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Dignity of Risk

How Direct Support Professionals Can Build Risk into Learning

By Amanda Hickey and Zoe Kariunas

Many professionals in developmental services find it difficult to think about risk when providing services to the people they support. Direct support professionals (DSPs) must build risk into the learning of the people they support like hikers preparing for rugged terrain. A gruelling hike takes preparation, awareness of the elements, wearing the appropriate attire, and choosing a hike that matches the hiker's ability. You do not hike wearing running shoes with worn soles, or without a plan or a map. This would be dangerous. Successful hikers will not let risk dissuade them from their hike. Instead, they make a plan that allows for success. Hikers ensure that the path they choose matches their athletic ability, they are prepared for all elements, dress appropriately, and have the tools they need; if they are going on a solo trek, they notify someone. Experienced hikers know, sometimes, you must abandon your plan and return to the beginning. DSPs must take the same approach when introducing something new to the people they support. They must consider their dignity. Many DSPs are well-intentioned but are heavily protective.

Olivia's pancake story perfectly exemplifies the well-intentioned direct support protector. Olivia enrolled in a cooking class designed for neurodivergent adults, but the neurodivergent adults were not allowed anywhere near the stove. They were not permitted to grease the pan or flip the pancake for fear they may get burned. This class lost the perfect opportunity to teach helpful kitchen safety and first-aid skills. Olivia was denied the right to learn and denied access to independence. The class instructors took away every risk and left the young adults with only whisking the batter. Where is the dignity in that? Safety has always been a priority in the developmental sector. During COVID-19, safety was DSPs' number one priority. Persons with intellectual and developmental disabilities were at higher risk of becoming seriously ill from COVID-19; our sector responded accordingly. After nearly three years of social distancing, they were wearing masks and face shields, and prioritizing safety above everything. DSPs are now faced with a new crisis of mental health related to isolation, loss, and cognitive decline, and it's more important than ever to reflect on how our support might be limiting opportunities for growth, and the inherent dignity that comes from making one's own decisions and facing the consequences. Like the hikers facing gruelling terrain, we must plan, ensure we have the right equipment, discuss with the people we support what paths they want to take, and ensure that the path they choose matches their ability. Persons whom we support must be set up for success.

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Olivia learned to make pancakes independently. She did not learn how to make pancakes safely at home in one or two classes. It was months of carefully layering the skills and building on her success until she could do it alone while her mom slept. Was there risk involved? Yes. The first thing we taught Olivia was first aid for burns. Olivia learned to immediately turn off the stove and place the burned area under cool water. We role-played several different situations where she accidentally burned herself. We created situations when the smoke detector would go off, and there was no fire. Olivia learned to turn off the stove, open the windows, and always ensure the fan is on when making pancakes. Before Olivia flipped pancakes on the stovetop, we practiced with a slice of bread, and the stove was off. Once Olivia was comfortable with the flipping technique, she transferred that skill to making the pancakes on the stovetop. The great thing about pancakes is there are natural opportunities to try again with a large batter. She burned some pancakes, but her DSP did not need to step in and take over immediately. When individuals we support are learning a new task, we often step in when things go sideways to spare them the frustration of getting it wrong. What if we allowed them to try it and learn from their mistakes to respect their dignity, and allow them the chance to take risks? Olivia learned how to recognize when she was about to burn a pancake. To some, it might just be a pancake, but for Olivia, it was so much more. It gave her a choice. Knowing she could make her favourite breakfast and have pancakes when she wanted them gave her confidence. Olivia did not have to wait for her mom to make them for her anymore.

The people we support are often vulnerable in many ways, and numerous policies, procedures, and informal routines often keep them in a position of being protected to never experience failure, leading to growth. This respect for the dignity of risk must be foundational to how we practice as DSPs and the system we work within. We must always give those we support the necessary tools and information to allow them to make informed decisions. When they decide, even when we, as the DSP, can see that their decision might have an adverse effect, we cannot stand in their way and prevent them from experiencing the consequences.

Bindu and his DSP went to dinner and the movies. With his DSP, Bindu had developed a budget. He had allotted money for his dinner and \$15 for popcorn and pop. When they got to the movies, the theatre was having a special on concessions: a large pop, large popcorn, and a bag of candy for only \$15. Bindu was excited. He could not believe he could have all this junk food for only \$15. His DSP gently reminded him of his sensitive tummy and their nutrition lesson about moderation earlier in the week. Bindu said he was a man and knew he wanted the concession special, and he had enough money. The DSP respected his choice. Bindu enjoyed the movie along with the entire concession special. Bindu was home alone that night; his parents were away. Bindu's sensitive stomach could not handle all the junk food he consumed. He got sick in the night, just as his DSP predicted he might. When the DSP visited him the following day, Bindu had cleaned up his vomit and slept with a garbage pail by his bed. He had taken care of himself. When Bindu saw his DSP that morning, he mumbled, "I know, moderation." Bindu learned from the natural consequences of overeating. The DSP knew that Bindu did not have diabetes; he had previously been taught what to do if he got sick at night and was confident that Bindu had the skills to problem-solve. It was a meaningful lesson he would not have learned if the DSP had prevented him from buying the candy, knowing he would most likely get sick.

Consider the context and ability level of those you support

Every person supported is an individual and requires learning to be tailored to their individual needs. Support needs change depending on the situation. A person we support might be very capable of getting to a known coffee shop in the neighbourhood and ordering a drink without any help but might need support in a new neighbourhood with a new shop that doesn't know them. Menus aren't always easy to read or understand, and prices vary significantly.

Considering an individual's skill development in the context of external factors that might change

the situation, and internal factors with the person you support is important. Someone tired or nervous might need more support with a task. We should also consider how past traumas impact those we support. Seeing dentists and doctors can be very challenging for many because of past traumatic events.

Ability is fluid, and we need to consider how our support might look different because of additional support required, or how we can step back in more familiar situations. For example, Toronto's TTC (public transit) is constantly under construction. There are always detours. Some people who have ridden the TTC independently for years may only require a simple explanation of a detour, whereas others may need to be taught and require more support. Annabelle was an avid TTC rider for years but recently grew to dislike the crowds on the TTC, and the constant detours. The TTC's unpredictable schedule made Annabelle anxious. The easy solution was to have Annabelle use Wheel-Trans (accessible transit) instead. She is eligible, which would mitigate a lot of risk; however, Annabelle still wanted to use the TTC because she liked the freedom it gave her. Annabelle and her DSP worked together to develop strategies that would empower Annabelle and give her the tools to ride the TTC. The DSP and Annabelle sought out TTC detours and practiced dealing with them; Annabelle learned to identify crowded streetcars, and that she could get off the streetcar even if it weren't her stop. Teaching Annabelle strategies that were tailored to her individual needs greatly benefited her and gave her the tools and options that empowered her. This is where DSPs can be instrumental in teaching. We can orchestrate real-world scenarios when things don't go as planned but be there to coach and guide through. For example, when doing transit training, maybe we choose a route where there will be a detour (that we know about), and we use that situation to coach through making an alternate plan to get to the destination.

Building Foundational Skills

The common thread in Olivia's, Bindu's, and Annabelle's examples is that they were all taught foundational skills that allowed them to take risks. Olivia can use the stove unsupervised because she knows what to do in an emergency. Bindu could stay home alone safely because he knew what to do if he got sick, and Annabelle could confidently navigate the TTC because she knew who she could call for support and what to do when there was a detour on the TTC. Foundational skills are the skills critical to gaining independence. We must teach foundational skills that can be easily transferred to all areas of our people's lives and allow the people we support to take risks. We aren't setting them up for success without helping folks to develop basic skills. Basic skills are the building blocks that lead to more complex tasks. The story of William and Thomas exemplifies the risks the people we support can take when they have strong foundational skills. William and Thomas wanted to go to Montreal to see the Canadian Railway Museum together. They wanted to go unsupervised. William and Thomas worked with their DSP for an entire year, planning the trip. They developed the required budget, including train tickets, hotel fees, daily food costs, transportation, and excursions. They made their daily agenda for the trip, found the hotel, and role-played different emergencies that may arise. Before they left, they planned the routes from their hotel to the Canadian Railway Museum and other activities. They even made a travel first aid kit to accompany them and planned for every probable risk. The trip to Montreal was a success! William and Thomas could go to Montreal without support because they had all the skills to execute the journey. Was risk involved in being almost six hours away from their support system? Yes. It was a risk that William and Thomas wanted and should take. Not every person we support will be able to take a trip to Montreal unsupervised, but every person we support deserves the dignity of risk.

It all starts the same way, with foundational skills. Breaking down skills into smaller parts and slowly layering on levels of complexity at a pace that is right for the person you support. Often, people we support have splintered skills. "Splintered skills are abilities disconnected from their usual context and/or purpose. An example of a splinter skill is the person you support can

memorize a bus schedule without understanding how to get to the bus station or buy a ticket” (Rudy, 2023). We must methodically teach each step and not assume that because they have one skill, they have the other. Being a DSP is a balancing act. It requires knowing when to teach, coach, support, observe, and fade into the background.

Kate desperately wanted to go to the Eaton Centre (large mall) alone or with her friends; she was done going to the mall with her mom or a DSP. She wanted to walk around the shops, get a drink from Starbucks and be like every other 20-something year old that she knew. Kate and her DSP worked together to build her skills to navigate the Eaton Centre safely. Kate learned what information she should take with her when she was going out on her own, to make sure her iPhone was always charged, who she could go to for help in the mall, how to ask for help in the mall, what people she should stay away from, what were the safe places in the mall, and how to use a pay phone. The DSP even pickpocketed Kate twice to demonstrate how to be careful and mindful of her belongings out in public. Learning can happen in various ways, but the most impactful learning comes from experience. After six months of lessons in different malls and locations around Toronto, the DSP slowly faded their support. Kate went to the mall alone and met with friends. She transferred her community safety skills and now goes to her local community pool, coffee shop, and gym, and out with friends alone. With her newfound freedom, Kate has made a few mistakes and spent too much money, but that is no reason to stop her from going out. It is an opportunity to learn a new skill: financial budgeting.

Interdependence Not Independence

Independence is often seen as the goal in the developmental services sector. Programs are often promoted to gain independence in a skill or environment, and many persons we support have independence as a personal goal. When drilling down into what independence looks like, it often means choice, knowledge, capability, and trust. Autonomy might be a more fitting goal for many based on this list. Their goal is autonomy in all the stories we have shared – Olivia, Bindu, Annabelle, William, Thomas, and Kate. To have the knowledgeability and support to make their own choices and take risks. Independence is funny because it views reliance on others as contrary to independence. You cannot be independent if you rely on someone or something. For how many of us is this realistic or even desirable in our lives? Many of us reading this article depend on other people for different things. Some examples are a contractor to repair your home, a financial advisor to help you invest your money, a cleaner to help maintain your home, public transportation to help you get to work, your family and friends to help you when you need them, your doctor to see you when you are ill, and so on. Some of the most powerful and capable people are the most well-connected ones. Interdependency should be the goal of learning and growing and knowing when, how, and who to contact when you need help is far more empowering than feeling an internal drive to know how to do everything alone when required.

Humans are meant to be interconnected and are often stronger as a group than we are alone. Why are we promoting complete independence to the people we support when it doesn't serve their best interests and, for many, is unattainable? Giving those we support a notion that they must be independent when it reasonably cannot happen due to support needs offers an elusive goal that diminishes their accomplishments. We should promote autonomy first and foremost, and not focus on independence but on interdependence to support people to live meaningful lives.

Informed Consent/Decision Making

Central to autonomy is the concept of informed consent. Informed consent requires the following conditions:

1. The person consenting must have enough information to make an informed decision
2. That information must be provided in the way the person has the best chance of understanding
3. The information provided should include the following information about the service: nature, expected benefits, risks, side effects, alternatives and consequences of not getting the service
4. The person must have an opportunity to ask questions and have them answered satisfactorily

(Hospice Palliative Care Ontario, n.d.)

Sometimes, we get hung up on capacity, and if someone we support can make the “right decision.” Speaking with a DSP a few years ago when COVID-19 vaccines were first made available, it was interesting how the conversation went. I asked how he supported individuals in deciding to get the vaccine. He replied that he told them it would be okay and offered comfort for the physical pain of a needle. I responded that that would be comforting, not supporting decision-making, and asked my question again. He seemed confused. Of course, we know that getting the vaccine is the right decision for almost everyone, but how are we supporting individuals to decide for themselves? Are we discussing the pros, cons, alternatives, risks, and consequences of getting (or not) the vaccine? Have we respected the central conditions of informed consent?

We can apply these principles to any decision an individual might make. There are times when a person can't make an informed decision. Still, I would argue that, as DSPs, we have a duty, and the required skills, and relationships to create conditions where the individuals we are supporting can make informed decisions about their lives. It can be as simple as Bindu, at the movies, choosing to buy the concession special. He knew it might make him sick, but he had the money, and it was his choice. Annabelle's choice not to use Wheel-Trans even when it would have been the simplest solution. She knows that Wheel-Trans takes time and planning, contrary to her desire to ride the TTC. William's and Thomas's desire to travel to Montreal by train and visit the Canadian Rail Museum. Before we even started planning the trip, we named the cost and the risks. They were fully informed. As DSPs, we are responsible for ensuring that the people we support have active roles in their lives. They make the decisions and take risks. Our job is to ensure they have all the skills and tools to take the risk. Sometimes, they may fail, and that is okay. As DSPs, we must ensure the people we support can take risks.

About the authors

Amanda Hickey is a passionate advocate for people with disabilities with over 20 years of experience. Amanda earned her degree in Critical Disability Studies from Toronto Metropolitan University. Amanda led L'Arche Toronto Trying It on For Size (TIFS) for the last five years. TIFS is an innovative program that allows participants to “try” living independently or with roommates. The TIFS program is not solely about independent living life skills. TIFS participants develop goals that enable them to take risks and have the life they want. Amanda believes learning a new skill should be enjoyable and enhance self-esteem and confidence. She strongly believes that learning must be strength-based and allow the person to shine. Amanda has been working for L'Arche Toronto for thirteen years. She has held several roles within L'Arche Toronto and is currently the Community Life and Volunteer Coordinator for L'Arche Toronto.

Zoe Kariunas is an experienced facilitator working with individuals and their support circles to create individualized living situations. During her time with LIGHTS at Community Living Toronto, she has walked alongside hundreds of support circles to create a vision, build a viable plan and budget, explore partnerships, and move their loved ones into more independent living. She currently works with Developmental Services Ontario in Toronto, housed at Surrey Place as a Housing Navigator. Her role includes consulting with families and professionals on community housing options and creating resources for those looking to learn about more independent living in community. Zoe also works with Siblings Canada, an initiative of the Canadian Centre for Caregiving Excellence, to co-facilitate ACT workshops for siblings. She is currently pursuing a Masters of Social Work at the University of Windsor and plans to continue working with caregivers after graduation.

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