

# Executive Functioning

*A Newsletter for Senior Leadership in Organizations Providing Human Services*

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Executive Functioning is entering its second year of publication. After evaluating the newsletter it has been decided that, instead of publishing quarterly, it will now publish twice yearly, September and April. This will give the editors the time needed to seek out authors and topics of relevance to senior leaders. Welcome to year two and, as always, let us know if there is a topic you'd like to read about or, even better, write about.

## **Self-Advocacy, Signatures and the Dotted Line**

**By: Jordan Hoath**

The Self-Advocate movement in human services has, in many ways, challenged service providers to ensure that the real, authentic, voice of people with disabilities is included in any discussion regarding how service is offered and how service is experienced. An increasing number of agencies have encouraged self-advocate organizations to form from within their client group. Many of those agencies have welcomed self-advocates to participate as a member of the Board of Directors. Self-advocacy is considered to be one of the cornerstones of 'best practice' for people with intellectual disabilities.

This article will look at how the principles of the self-advocacy movement can inform our approach to gaining consent and ensuring that a signed document truly represents the choice and the voice of a person with a disability within service.

### **Providing quality ... AND control**

Individuals in supported care have a higher quality of life than in decades past. Our field has moved away from a purely segregation based system to one of integration with a focus on quality of life. This has resulted in long lasting and positive change. This change is due in part to agencies supporting greater autonomy and self-determination for the people they support. From day-to-day decisions, like what to eat, to more significant ones, like what job they want, our clients now have more autonomy than ever before. But it is that enough?

The ability to make decisions for ourselves is a fundamental right. More importantly, it is also a basic need. People, ALL people, want to be in charge of their own lives. For years the assumption was that our clients' decisions must be made for them. The default position towards the very people we support was one of assumed authority. How much has that changed in practice?

We have relinquished control in areas we feel are acceptable, those areas we consider to be "low risk". But some of the more important decisions...finances, medical, even sexual decisions are often decided by family members or staff. Our clients may have relinquished control over some of the most important areas of their lives and many don't even realize it. Why do we, as caregivers, do this? It comes from a place of care, for the

most part. It comes from a place of concern. Whether we are staff, parents or someone in the community, the decision to take away our clients' decisions does not come from malice. But its impact cannot be ignored.

While we are trying to make positive change, we need to acknowledge that past practice has created a culture of dependence. We taught individuals that they need us, that they cannot make their own decisions and cannot be autonomous. Agencies may have provided clients with the opportunity to contribute to decisions but not the power to make them. Advocacy must come from the clients themselves, but all too often staff make the most important decisions for the people they support. Staff advocating for clients, no matter the intention, is taking power from them. And this all begins with a signature...

## **What is a Signature**

In the general population, the concept of a signature is reinforced from an early age. Personally speaking, I was taught not to sign ANYTHING I hadn't read. This was regularly hammered into me by my parents and TV shows. When I became a teenager, before I even had anything to sign, I knew I would read a document first before agreeing to its content. This is because I was taught a critical concept, i.e., my signature is powerful. It is my way of telling the world "Yes, I agree with this. You have my consent". That is a very important lesson; the signature means consent. It is a lesson that history neglected to teach the people we support.

## **A Signature is Power**

"Just sign it"

"Don't worry...I can get him to sign anything"

How many times have we heard this? How many times have we uttered it ourselves. Picture Steve. Steve is a 34-year-old man with a mild intellectual disability. Steve is at the doctor's office discussing a medical condition. Steve is accompanied to this meeting, as always, by his primary staff. His staff is listening intently to all the benefits and risks of this new treatment; there are side effects but this is what's best for Steve, he thinks. The doctor needs Steve to consent to this treatment and offers a form to the staff; the staff hands it to Steve imploring, "You need to sign this. Trust me". Steve obligingly signs the paper. Steve has now legally consented to the treatment and acknowledges all the side effects and legally waives any liability the doctor may have.

The problem is Steve doesn't know that. Steve just wrote his name where his staff told him to write his name. That makes the staff happy, which means they'll probably stop and go shopping after they leave the doctor's office. Steve loves shopping. The staff is happy because he/ she got Steve to consent to a necessary medical procedure. Steve is happy because he wrote his name down where the staff told him.

This story should make you uncomfortable....because you've likely met a dozen Steves. Lets get over that discomfort and acknowledge how often this situation occurs. And let's also acknowledge that Steve may understand the concept of consent. He took a class that taught him he can use his voice to say 'No'. When someone tries to touch him, when someone tries to hurt him, Steve knows to speak up. He knows when to say 'Yes' and when to say 'No'. The problem is Steve doesn't realize that his signature is a very powerful way of saying 'Yes'.

## **A Signature means Yes**

For us, a signature is our way of agreeing to something, i.e., entering into a contract with set terms. For our

clients, however, it is equivalent to giving something up. Their signature has power but whether they are signing a confidentiality agreement, consent form or other contract, they are usually giving away their authority. They are giving away their rights – their right to privacy, their rights over their own money or even rights they have over their own bodies. The individuals we support sign away many rights and they need to be fully aware of this...fully aware of what their signature means.

### **Yes, You Can Do This to Me**

As discussed in the story about Steve, medication management and medical procedures are a reality for many in our care. People often have conditions and illnesses that require care and treatment. The same can be said for mental health issues, which are disproportionately represented in this population. As such, decisions need to be made, weighing the pros and cons involved in consenting to treatment. Treatment can range from medication to behaviour therapy, but in any case a signature is a client's way of saying "Yes". Yes, you can give me this medication...yes you can ask me these questions...yes you can do this to me. To ensure this is the case, the following should always be verified to be true before a client signs a consent form for any treatment:

1. I know what you're going to do to me
2. I know how it could help me
3. I know how it could hurt me
4. I want you to do it

### **Yes, You Can Talk About This**

I'm going to set the stage: a case conference for a man in supported living. At the table are the man's parents, his case manager, two of his direct support staff, a behaviour therapist and a psychiatrist. At this table sit seven individuals, each with different and likely personal information about a single man. They share stories and details of his diet, bowel movements, masturbatory habits, living history and his current medications. They all speak openly and honestly, with the intent of providing the best support.

Now, imagine YOUR family, doctor, co-workers and friends are sitting at a table, on a quarterly basis, sharing the most intimate moments and aspects of YOUR life? The lives of the individuals we support are intrinsically more public than ours. To a degree this is a necessary evil; however, the extent to which information is shared is dramatic. Our clients' personal lives are laid bare but who needs to know what.

Clients need to understand how much information is shared by the service provider and how public their lives are; we can preach privacy but until we demonstrate and enforce it, policy does not become action. Before clients sign confidentiality agreements with a service provider, the following should be made clear and agreed to:

1. You can talk to these people
2. You can talk about these things
3. You cannot talk about these things

### **Rights**

The individuals we support come from a very different culture and set of experiences. There are social norms, rules and rights that are so engrained in *our* culture that we take them for granted. However, we cannot

assume they are equally understood by the ID population and may need to be explicitly taught.

The following are rights that are critical to learn when discussing signatures.

### **The Right to Say No**

Hand over hand...compliance training...from an early age our clients are taught that saying 'No' is rarely a viable option. Saying 'No' means non-compliance and leads to force or coercion, under the guise of therapy and training. This population has been dissuaded from saying 'No' or offering resistance. So we must teach them.

We must teach our clients that when they are asked to sign a document, they can say 'No'. This may sound strange to some, especially those outside our field. But very few individuals I've met would feel comfortable saying 'No' to staff, especially their favourite staff...their trusted staff. This, after all, is who will likely speak with the individual about the importance of signing. We need to reinforce the right to say 'No'..... 'No' to your staff, 'No' to your doctor, 'No' even to your parents. Just because THEY want you to sign a document doesn't mean YOU want to sign it.

### **The Right to Ask Questions**

Plain language. The goal for consent and confidentiality agreements is plain language, written in a way the target audience will fully understand it. Practically speaking, this is extremely difficult. The ID population is very diverse, with various learning and cognitive levels. Some clients will wear a cloak of competence, feigning understanding to avoid embarrassment or reprimand. A climate must be created where clients can ask questions without fear. Before signing anything, clients should be encouraged and assisted in asking questions for clarification.

Individuals might feel shy or uncertain in asking questions and possibly insulting someone. Again, one must understand how deeply entrenched compliance is for many of these individuals and how emotionally difficult any perceived insubordination would be for them. Questioning authority is a foreign concept; therefore many clients agree to things out of habit and social pressure rather than genuine agreement. Clients should feel comfortable requesting more information before signing and even negotiating the terms of an agreement. This starts with education, i.e., teaching our clients that they have this right. Then we must provide the opportunity for them to *use* this skill.

### **Challenges to Change**

To put it bluntly, we ourselves are the biggest challenge to bringing about this change. The resistance to change will come from the culture of staff and supports. The clients are the loudest advocates, and they welcome more freedom and control. We understand, however, that with increased responsibility comes increased risk, and our clients may make bad decisions. They may decline to sign over power and instead keep it for themselves. They may make decisions that we don't agree with. We may be tempted to convince them to sign for "their own good". We must resist this urge, resist falling back into our bad habits.

### **What Senior Leaders Can Do to Overcome These Challenges**

Such widespread change requires support from all levels of an agency. But it begins with management. The organizational policy and cultural change must be driven top down. An agency must subscribe to the philosophy in order to support the changes we are proposing, and to facilitate this, leaders can initiate the

following changes:

1. Develop and support a Self-Advocate Group within your organization. If you already have one, ensure that you have direct and regular communications with the members. Their value to the organization is determined by their interactions with the senior leaders and Board. To demonstrate a willingness to foster learning and engagement for members of the self-advocate group, you can provide funding for self-advocate conferences at a local or national level. Ultimately, this training would be of greatest benefit if delivered by self-advocates for self-advocates. This begins by developing a strong and powerful group.
2. Create policies that clearly indicate signatures will be respected. Staff need to know that if a client signs a confidentiality agreement that denies parental access to information, staff will not be in trouble for acting on that signature. People who have the power to make decisions sometimes make decisions that upset others. Policies need to assure both client and staff that they will not be in trouble for making and following a decision.
3. Ensure impartial third party witness to consent process and signature. The use of a third party witness, such as a case manager or advocate, serves two purposes. First, it provides the individual signing with an objective voice, if needed, to help weigh the pros and cons of signing and ensures the decision is well informed. As well, a third party witness' signature serves to demonstrate that consent was given without coercion.
4. Provide education for parents and care providers about decision making in the context of adulthood. It's important that people be made aware of the new direction taken by the organization in its goal to support people with disabilities in such a way that their voice, through their signature, has power.
5. Plain language: Plain language documentation should be the goal and standard of any agency. There should always be a push to create documents and contracts in terms that our clients can clearly understand. This will help ensure they are fully aware of what they are signing. History has taught us that failing this, our clients are more likely to acquiesce to our suggestions and sign, possibly agreeing to something without fully understanding the consequences.
6. Never assume decision making power: Often, far too often, parents and caregivers assume they are the legal consent sources for their adult children in supported care. Legally speaking this is not always the case. Obtaining a substitute decision maker or transferring decision making power is a legal procedure and it is typically undertaken only in one area of the individual's life. The aim should be to provide the individuals we support with the greatest autonomy and opportunities to demonstrate independence. It is critical that agencies assume that *adults can make their own decisions.*
7. Education: The above policies will provide individuals the opportunity to make well-informed decisions. However, the onus should still be on the agencies to provide the education our clients need to manage their autonomy and appropriately exercise their rights. Clients should be provided a curriculum highlighting the importance and power of their signatures, including the documents they may be asked to sign. It is critical that our clients understand the ways in which their signatures can be used...and abused.

## Summary:

A signature is a powerful thing. It says 'Yes'. It provides consent. It can give someone control over your finances, your health information and even your life. We support a population of individuals who need support and often need guidance. It can be very tempting to convince them, gently, to use their signature for their own good. Because we know better, it is justified, right? We need to remember: just because you can get someone to sign, doesn't mean you *should*. A signature is a powerful thing, and in our role as service providers we must respect that. Respect the power of the signature and instill in our clients a respect for and understanding of it.

## About the author:

Jordan Hoath currently works in the P.A.T.H.S clinic at Mackenzie Health as a Behaviour Consultant, providing assessment and treatment to individuals with intellectual disabilities and problematic sexual behaviour. He has been in the field of disability for over 10 years in a variety of front line and consultation roles and is currently completing his M.A. through Brock University.

