

# I Have Autism and I Need Your Help: Tailoring High School and Planning Beyond ...Into Adulthood

“IMAGINE A LIFE”<sup>1</sup>

by Teresa and Erik Hedley



## We’re Gonna Need a Longer Runway

**SO HERE WE ARE** at the tail end of a manufactured 13<sup>th</sup> year. “Grade 13,” Erik will tell you with a shy grin, “has been a very good thing.” It has given him time to get used to easing out of high school and to moving on. But to backtrack, it has also given him time to get used to collecting his diploma, to physically walking out of his high school – his mid-teen oasis – for the very last time. These final moments are emotional and they are significant, even for – especially for – a youth with autism. And paired with this transition is having to decide what to do next when you really do not know, and likely, when you are not quite ready to move on. There are simply too many lasts and firsts, and they come too fast, too soon – and all together. So we removed the firehose and replaced it with a garden hose. It is much easier to drink out of a garden hose.



Teresa

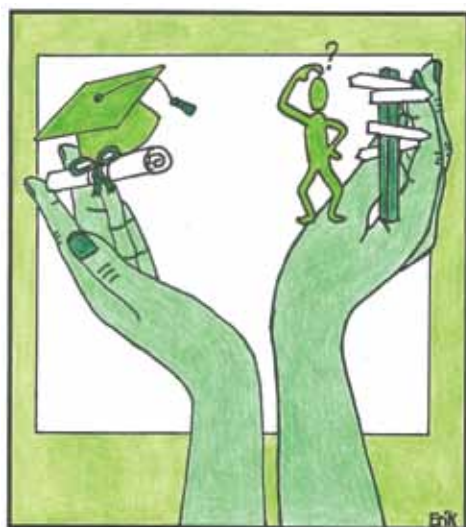
“With Erik,” my husband says, “the longer the ramp, the better.”

The more time we allow for Erik to grow into Erik, the more successful Erik is. And like a fine wine, our children with autism get better with time – we all do – so it makes sense to set the neurotypical timeline aside and create a tailored path. Why go generic when you can personalize? We always ask, “What feels right, right now?” and the next logical step most often involves an infusion of extra time. So be it.

In response to “the ramp” I smiled and said to my husband, “That reminds me of that iconic scene from the movie *Jaws*. You know the part where the guy says, “We’re gonna need a bigger boat?” Well, with Erik, we’re gonna need a longer runway. He’ll take off; he just needs more time and space to grow up.”

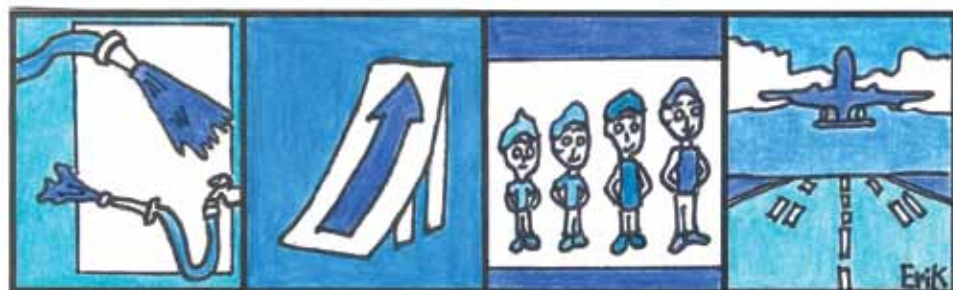
## High School: Creating Time and Space En Route

But this is nothing new. We’ve been doing this – elongating the runway – all throughout high school. With the help of learning assistance teachers, we built in spares; we



“*Tailoring the Transition to Adulthood*” by Erik Hedley. Erik chose green to represent new growth. He chose many shades of green to represent the green spectrum – colour in transition.

“*I Have Autism and I Need Your Help: Tailoring High School and Planning Beyond ...Into Adulthood*,” is the 19<sup>th</sup> article in the mother/son series by Teresa and Erik. The series aims to draw out the voice of autism – Erik’s perspective – and to interpret and teach – Teresa’s voice. The articles move from general to specific and offer strategies for building resilience and supporting autism. Up Next: “*I Have Autism and I Need Your Help: Reflecting Upon ‘A Life Imagined’...*”



**We’re Gonna Need a Longer Runway:** Fire Hose to Garden Hose; The Longer the Ramp the Better; Erik Growing Into Erik; Longer Runway Allows a Successful Take-off.

Note: Teresa’s voice is the main body of the article. Erik’s voice is indicated in script font.



took “learning strategies” classes twice: once for credit and twice for practice and a breather. We purposefully kept Erik two credits short of graduation and then built in a Grade 13. Being a couple of credits short allowed Erik time and space to absorb – and enjoy – Grade 12. It was a win-win.

Grade 13 – in our books – was all about slowing the pace and elongating the ramp. Our objectives were three-fold.

**One**, get used to the idea of graduating. How can you program the brain to wind down when you are fully immersed in challenging course work? You cannot. So we didn’t. We lengthened the runway. “Focus on getting the prerequisites this year,” we told Erik, “and graduation next year.”

**Two**, get some life experience. Our version of Grade 13 was to be about life experience – on the job training, so to speak – and sampling job sites.

**Three**, start to think of yourself beyond high school. Where do you see yourself working and contributing in society? What education or experience will be needed in order to activate your goals?

The transition beyond high school takes place in the head before it can even begin to happen in the body. “The body achieves what the mind believes.”<sup>2</sup>

By engineering high school to meet needs, students are given the time to absorb the work, but also the ability to think forward and to image themselves beyond high school. It takes personal experience to even begin to imagine a job setting. How can you know when you don’t know?

**Experience Beyond the Classroom – Now!**

So, in order to both “build a longer runway” and to possibly “know,” Erik signed up for high school co-op. We worked with the school to create a two-headed co-op.

One placement was technical: a cameraman position at Rogers Television. The second was social/emotional: a care aide at St. Patrick’s, a long term residential care home. Both were superb fits for Erik. He loves videography, so manning a camera at Rogers TV was a thrill. As for the long term care home, Erik is a sensitive young man, and he loves to know more about lives well lived. “I don’t see seniors,” he told me after a day or two at the facility, “I see stories.”

These were not just suitable environments; these were ideal matches: talent and inclination dovetailing with community need. Erik was making a meaningful contribution, and he knew it. He felt needed, appreciated and valued. He felt like Erik at Erik’s best.

When crafting an individualized path, go with your instincts and always, always default to this: “What feels right, right now?”

A second year of Grade 12 felt right, as did co-op, as did a dual co-op placement. The point being, create your goals and then make the placement work. Not the other way around. Because likely, the typical placements will be generic and will not meet the goals for your ASD youth. Make your goals first and then make the program work. That is the true meaning of tailoring: it is an adjustment

of what exists.

When a garment is tailor-made, it is made for you. You do not change shape; the cloth is made to fit. Likewise, when a program is tailor-made, it is made for you. You do not change your neurology; the program is made to fit.



Erik

**The Effect of Time and Space: Erik Speaks About High School**

*It’s Erik here to talk about building real-life experience into high school. I will answer some questions about topics that changed the high school experience for me.*

**Talk about your co-op year. Did anything surprise you about your co-op placements?**

*Rogers TV – The thing that surprised me about working at Rogers TV was that I expected it to be more individual – just operating a camera. It turned out to be better than that. The people part is what surprised me ...that three of us formed a camera team. I liked the feeling of belonging in a group. It was like a team effort, and I didn’t expect that.*

**St. Patrick’s Long Term Health Facility –** *At St. Pat’s, I learned that care is beyond the physical job that needs to be done. It’s also about getting to know the people and making connections with their lives. It’s about listening to their life stories and making them feel appreciated and cared for. I*



**Why Create Time and Space in High School?** *Absorb Coursework Pre-Requisites in Grade 12; Focus on Winding Down and Graduation in Grade 13; Build in Life Experiences/Co-op; Think Beyond High School – Gearing Up to Working and Contributing Meaningfully*

liked learning from their life lessons. Sometimes I would wear travel T-shirts as conversation starters, and we would talk about places that we've travelled to. This made the residents feel more like people and less like patients. I know that this was important to each person.

Working at St. Pat's reminded me of something my parents have told me: it's not usually about the place; it's about the people. Now I understand that.

### What are the benefits of co-op? Lessons learned.

I learned that:

- work that highlights my interests (videography) and qualities (wanting to help others) is most satisfying
- work that involves helping

### Articulating What's Important and Investigating What's Out There

So we took Erik's wishes and we thought about context. Knowing Erik and knowing autism, we are aware that Erik – and those with autism collectively – are best when their environment supports and nurtures them. Environment is key to success.

And then it came to us: We were looking for a supportive academic program *and* a supportive, nurturing, living environment *and* a job with a good environmental fit.

It was then I read an online newsletter for a college in my home town on Vancouver Island. A testimonial from an international student leapt out at me: "I



Teresa



*The Effect of Time and Space: An ASD Perspective: Experience Real-life Environments; Experience Teamwork in a Workplace; Helping People is Satisfying; A Calm Work Environment is Important*

people is a good fit for me: help is healing

- a work environment that is good for the clients/residents can also be an ideal environment for me – i.e. quiet, happy, positive and organized.

### What Feels Right, Right Now?

Taking an extra year and slowing things down gave me time to think about what I wanted to do

and how and why. It gave me a chance to think about some objectives that are important for me. In the coming year, I want to:

- transition to college and feel what it's like to be on a campus
- sample some college courses in an area of interest.

These points are just ideas right now. Now I need to make a plan to make my thoughts a reality.

was looking for a quiet place to start my post-secondary education ...and I found it."<sup>3</sup>

When I read it, I thought, "That's it! That is also what we're looking for!"

The college itself is idyllic, like a west coast rain forest getaway; a place where massive cedar-timbered buildings look more ceremonial than educational; where towering Douglas firs intermingle with striking totem poles and where forest floor pathways connect buildings and departments. A stunning Island glacier forms the backdrop, resting quietly on the periphery. The campus is small, inclusive and it is nature nurture at its finest.

And now the clincher. This college has a program for those with alternate neurologies. The British Columbia government mandates access for students with different abilities, and it is up to each college to facilitate access and craft a way forward for those who require a little more time and space to get there. In this

case, it is a "Transition to Employment" program, and it allows job site sampling and teaches nuanced and necessary job skills and attributes under course titles like "Workplace Expectations," "Workplace Relationships," "Workplace Communication," "Workplace Safety" and "Workplace Experience." It also allows for further study in other campus departments, if desired and appropriate.

We had found our match, and with it, what appeared to be an ideal academic environment.

Soon after, we discovered and secured an equally ideal living space: a nature lodge, part of a larger beach resort right on the ocean, rented out in winter months to those who seek the solace of the sea. It was exactly right for us, and it was what I had wanted for Erik: a natural place but also a social place and a sense of community and belonging within a larger community. The pieces were coming together.



### Imagine a Life: The Path Ahead

And now comes the uncanny overlap. We had some wishes and some vague goals; we had discovered a nurturing academic environment and nature nurture in both school and home locales. And then we stumbled upon a plan.

Pat O'Connor runs an autism support centre out of Barrie, Ontario called "Integrated Autism Consulting." In addition to her successful "Transition to Life" program, Pat has recently added "Imagine a Life." This course recognizes that parents often help to orchestrate and facilitate the transition to adulthood. In instructing parents of youth with autism, the program helps parents work alongside their young adult and fashion a path forward that works.

Reading the course description and the course objectives, I thought, "Well, this is absolutely us!" As well, Pat's course objectives made me realize that



*A Life Imagined: Transition to Employment Program; Sample College Courses; Learn Life Skills-1 (public transit, driving, cooking, money); Learn Life Skills-2 (friendships, leisure, self-regulation)*

our time out west could be and will be so much more than "just college." An adult transition plan can – and should – be a multi-faceted and all-out blossoming of self ...well beyond work or school.

I sat there, feeling a lot like the Grinch experiencing "the big epiphany." And like the Grinch, it suddenly dawned on me that the true meaning of "transition" is so much more than I had at first thought. Transition beyond high school is about sampling life and fleshing out

the whole person and the everyday tasks and experiences that accompany education and work. We would be purposefully creating well-roundedness, and in so doing, lengthening the runway and allowing time for Erik to grow into Erik... to truly try life on.

"Imagine a Life" provided the structure and purpose for moving our goals beyond wishes and into a workable plan.

"A goal without a plan is just a wish."<sup>4</sup>



Erik



Teresa

### A Life Imagined: A Purposeful Plan, Inspired by "Imagine a Life"

Using "Imagine a Life" – and augmenting it with thoughts of our own – Erik and I listed possible objectives, and after each, life's details. Our transition plan began to take shape, and inspired by Pat's vision and our own inclinations, we fashioned a sort of fusion: Vision + Envision = A Life Imagined.

Here's what we came up with:

#### 1. Work Readiness:

Take courses in the "Transition to Employment" program such as Workplace Safety, Workplace Expectations, Workplace Relationships and Workplace Experience.

#### 2. Life-long Learning:

Sample college courses in the Health Care Assistant program and take prerequisite courses like CPR, Food Safety, WHIMIS.

#### 3. Advocacy and Education:

Continue to advocate for the voice of autism; cultivate a social conscience and "Make things better..." Leave things better than you find them.

Work with the local RCMP to create an autism registry and to educate first responders about autism.

#### 4. Life Skills:

Learn and practice life skills such as driving, taking public transit, cooking, cleaning, renting and being a renter, money management.

"The body achieves what the mind believes."

**5. Community Involvement:**

Volunteer at places such as the Child Development Centre, Therapeutic Horse Riding. This time I am the giver of care vs. the receiver of care.

**6. Health and Wellness:**

Develop active routines like working out, yoga, ocean and river kayaking, windsurfing lessons, maybe golf and tennis lessons.

**7. Outdoor Nature Nurture:**

Explore Vancouver Island and enjoy our "Pacific Playground."

**8. Family Involvement:**

Spend time with west coast family like Gramma and other relatives.

**9. Friendships:**

Rekindle old friendships and make new friends; invite people over and practice what it is to be a "good host," become part of a beach community and also a college community.

**10. Social Understanding and Sexuality:**

Expand and practice knowledge of social and sexual self through videos, books, programs, clubs, conversations.

**11. Self-Regulation:**

Practice self-awareness and bring myself to an ideal state depending upon the activity and what is needed. Do things such as listening to music; watching family videos; going for bike rides, hikes and beach walks. Do whatever makes me feel good and happy.

This is the plan on paper. And our compass? "The body achieves what the mind believes."

**Footnotes**

- <sup>1</sup> Pat O'Connor; Integrated Autism Consulting; "Imagine a Life" program; integratedautismconsulting.com
- <sup>2</sup> Pinterest Fitness Post; May, 2017; www.pinterest.com
- <sup>3</sup> North Island College Online Newsletter; 2016; www.nic.bc.ca
- <sup>4</sup> Pinterest Fitness Post; May, 2017; www.pinterest.com
- <sup>5</sup> *The Best Exotic Marigold Hotel* movie; 2011
- <sup>6</sup> *The Best Exotic Marigold Hotel* movie; 2011

**References:**

1. Pat O'Connor; Integrated Autism Consulting; "Imagine a Life" program; integratedautismconsulting.com
2. North Island College; 2017; www.nic.bc.ca
3. Artwork windows by Erik Hedley, 2017. In order to illustrate transition, Erik chose to colour using a colour spectrum within five bright colours.

"...everything will be alright in the end, and if it's not alright, it's not yet the end."

*Your thoughts? If you would like to offer your thoughts, suggestions, or ideas, please connect with us via [son\\_mom@live.com](mailto:son_mom@live.com). While we do not promise to return e-mails, we welcome your feedback. ■*

**A Life Imagined: A Postcard From the Edge**

So our plan is to go and live and purposefully transition... and then to compare "perfect on paper" with the reality of practice. What worked? What was slightly less than perfect? And what surpassed our expectations?

In fashioning this transition, we are meticulously planning but we are also leaving room for flex and for serendipity.

"Sometimes what happens instead is the good stuff."<sup>5</sup>

Sometimes the little things become the big things. Sometimes the unexpected is the big deal, and it is what turns out to produce the best outcomes. We'll find out.

The plan is to assess, and in the spring, write an article from the shores of the Pacific Ocean, a summary article and indeed a series summary.

Erik and I began writing together six years ago when Erik was 13 and in Grade 8. We'll wrap up at 19, in a pre-college program. It has been a captivating, all-consuming journey, and one that has been documented through this magazine since 2012. Wrapping up feels like an ending but also a beginning. Life is like that: it is a constant renewal.

"So we must celebrate the changes; everything will be alright in the end, and if it's not alright, it's not yet the end."<sup>6</sup>

From

To