to give a student a voice.

Imagine a particularly killer day at school. Your ability to keep teaching is dependent on the consumption of coffee. For some reason, you have no voice and no way to write- no way to tell your need for coffee. (I know some readers will be able to relate). A colleague senses something is wrong and kindly brings you a salad. Very nice – but not what you want. A sweet student brings you a glass of water and again, you are grateful but you really *need* a coffee. The principal arrives at the door with a pile of report cards that need editing. Exhausted, tense and frustrated, your mood gets edgy. The people around you write off your mood as being "grouchy" – maybe even, "inappropriate." But, you really aren't in a foul mood, you just need coffee!