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The Three Faces of Integration and Inclusion (and a choice you need to make)

By: Dave Hingsburger

Inclusion isn't an outing. Taking someone to the movies, going shopping, going to the park – these are 'outings' not inclusion.

Integration isn't an activity. Going swimming, going for a walk, going to a restaurant, having a coffee in a coffee shop – these are 'activities' not inclusion.

Inclusion and integration (I:I) can't be plotted out on a calendar, written in red for outings and green for activities. I and I can't be counted and graphed and presented at a team meeting, or to management, or at a conference.

I've never said, ever in my life, "Joe, do you want to go to the mall to experience my inclusion and integration with me?" We must remember that when people lived in institutions they had outings and activities too. We, however, work in the community and, therefore, should have a better understanding of what those two words mean.

What the Dictionary Says:

Inclusion: the action or state of including or of being included within a group

Integration: full participation in society

Being included within a group, having full participation in society sounds nice doesn't it? But what it doesn't sound like is a van ride and drive-thru coffee.

I'm going to be using the short form for integration and inclusion in the rest of this article (I:I), not just because it's shorter and, therefore, easier to type, but because it also looks like a graphic representation of what those two words mean. I:I. One person (I) in relationship to, in connection with another person (I). Because that's what this is about – relationships. Relationships with people, relationships with groups of people, relationships with the community and community helpers.

**Editors: Dave Hingsburger, M.Ed.
Angie Nethcott, M.A., RP**



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The Faces

I:ME

Let's start with the primary relationship that we all need to have. We often speak of I:I in regards to the community, but we need to start with the relationship we have with ourselves. Sometimes we are wanting to jump to I:I when we've missed I:Me. Me in relationship to myself, my I is of ultimate importance to how I relate to everything else. We all need to discover who we are, what we love, who we love and where our passions lie.

So many people have been pushed into the community when they've had no real opportunity to take the journey within. So many people have been told what they like, what they don't like, what they want, and what they don't want, that they have learned that they like what makes the staff happy. What they do is acquiesce to staff's tastes in music, in food, in recreational activities, in watching television.

I worked with a fellow who had lived in an institution for much of his life and, when he moved out, the staff said during a transition meeting how much they were going to miss 'coffee time' with the person moving out. "They love coffee, it's the best part of the day for them, sitting down for a coffee, going out for a coffee. Make sure he has coffee because he just loves it."

So that's what we did.

But a direct support professional began to wonder if this were really the case. She did not see the excitement on his face when coffee was offered. At first, she put that down to the fact that he was missing the staff he had been with for so long. But then she wondered. Under guidance from a clinician, it was decided to attempt to offer him other kinds of hot drinks. It turns out that he's a tea drinker, and that he likes all sorts of flavoured teas. From that day forward, he has always turned down coffee and always smiles a satisfied smile after his sip of tea.

Our power and our choices sometimes translate into "make me happy and do, or want what I do or what I want." It's time to take a step back.

How do we do this? Well the answer is simple. Do what you did for yourself. Experiment with things. Try out new things; find people and situations where you feel comfortable versus those where you don't. None of us ever really arrive at 'finished.' None of us know how our tastes will change, how our experiences will shape us. The same is true for people with disabilities.

Except.

Their willingness to communicate true wants and desires may be fraught with fear. Where there is punishment for truth, there is no truth. "I get so frustrated because she only ever tells me what she thinks I want to hear." That statement is so often said but rarely ever heard. What it means is that she is so afraid of you and your reaction that she is giving you what you want to avoid being hurt, or punished, or ridiculed. Think of the history behind that statement.

Opening the world, experience by experience, trial by trail can only be done when your critical tongue is stilled. "You don't really like *that* do you?" This journey into one's self is a delicate and fragile one, direct support staff need to understand their role here isn't one of commentary but one of discovery. It's an honour to be able to do this with another person and that honour needs to be reflected in everything said or done.

The discovery of passions and interests and things that give joy will give you the groundwork and pathway toward I:I.

The next relationship that we need to look at is the relationship that people with disabilities have with you and the value they experience from their relationship with you as a direct support professional.

I:DSP

I was meeting someone at their gym after their workout, and I waited by the pool where there were people also sitting and waiting on the benches outside the pool. The view of the pool was unobstructed because it was floor to ceiling window. In the pool was a group of six people with intellectual disabilities and three staff. One staff was playing catch with four of the folks in the pool. Two staff were standing in the hot tub talking to each other; there were two people with disabilities in the pool with them, one on either side and, at no time during my wait, did they look at, or interact with the people they were supporting.

What? They thought that no one was looking? Yes, one staff was demonstrating respect and inclusion; he chose an activity that was active on both parts. The ball needed to be thrown and then thrown back. Those people with whom he was involved were experiencing inclusion. Let's go back to that definition: (the) action or state of including or of being included within a group. You see those words turn into power in the hands of a staff who fully respects the people he serves, the job he has, and the mission of his agency. The other two are actively isolating two other people, two people who sat unacknowledged. Actively isolating. Don't do the 'they didn't mean to' because what they did was mean. They isolated two people who depended on their care and support. They communicated that they didn't have enough worth or value to be spoken to or to be considered social equals. Worst of all, the people watching saw them, standing in the warm water, and identified with them. They thought their reaction to disability was normal, and the guy throwing the ball as exceptional to the point of irrelevance. They learned that it was okay for them, like the staff, to see disability as something that makes a person unworthy of time and attention and, therefore, unwelcome in their world. We are watched. What we do matters.

It's harder for DSP's to think about themselves as people who introduce or strengthen the possibilities and hopes that people with disabilities have for a full life these days. It takes a thousand acts of intention throughout a shift. It means fighting the urge to be on the phone, texting selfies, and tweeting funny quotes, and living life in Facebook. These things pull you back and away from real people in the real world who need you now.

But imagine you were on a first date; imagine that you were really interested in the person across the table. Imagine as you were talking, they pulled out their phone, without apology, and began to read their messages, laugh and text back. My guess is that you would consider yourself uninteresting, yourself not worth your date's time, yourself as having less value than the people on the phone. We do this to ourselves. We assume that we lack value. We forget that it's rude to engage in that behaviour.

And how much worse is it when you are paid to give time to people, and you thief that time back by giving time to others on the phone. It's worse because you are communicating to people who have often lived without a sense of worth that they aren't worthy enough of your

time and your attention. People impoverished through the devaluing of their lives often wait for and thrive from the attention of their staff. Think about it. Should your time and your attention really matter as much as it does? No, of course not. But it does. Not because of you. But because of the burden of history that people carry. And their burden, as big as it is, isn't a place to sit and check emails.

And about the idea that: "I'll check so see how many 'likes' I got for my post, it'll only take a couple of seconds."

No it won't.

And even if you manage 'just a few seconds,' do you remember how long that felt for you, when you were dependent on someone else for assistance, for an answer, for information? If you've ever been in that position, you were probably screaming, in your mind, at the person you were waiting for ... "STOP THAT AND ATTEND TO ME." So a few seconds is a really long time.

Notice how desperate you are for 'likes,' and how much you want the approval and attention of others. Notice that many of the people you support want the same thing, only from you. You have the capacity to give what you want. There's an old expression that predates Facebook likes and comments. I'll translate it into DSP language: Do unto those who you are privileged to support what you would have others do unto you.

When your attention and focus is on something other than your job, the result is isolation versus I:I.

Inclusion and integration begins at home. It begins wherever you are, and whatever you are doing to support an individual. Do you give space for people to determine their own pathway? Do you listen, without judgment, to the choices that people make? Does your behaviour – all of it – communicate value and worthiness to the people you support. Are they learning from you about reciprocity and respect and regard? Are you readying people for relationships by encouraging relationship skills through modelling those skills in interactions between the two of you?

If you practice respect, you will get good at it.

If you practice respect, others will learn from you.

If you practice respect, you will create a culture of respect around you.

I:The World

Take a look at this video, really, honestly, take the time before reading on:

<https://vimeo.com/251019288>

The video shows how torn a man with Down syndrome is by the forces around him. Finally, someone who would make a great DSP pulls him aside and asks him, and him alone, to make a decision. What does HE want? Separate from his mother and father who want different things from him in that moment, what does he want?

That's where and how we connect with our world. We first discover our passions; we then look for others who share those passions. Once we find them, we start on a level playing field.

One thing that is important is that we have not really understood the smallness of the word community. Mostly we think of COMMUNITY as this big place that happens right outside our door step. People have not been to the community because they've been to the mall. This has no real bearing on I:I.

Consider the fact that most of us relate to something different. The COMMUNITY of smaller communities. For example, as a gay man, I go to events where I feel welcomed. There is a particular bar I like; there are all sorts of ways for me to go to places where welcome is established – sports leagues, book clubs, bridge nights. I have a lot of choices. Then there's the place I go for tea where I am known and welcomed, where the shock of my difference as a fat-wheelchair user has worn off, and I'm just Dave to everyone there. There's the bookstore where we like to spend a lot of time; we know the others who also linger, loving the smell of books. Every passion, every difference, has community options where the welcome mat tells the truth.

I was at an event recently where I was behind a staff person supporting someone with a disability. A clerk asked the staff if he'd like to try a product. The staff, who was clearly interested, said to the person he was supporting, "Would you like to try it?" The person gave a whispered, "Yes." The staff suggested that the person he was supporting ask to try it. He did. He ended up in a conversation about the product with the vendor while the staff looked on. Then the staff saw me and recognized me; he looked a little embarrassed, wondering if he'd done okay. He said, "I'm working so I figure this is his time to try things, not mine." I told him I totally agreed.

That's not a relationship between the person with a disability and the vendor, but it's I:I. It was him relating person-to-person with someone he didn't know, and he was using all of his social skills in the encounter.

Practice.

Relationships and friendships take practice.

This staff made it possible for the person supported to have the opportunity to practice I:I while experiencing I:I on a small scale.

That's what we do right?

We make it possible for connections to be made, for people to feel valued, and for someone who lived at the fringe to become part of the rug.

Summary

I:I (Integration and Inclusion) begins and ends with shared interests, passions and identities. But for people with intellectual disabilities, it's what happens in the middle that matters.

And that's us.

What we do matters.

We can communicate value and worth to people with disabilities.

We can communicate, through the way we work, that people with disabilities are deserving of respect.

Or not.

It's the decision of everyone who provides service who they want to be as a staff and how they want to spend their days.

About the Author

Dave Hingsburger, M.Ed., is the Director of Clinical and Educational Services for Vita Community Living Services, and is a well-known speaker, writer and consultant on the topics of disability, sexuality and self-advocacy.

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