

Executive Functioning

A Newsletter for Senior Leadership in Organizations Providing Human Services

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Restrictions on Autopilot: Protecting People with Intellectual Disabilities from Random Acts of Power

By: Stephanie Ioannou

Direct Support Professional #1: We don't restrict Jason's ability to go out; he goes out all the time.

Direct Support Professional #2: Oh, how come Jason didn't go out today? I heard him saying he wanted to go shopping.

Direct Support Professional #1: That's because he was aggressive in the morning so now he can't go out.

When we use the words *restrictions* or *intrusive measures* in the field of adult social services, most people have some ideas of what those entail. The most obvious and well understood examples of restrictions are physical restraints, limiting someone's cigarette or coffee consumption, and having a locked fridge and utensil drawer in their house.

There are countless other restrictions that are used in adult social services, many of which families, direct support professionals, supervisors, upper management, and the individual with an intellectual disability don't know are restrictions. Some of these include:

- Limiting someone's outdoor access (i.e. through electromagnetic locks)
- Setting an early bedtime to accommodate staffing needs
- Preventing someone from going to an outing or event due to negative behaviour
- Taking an item away from someone as a 'consequence' due to negative behaviour
- Preventing someone from going out because they did not shower
- Limiting when and how much an individual can eat or drink
- Removing/limiting somebody's access to a particular community service
- Behavioural PRNs
- Denying an individual contact with their parents because they acted out
- Limiting someone's internet use
- The use of a 'onesie' to prevent an individual removing their clothes or putting their hands in their pants
- Preventing free access to their belongings (i.e. locking up clothing, hygiene materials, etc.)
- Redirecting someone to their bedroom

The list of restrictive and intrusive measures can be endless.

Restrictions are taken very seriously by those who write behavioural programs and by the governing bodies that oversee the use of behavioural technology. Typically, if a restriction is going to be used, there has to be data produced that supports the need for a restrictive procedure. There also needs to be clinical oversight, and only specifically identified people can sign off on the use of those procedures. Also, rights review committees need to look at, comment on and have input into programs that have any kind of restrictions.

The concern is that restrictions are often used haphazardly and inconsistently within the dynamic of the relationship between direct support staff and the person they serve. It's often implemented by the staff as a means of gaining control of what they perceive to be inappropriate or challenging behaviour. They don't see that 'withholding dessert' like their parents used to do, is a restriction that would need any oversight at all!

The purpose of identifying some of the most common, yet unknown restrictions, is to bring awareness of these practices to service providers. Typically, the types of restrictions used in social service agencies fall under the following categories: (i) access and autonomy, (ii) relationships and community supports, (iii) safety, security and privacy, and (iv) control and decision-making (see Griffiths et al., 2003).

Rather than trying to create and memorize a list of restrictive measures, one way to wrap our heads around whether something is restrictive or not is to ask ourselves: "Would this rule apply to me in my day-to-day life? Is my internet limited to 30 minutes once per day? Do I get redirected to my bedroom when I'm angry? Does my iPod get taken away when I don't do a chore? Can I only go out after I have a shower?"

By the very nature of having an intellectual disability and what it means to live with a disability, people identified as such are automatically in a place where they have fewer choices and freedoms than the rest of society.

Though I am now a Behaviour Therapist, I began my work in this sector as a direct support professional and have held a variety of positions in several different agencies. Even so, there has been a commonality in attitudes and practices regarding the use of 'consequences,' which was often a code word for 'restriction.' In past work, I have heard comments from direct support professionals about the field going "too far with this rights stuff," because "I don't have a choice about having to go to work every day," or "I don't get to go to the movies any time I want, so why should they?" These statements are simply not true. You may not want to go to work every day so it feels like you don't have a choice. However, you choose to go to work every day so that you can be paid, support yourself and your family, and be able to afford vacations and other activities that you enjoy. You also know that, if you don't go to work, you will get fired, won't be able to pay your bills, and won't be able to afford activities and hobbies you enjoy. Therefore, you make the choice to go to work because you are aware of both the risks and benefits of such a decision.

People with intellectual disabilities often don't have these choices. They do not choose where they live. They do not choose with whom they live. They do not have as many choices of where to work, or attend

day programs, activities to engage in and when to do them. Rather, people with intellectual disabilities are given a *menu of choices* where they are presented with options that are within the borders of what a supporting agency, or staff of the day, wants to offer. This reality doesn't mean we are providing poor service to people with intellectual disabilities. Rather, it means within congregate settings (i.e. group homes), there tends to be more focus on fitting the person to the location and less attention paid to individualized planning than in other settings such as semi-independent living. However, we still have to be aware that people's right to choice and freedoms may be overlooked and unjustifiably restricted.

Why We Use Restrictive Measures

The most common reason that restrictions are used in provision of service to people with intellectual disabilities is due to concern over the individual's safety and well-being. Simply put, we are worried that they will make poor choices. It is true that people with intellectual disabilities may act in ways that hinder their success in the community and can have dire consequences to their quality of life. People with intellectual disabilities should have the same rights and freedoms as those without a disability. Similarly, all citizens, disabled or not, have a responsibility to follow the law, practice mutual respect, and abide by social norms. When an individual with an intellectual disability is not following these societal standards, we as service providers have a responsibility to intervene. These individuals are receiving service for a reason. If they could always foresee and understand consequences of their actions, if they had great problem-solving skills, if they had good emotional regulation skills, if they were able to communicate effectively to get what they want, they would not be receiving our service. Intervention on the part of the agency may include natural consequences, things we would all face as a result of our actions. It may include needing to implement a restriction for the short-term, while simultaneously educating and teaching the individual so that the restriction can be removed.

Towards a Culture of Habilitation

Our goal in support services should be to teach individuals with intellectual disabilities all the skills that they need so that they can live as independently as possible. This is the definition of habilitation. Putting a restriction in place as a means to reach habilitation should always be at the forefront of implementing restrictions. During the time that the individual has a restrictive measure, they should still be given as much choice as possible, within the context of the restriction. For example, it is common for people on the autism spectrum to need a structured daily schedule in order to reduce anxiety and cope with transitions and impending future events. Although the individual has limitations around their daily schedule of activities, the idea is that they have ample choice built within the structure of their schedule.

A restriction should never hinder an individual's habilitation or opportunity for community participation. If the individual requires a staff to supervise them in the community while they are learning community safety skills, then a staff should be available to ensure the individual can go to the community. The individual should not miss out on their regular church attendance because a staff isn't available to supervise them. The individual should not be prevented from attending their weekly dance because a staff can't take them.

In these instances we would be wrongfully and unethically using restrictions. In these situations we would be in the territory of neglect and abuse of power. If restrictions cannot be used ethically and responsibly, then they should not be used.

A note of caution: The use of restrictions can create a vicious cycle. Problem behaviours are present so restrictions are put in place. Problem behaviours continue to be present or intensify, because we have taken away the individual's opportunity for choice and control in their life. Restrictions stay in place because problem behaviours are still present or have worsened, and so on. This highlights the need for preventing random restrictions being placed on individuals and having a strict, ongoing process for implementing restrictions.

Influencing Change through Positive Based Approaches

Restrictions and punitive measures must always be a last resort with proper data collection and approval. However, this isn't seen in practice. If something should be a last resort, why is it the first thing that comes to mind? A go-to response of using a restriction isn't necessarily for malicious reasons. It is easy. It is quick. It usually elicits immediate results. Also, support staff and management don't always know that what they're doing is in fact a restriction, and are unaware of all the negative implications restrictions can have on a person's mental health and well-being. However, we cannot use ignorance or the need for immediacy as justifications for the use of restrictions. That is not what we're here for. We are not here to manage people. We are not here to change people in the most convenient way possible.

When restrictions are put in place, they usually aren't out of nowhere or for no reason. It is because there is a problem and a restriction is the solution that has been decided.

Let's look at a common example of a restriction that simply doesn't need to be used. One of the most common issues is showering. Numerous times I have seen rules in place where a person with an intellectual disability is not allowed to go out unless they shower. People have missed their favourite outings and opportunities for community participation because they did not shower. A common response justifying this rule's utility is, "Otherwise, they'll never shower."

Limiting or denying someone's community access because they haven't showered is a restrictive measure and it is unnecessary. We cannot lose sight of what the concern is, but we can change our way of thinking, as well as how we problem solve and approach these concerns. The concerns around a person with an intellectual disability not showering relate to the health risks associated with being unhygienic, as well as the community's response to someone looking unclean and potentially smelling bad. Remember, our goal is habilitation, to teach individuals all the information and skills they need to be as independent as possible. In this circumstance, if there is a knowledge gap, we should start with educating the individual on the health risks of not showering, and how they might be negatively perceived and treated in the community (i.e. most people don't want to be around people who aren't clean. This is true for everyone!). They should also understand the benefits of showering and looking good (when you look good you feel good!). This example is an opportunity for caregivers to use positive approaches and motivate the

individual to do a desired behaviour. Plan a fun trip to the community where they buy nice smelling soaps and shampoos that they are excited to use. Perhaps they will be excited to use a new loofah that's their favourite colour. The next time they shower, compliment them by telling them how great they look.

This example of showering presented an alternative strategy to dealing with a concern. It used positive and motivating approaches, instead of a restriction, to address an issue. A restriction might have been faster and easier for the support staff. The positive approach may take more time and effort on the part of the support staff. However, using a restrictive measure in this example removes the individual's choices and control over that aspect of their life. It affects their dignity. It creates power struggles. It takes away their sense of empowerment. It damages rapport with service providers. Using a restriction can create more harm than good.

This method of using positive-based approaches wherever possible to replace intrusive and restrictive methods is the Positive Behaviour Supports model.

A positive and motivating approach is empowering to the individual and is in line with the practice of habilitation. It will lead to long-lasting intrinsic change for the individual that will not require constant external supports and controls.

When Restrictive Measures May Need to be Long-Term

There are cases where an individual may have to live with certain restrictions for the long-term. This should only be seen in cases where there is high risk of harming themselves or others and managing the risk can only be done with the use of a restriction. Coming to this decision should involve constant discussions and monitoring of the individual's progress. Determining the need for long-term restrictions must be done through objective data collection and not through opinion. The use of long-term restrictions may be due to crimes committed in the past or due to some aspect of the person's cognitive development where they are unable to learn the skills to reduce the risk to a level that the restriction can be removed. When it is done correctly, long-term restrictions can improve an individual's quality of life more so than if they did not have the restriction. It can allow the individual to participate in the community and be a functioning member of society, while maintaining their own and other's safety. Once the long-term need for a restriction has been justified, we do not stop there. Every person with an intellectual disability who is in service should have ample opportunities for autonomy, choice, skill building, learning opportunities, leisure activities, and building relationships to name a few. These are just some of the bases of many quality of life models. When restrictions are in place, the emphasis on ensuring these items are in position truly becomes mandatory. Attention and effort towards quality of life factors and skill building need to be even more present when restrictions are in place. This is so there is a balance. This is so we aren't jailing people in the guise of risk and safety.

Implementing Restrictions is a Process, Not an Event

The following is a process that should be followed for the use of restrictions:

1. **Data Collection:** This should incorporate both direct and indirect measures such as: direct observations of the individual, historical file reviews, and interviews with the individual and people who know them best. The purpose of this is to develop a proper rationale and justification for a restriction to be implemented.
2. **Written Plan:** The plan should justify why the restriction is needed (supported by data), the procedures for how the restriction is used and by whom, and a fade-out plan that outlines when and how the restriction will be removed. The plan must also incorporate teaching and skill building strategies that will replace the need for a restriction and move towards habilitation.
3. **Proper Approval:** Legislation in Ontario (Quality Assurance Measures) outlines that a Psychiatrist, Psychologist, or Board Certified Behaviour Analyst must approve restrictions, prior to any restriction being implemented. The individual with an intellectual disability and/or their substitute decision maker must also consent to the restriction, with an understanding of the pros and cons of having such a restriction.
4. **Staff Training:** If a restriction is in place, support staff and supervisors should be taught the skills to implement the restriction correctly, including the ability to teach the individual habilitative skills. Staff and supervisor adherence to proper implementation of restrictions should be monitored.
5. **Regular Monitoring:** The use of the restriction should be monitored through data collection and be reviewed on an ongoing basis by a clinician with training/experience in rights restrictions and a rights review committee.
6. **Balanced Quality of Life:** Restrictive measures must be balanced with frequent opportunities for reinforcement, teaching skills, and monitoring their ability to achieve both short and long-term goals.
7. **Training for Individuals Supported:** Every individual supported should receive education on abuse prevention, which should include the misuse of restrictions. Individuals need to have the knowledge and a method of reporting the misuse, as well as the opportunity to speak directly to their rights review committee.

Why Does All This Matter?

Legislation makes habilitation a requirement. Funding is dependent on standards of quality of life and therapeutic and safe environments that are supportive of teaching and fostering independent living skills.

In addition, fostering as many positive-based approaches is an agency-wide investment. It is cost effective, it is ethically sound, and results in the need for less resources later on.

Where to Go From Here?

Agencies, their management, and staff who are open to improvement in providing service to people with intellectual disabilities, including enhancing their quality of life should consider the following next steps:

Training: The entire agency from the upper management to the direct support staff must be trained on restrictions and intrusive procedures, with a clear understanding of what encompasses restrictive measures and why. Complimentary to this, training should also include positive-based interventions as alternatives to restrictions wherever possible. Begin to have dialogue and knowledge dissemination in order to facilitate system-wide change.

Regular Oversight: Do a thorough review to determine if unapproved restrictions are being used within the agency. If a restrictive measure is being used without proper approval, oversight, and data collection, it should be removed immediately, or faded out if risk is a concern. Restrictive measures that have been deemed necessary through data collection and proper approval should be reviewed at least every three months to determine if the restriction is still necessary. If service providers and direct support staff are using random acts of power through unapproved restrictions, it means there is a problem and training, oversight, and accountability should be tightened.

A hopeful outcome of this article is that it will encourage agencies to review their practices, and identify problems and make change where change is needed. I hope too, that this will stimulate constant discussions and questioning about the decisions we make over the lives of people with intellectual disabilities, encouraging service providers at every level to look at seemingly small actions from a critical lens.

Every agency that supports people with intellectual disabilities is dedicated in providing the best support possible. Quality care is evolving. To continue to strive towards excellence in care, we need commitment at every operational level, to review and monitor our current practices with the goal of continual growth and improvement for the individuals we serve.

For additional information and reading, see:

Bannerman, D.J., Sheldon, J.B., Sherman, J.A., & Harchik, A.E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis*, 23(1), 79-89.

Griffiths, D.M., Owen, F., Gosse, L., Stoner, K., Tardiff, C.Y., Watson, S., Sales, C., & Vyrostopko, B. (2003). Human rights and persons with intellectual disabilities : An action-research approach for community-based organizational self-evaluation. *Journal on Developmental Disabilities*, 10(2), 25–42.

LaVigna, G.W., & Willis, T.J. (2012). The efficacy of positive behavioural support with the most challenging behaviour: The evidence and its implications. *Journal of Intellectual and Developmental Disability*, 37(3), 185-195.

About the Author:

Stephanie is a Behaviour Therapist at Vita and a Board Certified Behaviour Analyst. She has implemented a Positive Behaviour Supports curriculum in a community service agency and has presented in Canada and the U.S. on the topic of positive-based approaches and balancing rights and risks for people with ID.

