

Service, Support and Success: The Direct Support Worker Newsletter

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“You Just Don’t Do That!”

Drawing the Line Between Direct Support Staff and People with Disabilities

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When it comes to going out in the community, we can all think of things that other people do, people we don’t really know, that drive us nuts. We all have things that irk us, things that make us think, “Really? What are you *doing*?” One example of this is when people invade your personal space. How many times have you been in a line-up somewhere and the person behind you is standing so close to you that you can feel them breathing? Or you are walking on a very spacious street and someone walks past you and brushes your side with their body? Sometimes you just want to say, “Back off and give me some space!” Yup, we’re talking about the “B” word...boundaries. We all have our own boundaries that we don’t like being crossed. It is interesting to note that all human cultures have boundaries, no matter where you are in the world there are parents saying to children, “You just don’t do that!” Thankfully, there are some “common sense” boundaries that we can follow in human services that keep everyone safe and well supported.

For the most part, if you are meeting someone for the first time, you would likely shake their hand rather than give them a big, tight hug. If you saw someone coughing and sniffing on the street, you probably wouldn’t put a tissue up to their nose and tell them to blow. Most of us would be weirded out if we were on the receiving end of these interactions because, well, *you just don’t do that*.

Wait a minute. Is this really common sense? Aren’t we taught these appropriate social cues and gestures from a young age? Being able to differentiate between strangers, friends, family, and acquaintances is taught to children as community safety rules from as young as two years of age (remember the popular social circle diagram?). People in our community have different roles based on how we have categorized them: stranger, acquaintance, friend, family, intimate partner. It is even more complex than this, as we all have different levels of friends and family, and maybe even intimate partners depending on what you’re in to. I don’t know how we keep it all together.

Who am I kidding? There are a group of people who are not commonly taught these community safety and social skills. People with intellectual and developmental disabilities. For those who have moved from institutional to community living, direct support staff not only have to work to eliminate inappropriate behaviours learned in the institutions, but also to teach appropriate boundaries and behaviours. Realistically, how do individuals with disabilities learn about boundaries? They learn through modelling from the people they are around most, from their interactions with direct support staff.

It can be difficult for someone without a disability to grasp boundaries and appropriate social interactions. We all feel socially awkward sometimes. So, it can be extremely challenging for someone with a disability who has never been taught these skills and has difficulty with abstract thinking.

Being a direct support staff is a challenging job, especially when it comes to boundaries. We work closely with these people almost everyday. We may even feel a close connection to them, we develop soft spots, and our emotions get involved, so crossing the professionalism line naturally happens. We're human. Where our job becomes even more difficult is when we must enforce and maintain healthy boundaries with the people we support, people who we know and understand well for many years, people we have become comfortable with.

Some of you might be thinking, "Oh no, not boundaries again. I know all this already!" Well, situations of inappropriate boundaries still happen more often than you might think, and you might be some part of these situations without realizing it. So let's put it all out on the table. The following are examples and situations where staff can cross boundaries with people with disabilities in their care.

Up-close and Very Personal

1. *Personal Care.* Some people with disabilities require full support with extremely personal and intimate tasks such as eating, bathing, changing, daily hygiene, and getting into bed. By having to assist some people with disabilities with these tasks, we are already in their personal space and beyond, making it even more important to be cognisant of this and keeping it as professional as possible. Any additional and unnecessary touching during these tasks should be avoided, as it takes the degree of intimacy and closeness between staff and the individual up a level. This can include a staff member rubbing an individual's back while going to sleep, or unnecessarily touching their head, arm, shoulder, or other parts of their body in an affectionate manner during any of the activities of daily living. Of course it is important to make sure the individual is comfortable, however, this can be done in other ways, such as talking to them, or even singing a song.
2. *Outings and Activities.* Sometimes direct support staff take the same individual out for certain activities or outings in the community. This isn't referring to individualized outings, but outings that any other person in the home could enjoy or benefit from. In a home of 4 people, Jimmy always takes Bill grocery shopping. Let's face it, deep down, we all have our favourites. This should not be made known to the people we support, through any form of language or our actions. What kind of message does this send to the individual, as well as others in the home? As a staff, having a favourite individual you

support and showing it through your words or actions is crossing the line. It tells the individual that you like them more than other people in the home, and that they are especially deserving of more of your time and attention. This is no longer a professional staff-client relationship. If you have favourites, keep it to yourself and ensure every individual you support has an equal opportunity to attend outings and participate in activities.

3. *Seat Belts.* This warranted a bullet point of its own. First and foremost, if an individual with a disability is capable of putting on their own seat belt, even if it takes them a long time, wait for them to do it themselves. Sometimes a person with a disability cannot buckle up themselves and requires staff assistance. To put on someone else's seatbelt means you are going to be in their personal space, so be mindful of this and try to keep as much distance as possible. Pull the seatbelt out as far as it can go. This task is the epitome of violating personal space. Too often, staff get so close to the individual and, let's state the obvious – some female staff are well endowed, making it a free peep show for the person getting buckled up. Staff-client boundary officially gone.

It's a Job, Not a Date

4. *Dancing.* Direct support staff may attend Christmas parties, Halloween parties, New Years Eve parties, and other various gatherings with people with disabilities that involve music and dancing. Most dancing involves physical contact, whether it is holding hands or through slow dancing. This type of dancing that involves touch needs to be avoided. Other types of dancing like "fast dancing" where touch is not involved is a safe zone, as this is seen more as a social activity than an intimate one. People dance with their parents, their children, aunts, uncles, and co-workers all the time. It is important to draw this firm boundary with the people we support so that the professional relationship is clear. On the other hand, if we know that an individual we support has a crush on us as a staff, is it advisable to dance with them? Probably not, as this could potentially send the wrong message, just as it would with anyone else in our lives.
5. *Holding Hands and Hugs.* Sometimes direct support staff feel the need to hold hands with people with disabilities to whom they provide care. It could be a way of showing we care, a form of affection and comfort, or it could be to help guide those who have difficulties with mobility. This gesture is too intimate and sends the wrong message to the individual about appropriate boundaries. There are other more appropriate ways to show caring, and someone who needs help with mobility can hold on to the staff member's forearm or elbow area.

Hugging people with disabilities whom we support has sparked some debate. To put it simply, there is one rule we should all remember as support staff for people with disabilities. Depending on the context, side hugs are okay, any other form of hugs, such as a "front hug" is not. In terms of front hugs, close friends give hugs. Family give hugs. Intimate partners give hugs. Staff who are in a paid relationship with an individual with a disability should not be giving or receiving these types of hugs. There are situations where giving and receiving side hugs is an appropriate gesture if you've known the

individual for more than 6 months, such as during times of congratulations, celebration, and grief. Otherwise, keep the roles of different relationships clear. Keep it to hand shakes, high fives, back pats, and the “fist bump.”

6. *Gifts and their Intentions.* Buying gifts for the people we provide support to should be avoided because it can send confusing messages about the type of relationship we have with the individual. The person receiving the gift can attribute deep meaning and affection behind the gift, even if the staff did not intend it that way. This creates a false sense of a more meaningful relationship that can have very hurtful consequences when the staff member no longer works with that individual.
7. *Phone Calls.* Sometimes direct support staff give out their personal phone numbers to the people with disabilities they support as a sort of offering to receive phone calls from them on their days off. This is unacceptable because we are no longer dealing with an appropriate professional relationship. This opens the door to extra communication and interactions that are beyond the scope of our jobs, and pushing the limits of an appropriate staff-client relationship.
8. *Our Family.* Bringing the people with disabilities we support home with us for holidays or special occasions is off limits. On the surface, it seems like a very generous and thoughtful gesture, which you may very well intend it to be, however, this is blurring the line of the relationship between staff and the people in our care. Sometimes we feel sorry for the people we support because they may not have family or friends to with whom to spend special occasions. Bringing them home to our families is not part of the job and gives the individual a sense of a more meaningful relationship that isn't really there.
9. *Their Family.* Another concern with crossing boundaries that can occur is when staff become too close and too involved with the family of the people with disabilities in our care. Yes, it is our job to support these individuals to family events if they need it, or talk to the family about how they are doing. However, sometimes the family may feel a close connection with the staff and always request to speak with them or invite them to special events, or vice versa. This seems harmless, what's so wrong with becoming close with the families? Doesn't this make me a better support staff? We need to maintain a professional working relationship with the people we support, including their families. Having the same staff always attend special events or always talking with the family is changing the dynamic of a working relationship into something more. Emotions get involved, judgement becomes clouded, and we can no longer support the individual in an unbiased and professional manner. Staff have to recognize when they are becoming too close to the family, and put the wheels in motion to back off to an appropriate level.

People with Disabilities Cross Boundaries Too!

Okay, okay, let's take the heat off the staff for a minute. Crossing boundaries can go both ways, sometimes, the people with disabilities we provide care to can be inappropriate with staff. Whew! Finally, some pressure is off the staff and the responsibility can be put on someone else, right? Wrong. The people with disabilities we provide support to can cross the line and be inappropriate with their staff, but the onus is still on the staff to speak up and tell the individual

that what they are doing is unacceptable. Here are some examples that do happen of when the people we support cross the line, and how it is up to us, the staff, to respond appropriately.

Crushes, Affections, and Attractions

We all know that people with disabilities, no matter how severe the disability, have sexual needs and desires just like the rest of us, right? Good. The people we support may develop crushes on their staff or become sexually attracted to them. This happens more often than we think, but it is not acknowledged. It is a common error for staff to think things like, “He has a disability, he doesn’t know what he is doing,” or “Aww, how cute! Sarah has a crush on me, that’s so sweet.” Let me put this bluntly. It is not cute. It is not sweet. They DO know what they are doing. It can be downright dangerous.

1. *Initiating Hugs.* Talking about hugs, *again*? It is worth mentioning here as well because of how commonly this happens. The people we support may see a staff and say, “Where’s my hug?” or become excited to see a certain staff and run up and give him/her a hug. This is where we as staff really need to step up and say “No.” Use the other forms of greetings as previously mentioned, and let the person know you aren’t comfortable with them hugging you. There may or may not be a sexual attraction behind this hug, but it doesn’t matter. If they can hug you, then they can hug someone they don’t know in the community without consent, and that is assault. Plain and simple.
2. *Showing High Interest in Personal Life.* Really? Just because someone I support is showing interest in my life, you are saying it is inappropriate? Two factors must be present here: a crush or sexual interest *and* showing high interest in your personal life. There are clear boundaries that must be present with sharing personal information with the people we support when a crush or affection isn’t present as well, but we won’t get into that here. To maintain a professional relationship with the people we support, we should not delve into detail about our personal life. If they ask personal questions, we have to be able to say, “I’m your staff and don’t feel comfortable answering that question” so that they know they crossed a boundary and this isn’t the kind of information that should be shared between them and a paid worker. It is our job to have knowledge about the people in our care in order to support them effectively, while still maintaining as much privacy as possible. It is not their job to know details about our personal lives.
3. *Breasts’ and Buttocks.’* The people we support are smart. It does happen where they “accidentally” graze, touch, brush, or skim a staff members breasts, buttocks, or other more intimate parts of their bodies (abdomen, sides, back). *Please* do not assume this was by accident. Of course you don’t want to turn into a cynic and assume everything has negative or inappropriate intentions, but assuming the inappropriate touch was an accident creates more harm than good. If this happens, we need to tell the individual very sternly, “I am not okay with how you just touched me. Don’t do that again.” Let’s say it wasn’t intentional and there were no inappropriate or sexual intentions. We still need to confront the individual and tell them that it is unacceptable and they should be providing more personal space so that wouldn’t happen in the first place. Remember,

they are living in the community now. Whatever they get away with in front of their staff tells them they can get away with it with a community member which won't always be the case.

4. *Compliments.* When an individual with a disability whom we support goes over the top with complimenting us, it's a fairly obvious sign that they have a crush. 'Expected compliments,' like when you dye your hair or get a new hair cut, are fine, but not when the same individual consistently comments on the nice colour of the shirt you're wearing, how good you look today, or how skilled you are at making coffee and tea. It is always nice to hear compliments, but we shouldn't be accepting them from the people we support when it is clear they have a crush. You might be thinking, "What's so wrong with giving compliments? That's an appropriate social behaviour; you want us to teach them that something nice is actually wrong?" Not exactly. If they want to compliment someone with a disability who *isn't* a staff and who they have an interest in, that's great! It might lead to a date and a relationship with that person! Constantly complimenting a staff they have a crush on may lead them to believe an intimate relationship is possible, when it's not. Among the series of compliments, let them know, "I would rather not hear that from you." Save the compliments and smooth talking for someone with whom they can have an appropriate relationship.

To drive the point home, let's throw a seemingly obvious question out there: How do we *know* if someone we support has a crush? How can you tell? Well, how can you tell if someone without a disability has a crush on you? It is usually very obvious, so don't think that someone with a disability doesn't fall under the same "crush behaviours" as someone without a disability. Sometimes they can even be quite blunt about it! However, for those of us who can be clueless about when someone likes us, ask yourself these questions: Do they consistently go out of their way to talk to you and/or be near you? Do they frequently touch you or want to make physical contact? Do they ask a lot of personal questions? Are they constantly complimenting you? Do they stare at you? Do they act this way fairly equally with other staff? These questions do not provide definitive answers to the 'crush question,' they are simply things to keep in mind and look out for. The rest of the time, go with your gut.

Note: In no way are these examples exhaustive of the ways the people with disabilities we support can be inappropriate with staff. Just always keep in mind that it is the staff's responsibility to say, "No, that is not okay."

What's the Big Deal?

Most staff aren't crossing boundaries on purpose or to be harmful in any way. We likely don't know that what we are doing isn't okay and the negative implications it can have on the individual. Sometimes, we just don't think. Or maybe you outright disagree and see nothing wrong with the above examples. Well, let's talk about *why* these are crossing boundaries and the negative affects it can have on an individual with a disability whom we support.

1. *We Are Their Staff. Not Their Friends. Not Their Date.* Most of the above examples are things you would do in a more meaningful relationship such as with a friend, family, or intimate partner. We need to be clear with the people we support that we are not friends, family, or someone they can date. *We do not pay our friends to hang out with us.* We need to teach them the true meaning of a friendship so that they can develop their own and do all the appropriate gestures to maintain a healthy friendship. If we act like friends through our gestures and actions, it creates a very confusing situation for that individual. There's a lot of staff turnover in this field – people quit, switch locations, get promoted and so forth. There will come a time when you may not support the same people anymore, and if we as staff have made them feel like they had a close, beyond professional relationship with us, when we leave, they will feel like they lost a close friend for no reason. What did they do wrong? That hurts. It is not teaching them the proper roles of having a friendship which is hindering the skills they need to learn to develop and maintain relationships of their own.
2. *People Do What People See.* This goes back to Bandura's social learning theory where we learn from each other through observation, imitation, and modelling. The people we support are learning from the way their direct support staff interact with them. Ask yourself, who can go in your 'personal space bubble'? Likely your close friends, family, and intimate partners. Since it has been determined that we are not their friends, we should not be in their bubble. Otherwise, they are learning from us that if we can violate their personal space and we aren't friends, family, or partners, then they can do the same to someone they barely know. It's a simple equation, really. We are the people they are around most and, therefore, the people they will learn social skills and appropriate boundaries from. If we aren't practicing appropriate boundaries with them, then they will not practice appropriate boundaries with others. If we allow them to be inappropriate with us, they will continue to be inappropriate with others. Let's say it like it is. People in the community are already uncomfortable around people with disabilities. There is a stigma attached to disability that brings a host of discrimination. The last thing we want to do is validate their discomfort by inadvertently teaching the people we support inappropriate boundaries and social skills, either by our own inappropriate behaviour or by not calling them out on theirs. This will have harmful consequences on their quality of life, including their ability to make and maintain close relationships, the ability to participate fully in community events and activities, feeling welcome and accepted, and even result in negative consequences with the law.

So there you have it. Boundaries. There's a lot to be said on this topic, but hopefully this article helps you become aware of the various lines that can be crossed and why it is so important to practice appropriate boundaries with the people we support. A common concern among direct support staff regarding this issue is, "What if the people we support have no family and friends?" This is quite common. So then, shouldn't we, the staff, fill that void and act as a friend or family member? No. The key word there is *act*. We would only be acting like a friend or family, not truly being their friend or family. What we can do is help them develop the skills and learn the appropriate boundaries in order to make their own friends who eventually, may become just as close as family. Think of our role as a direct support staff. We are there to teach. We are there

to help. We are there to support. We are there to advocate. Always be mindful of your interactions with the people with disabilities whom you support, so that you can equip them with the skills and knowledge to have a fulfilled life, with acquaintances, friends, family, and intimate partners.

About the Author: Stephanie is currently completing a Masters of Arts degree in Applied Disability Studies, specializing in Applied Behaviour Analysis at Brock University. Since finishing her undergraduate degree, she has been working as a front line staff with people with disabilities, and, most recently, worked part time at Vita Community Living Services as a direct support staff with people who have disabilities and a history of offending behaviour.

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