

Service, Support and Success

The Direct Support Workers Newsletter

Cognitive Ramping: Principles of Plain Language and Accessible Communication



By: Dave Hingsburger

We have come a long way in our understanding of the need to adapt environments for people with disabilities. Curb cuts are common, automatic door openers are becoming more frequent, tall toilets and grab bars are no longer rarities. Physical disability is something that we, in the helping professions, understand needs adaptation. Yet for those who work with people with intellectual disabilities the idea of accessibility is still relatively new. Accessible communication is a new, and helpful, way of framing the need to adapt our language and our process of communication for people with intellectual disabilities – it's also one aspect of cognitive ramping.

If we saw someone pushing a wheelchair into a set of stairs and then being angry at the wheelchair user for the fact that the wheelchair isn't made to climb stairs, we'd be horrified. Yet it isn't uncommon to see someone completely frustrated and angry at someone with an intellectual disability who gets stuck at a 'cognitive curb' that they just can't get over. If we can't see the barrier, we assume it isn't there. We begin to treat people with intellectual disabilities as just being willful and stubborn and, god forbid, non-compliant.

In our frustration with those 'behaviours,' we can lose all sense of logic. Why would someone who is otherwise a happy-go-lucky person choose an issue or two just to make you upset? Do you really believe that the people you serve are up at night, down in the basement, plotting to ruin your day?

A Note from the Editors,

When this newsletter was begun, we envisioned something that would provide two things. First, to provide information that was interesting and relevant to the experience of providing direct support to people with intellectual disabilities. The second was to encourage anyone who was in any kind of care providing role to take their experience and expertise and write them up in article form for sharing. We have been more successful at one than the other. We really want to encourage submissions and we are willing to work with first time writers. The article that follows is set up in the format we prefer: Introduction, List of Suggestions or Ideas, Summary. We don't want long words or whacks of references; this isn't that kind of publication. So, if you have an idea, please contact us and talk about what you'd like to share. We would like to have more of a variety of voices here in the newsletter – so if you want to become a published author, if that's on your bucket list – it can happen.

Let's take a common frustration: Someone with a disability makes the same mistake over and over and over again, they engage in the same problem behaviour over and over and over again – and yet when you sit down to talk with them, they can always tell you what they should do, but THEY NEVER EVER EVER DO IT!! It drives you to apoplexy! Have you ever thought about why that was?

Notice that when we talk to someone about something we check out their understanding by saying something like, "Tell me what I've said?" Then we listen happily, congratulating ourselves along the way, when the person parrots back what we've said. So that means they get it, right? Wrong. Often people with intellectual disabilities are listening to repeat, not listening to comprehend. They know the question is coming, they know they have to pay attention to your words, so they simply 'learn' the answer. We all know, from personal experience that 'learning the answer' isn't the same as 'learning' at all.

Maybe we need to think about how to 'ramp learning' – even the smallest adaptation to your communication style or your teaching approach that is aimed at making information, ideas or concepts more acceptable is 'cognitive ramping.' It means that you are tailoring your approach (building a ramp) so that the person can learn new skills or new behaviours or understand new ideas.

Accessible Communication, Cognitive Ramping and Plain Language: Some Hints

- 1) **Get it Straight in Your Head First:** Before beginning, take some time to get yourself ready. Organize your mind, declutter your thoughts, and be clear about your objectives. If you are going to talk to someone about something important, then approach it like it matters – take time! Jumping from topic to topic, scrambling and unscrambling your thoughts, getting started and then pausing to figure out where you are and where you want to go is frustrating! Let's be clear, it's frustrating for everyone – but for people with intellectual disabilities it can be frustrating to the point of being debilitating. So map out what you want to achieve and how you want to achieve it – that done, get started.
- 2) **Start at the Beginning:** Have you ever had a conversation with someone that you just couldn't follow because they simply assumed that you knew what the hell they were talking about? What do you do? You begin to ask clarifying questions ... you say things like, "back up a moment," or "where is this coming from" ... you work really hard to understand the context of what's being said. Simply said, "Don't do that." Learn to start at the beginning, make sure the context is well establishing. Back up a few paces and ensure that you are clear about what is being said, why it's being said and where it fits into the conversation. Because you took time to 'get it straight in your head first' this shouldn't be too difficult to do.

- 3) **One Thing at a Time:** Whenever you are in a relationship, of any kind, with anyone, there is a tendency to bundle up a bunch of things together. A single issue becomes a laundry list of problems and concerns and frustrations. It's overwhelming. Stick to one thing at a time – don't let your desire to accentuate your point lead you to drag up a lot of history and a myriad of examples. The acronym K.I.S.S. ... Keep It Simple, Silly ... really does apply. Focus your attention on accomplishing what you set out to do.
- 4) **One Step at a Time:** Many of you will be familiar with using a task analysis for teaching a skill. This means that you break the skill down into its component parts and teach it one step at a time. Doing a task analysis will help in two ways. It will keep you organized AND it will remind you how difficult some things really are. Just write down all the steps involved in brushing your teeth and you'll find that, wow, it really is a lot to learn. Using a task analysis approach to communication should become a natural part of any meeting where there are things to be learned or achieved. Take the time to know what happens when.
- 5) **Use Repetition:** You may have noticed I've done this already.
- 6) **Watch Your Words:** I am forever convinced that most of us can live our lives without ever having to say 'contraindicated' ... big words for small concepts may pretty up language but they can obscure meaning. In this article thus far, I've used these words ... 'apoplexy,' 'debilitating,' 'myriad,' and even 'obscure.' Lovely words, but they shoot up the difficulty of reading this piece. "It drives you to apoplexy" and "It makes you mad" mean pretty much the same thing; one is much more accessible though. What matters is meaning. To get meaning across, keep your wording simple, no need to show off. It goes without saying that 'jargon' is unnecessary and for heaven's sake ...
- 7) **Avoid Acronyms:** I had to go see a specialist and when she was interviewing me, right at the start, she asked me if I had odious pee. I was a bit shocked at the question and answered, "No, my urine is normal." She looked up at me perplexed at what I had said. She said again, "Odious pee?" I answered again, "No, my urine is fine." As it turned out she was asking if I was receiving the Ontario Disability Support Program benefits. The acronym O.D.S.P. was unknown to me at the time because my work has never been about that aspect of disability. I heard something very different than what she was meaning. I'm glad that you know what those letters mean, that doesn't mean that everyone else does.
- 8) **Readability:** I was recently asked to look at and then write a summary of a piece of legislation that affects service delivery. I was game for the exercise and looked up the legislation on line. Yikes. In fact, YIKES squared. I was lost within minutes of reading. First, because it was really difficult to read. Their definitions of things that I thought I understood made me doubt if I understood anything at all. Further, it was mind numbingly dull; it was like my brain was on Novocain and I fought the desire to fall into a slumber. I gave up. Conceded defeat. I can't access and process information when it's presented in that manner. If you look up 'readability,' you'll find that they really look at a couple of things. Sentence length and number of syllables

are primary measurements. Well 'readability' can teach us something about 'speakability' ... a word I just made up ... Keep your sentences short, keep your words shorter. And, if you are communicating by writing, use a readability scale to determine if you are being clear. I just ran a section of this paper through this scale: <http://www.readabilityformulas.com/free-readability-formula-tests.php> and found that they say what I've done so far is 'fairly easy to read.' Rah, me. My problem, and I know it, is that I write sentences that are way too long. I've been working on changing this and have managed fairly well.

- 9) Get Off Your Butt: If someone with a disability is struggling to tell you something about what happened in the kitchen and you are in the living room ... go to the kitchen. Reduce the need for vocabulary; increase the opportunity for using gestures and indicating what happened where. Ever notice on 'cop shows' that they often take someone to 'the scene' to 'walk through it' ... ever wonder why they are doing that? Its way easier to tell a story in the place where it happened. Sometimes people with disabilities have difficulties with putting things in order or finding words for things – this can be alleviated by just being where the story happened. Not only that, this shows genuine interest in hearing and understanding what someone is saying.
- 10) Picture This: Using pictures as part of a communication process can make things so much easier. With everyone, or pretty much everyone having a camera phone, using it for communication just makes sense. Take a picture of each room of the place you work, let people use those pictures to help them communicate, use them yourself when you are describing something that you'd like the person to do or to understand. If you can show it, show it! Computers can be a help too – if someone is struggling to identify emotions, look up emotion faces on the computer ... let the person look at a bunch of faces. Go to Google, hit the button for images, type in the words "emotion" and "faces" and search. There are a wealth of images that pop right up. Doing this together can ease the frustration of a moment, it's fun and it's distracting to use the computer – looking together at these images can create something that feels more like an activity, a 'doing together' rather than a 'session' or a 'talking to.'
- 11) Video Positive Behaviour: With permission of the person you are working with, make a short video of them doing what they need to do to accomplish their goals. We use such vague phrases ... what does 'you need to calm down' mean ... how is that calming to be done? I'll bet you I calm down differently than you do; I'll bet you I have different strategies for coping than other people. By having them demonstrate what their goal is, what their strategies are, they can watch themselves be successful. It's handy when reviewing how things are going ... it translates words into images ... which is a quicker way to encourage change.
- 12) Adapt, Adapt, Adapt: When something works, do it that way! I know this sounds way too silly to be a piece of advice, but it's amazing how often we want the person to do it the way we want them to do it and we want this so badly that we try to get them to do it our way even though their way would work perfectly well. (Remember what I said about having a problem

with writing sentences that were way too long? That sentence was 57 words long – whoops, I’m still learning.) Take the lead from the person you are working with, notice when they handle things well, notice the strategies they use – then adapt their strategy into yours. If you work with adults then they’ve had their whole lifetime to figure out how best to communicate – watch, listen, learn, adapt. It’s simple really.

Well, that’s enough for now. Every time you see a ramp in a mall, a curb cut on a sidewalk or a grab bar beside a toilet, take that as a reminder to keep your communication accessible, to make a ‘cognitive ramp’ for the people you work with. Having an intellectual disability means living with lots of frustration – we should be doing everything in our power to ensure that being with us, talking with us, receiving support from us isn’t on their list of ‘things to cope with.’ It only takes awareness and willingness – and we all have those things, don’t we?

Letter to the Editors

In response to the “Inclusive, Exclusive Vacations: Planning Vacations for People with Significant Needs” article in August, we received the following response which is reprinted here with permission:

Thank you for such a timely newsletter. We just took our 19 year old son with profound disabilities, and his brothers on a camping trip in the Shenandoah mountains. His stroller didn’t fit in the car and we realized it would have been useless on the hiking trails the minute we set foot on one. So we went to plan B and held his hand, walked him and my fiancé carried all 85 pounds of him up and down every mile. He slept in his sleeping bag (lined with waterproof pads), he ate lots of applesauce and oatmeal (pureed diet) and didn’t miss any meds. He didn’t miss a thing and neither did the rest of us. Mission accomplished. You can do just about anything you put your mind to if you want it badly enough.

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Answers to FAQ's about the Newsletter

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