

## Commentary

# Reflections and considerations for knowledge translation efforts on pain training for caregivers of children with intellectual and developmental disabilities

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For those who may have difficulty with self-report, such as children with intellectual and developmental disabilities (IDD), pain should be regularly assessed, re-assessed, and documented to help inform necessary intervention (Herr et al., 2019). Provision of pain management and comfort is reflective of beneficence and nonmaleficence (Herr et al., 2019), and is a human right (Brennan et al., 2007). Despite (a) the frequency with which children with IDD experience pain (Breau et al., 2003) and (b) its negative short and long-term impacts on functioning and development (Breau et al., 2007), these children frequently suffer from unidentified and mismanaged pain (e.g. Malviya et al., 2001). Imagine the frustration and fear children with IDD must feel when experiencing and struggling to communicate their pain. Consider the dedicated and loving caregivers who, despite their best efforts, may feel as though they are falling short when it comes to knowing when a child is in pain or what to do about it. If anything, the vulnerability and complexity of these should justify and drive research. Yet, only a small, slow moving body of pain research in IDD populations exists. What good is knowledge if it is not shared with those who need it, such as caregivers of children with IDD?

Substantial knowledge-to-action gaps exist in the field of pediatric pain; unfortunately, traditional knowledge-to-action initiatives such as clinical

practice guidelines appear necessary but insufficient to ensure improvement in clinical practice (Chambers, 2018). As such, the focus on dissemination and implementation by funding bodies continues to grow (Chambers, 2018). Knowledge translation is “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge” (Canadian Institutes of Health Research - CIHR, 2016).

As part of a larger research program targeting the knowledge-to-action gap in pain in children with IDD, we developed *Let's Talk About Pain*. This program introduces evidence-based pain assessment and management approaches that can be used by respite workers when caring for children with IDD (Genik et al., 2018; Genik et al., 2020a; Genik et al., 2020b). It has been successfully piloted (Genik et al., 2018) and evaluated using a randomized controlled trial with promising outcomes (Genik et al., 2020a; Genik et al., 2020b). This commentary: 1) outlines our reflections while planning, conducting, and publishing this work, 2) provides recommendations to other researchers in the field when conducting knowledge-translation based work; and 3) serves as a call to action for further research and knowledge translation in this area.

**On knowledge translation in slow-moving, complex fields**

When is the right time to share information? When do we know enough to share? When do benefits of sharing preliminary findings outweigh the costs of waiting for more conclusive support? A degree of uncertainty and complexity accompanies caring for children with IDD (Carter et al., 2002), and the need for individualized approaches with these children was commonly discussed by participants from a randomized controlled trial who completed the *Let's Talk About Pain* training program (Genik et al., 2020b). These care providers appeared aware that there is no magic bullet and were appreciative of attempts to join them in the trenches and work together with the tools we do have to support children as best as possible. There will always be more questions to be asked and there may not always be an easy or straightforward answer; however, sharing what we do know in a timely way and helping stakeholders to become critical users of information is important.

**Recommendations.** Researchers conducting similar work are encouraged to think critically about the state of research in their field. What information needs to be shared so that the target audience has adequate understanding of the field, related research findings, and implementation in practice? Think carefully about potential advantages, disadvantages and ethical concerns of what to share and who will share it. For example, are there risks of sharing a psychological pain management strategy that may have limited research with your target audience? How much time will you need to spend to properly introduce and explain a strategy like deep breathing? Could these programs be delivered by those working on the front lines rather than researchers? If implementing a training, consider what interactive activities will provide an opportunity to check in with participants' knowledge and understanding.

### **On ensuring audience impact for a heterogeneous population**

Structure is important when completing systematic program evaluation; yet, a program that is too structured is unlikely to be effective when implemented broadly. In the context of IDD, both the needs and abilities of children and the respite programs from which these children receive support

are varied. For example, respite organizations with staff participating in *Let's Talk About Pain* varied in their staff to child ratios (e.g. 2:1, 1:2, 1:10), program locations (e.g. group home, community, family home), staff educational backgrounds (e.g. personal support worker, nursing), children's needs (e.g. medically fragile, behavioral support), and children's diagnoses (e.g. autism spectrum disorder, global developmental delay, cerebral palsy). To ensure the program was effective despite this heterogeneity, *Let's Talk About Pain* ensured that programming included interactive and discussion-based activities where staff could critically review evidence-based measures, determine best fit, and discuss how to adapt to their context.

**Recommendations.** Meaningful application of knowledge is likely enhanced by in-depth exploration of key issues and interests specific to the audience. Researchers are encouraged to spend time getting to know their stakeholders and audiences, paying close attention to heterogeneity within and across groups. Researchers may find value in ascertaining which information is considered core information (i.e. information which is critical to provide regardless of differences in a given setting) and which information may need to be tailored to ensure it is applied in meaningful ways. Further, one might consider how individual participant differences could influence how information is delivered. These pieces of information help determine how to present information and what types of interactive activities to include in educational programming.

### **On building a sustainable program**

Collaboration and research partnerships are important and necessary work for researchers and program developers; however, they are insufficient for the successful implementation of a program or research project, and certainly do not guarantee sustainability. In addition to research-specific considerations, organizational structures are everchanging, and many factors influence sustainability. In the case of respite organizations, these factors can include the economic culture, time of year, policies and procedures, and logistical barriers. This means that, for example, although efficacious to have an external facilitator provide

*Let's Talk About Pain* in the context of our research, it is not feasible that such a program could live on with one primary facilitator. Further, many organizations would not be able to regularly host staff trainings were there associated fees.

**Recommendations.** Researchers are encouraged to find ways to balance stakeholder preferences (e.g. in person trainings; Genik et al., 2020b) with more realistic and sustainable approaches (e.g. in house champions, train-the-trainer).

### On creating community-wide capacity

Despite *Let's Talk About Pain's* success with respite workers, further knowledge translation is needed in the broader societal context. How do we avoid inadvertently creating silos across caregivers supporting children with IDD? Parents and healthcare providers could also benefit from provision of evidence-based resources and knowledge to further support their experientially acquired knowledge and skills. Dissemination and implementation which includes a range of caregivers supporting children with IDD may allow for more coordinated, effective, and consistent care for children with IDD. Parent involvement is particularly critical. Involvement of parents may facilitate information sharing about pain and pain behaviors through structured tools (e.g. see Malviya et al., 2006; Genik et al., 2019). Parents are vital stakeholders who could advocate for the importance of continued pain training for those caring for children with IDD and help co-facilitate educational programming.

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**Recommendations.** In initial stages, one must consider feasibility of research reaching multiple target audiences. However, once a training is more established, researchers are encouraged to consider the ways in which they can connect various silos to encourage coordinated, effective, and consistent implementation across settings.

### Closing remarks

As we generate knowledge and share this information, we must continually adapt our approaches to suit those working on the front lines. In our experience working with pain in children with IDD, the delay in relevant knowledge generation and translation is unacceptable; we need to move forward in a coordinated and helpful way. The proactive consideration of the above recommendations by researchers and stakeholders in program development has potential to streamline the development of trainings and improve their impact in the field of pain and childhood disability. Furthermore, it is critical to think beyond goals of initial knowledge translation and towards the integration of interventions into direct care. For example, the training could be provided while resources like pain communication tools are simultaneously incorporated into child intake packages of an organization. Knowledge is only potential power. As researchers, it is our responsibility to ensure it is harnessed and used for the greater good of children with IDD and their families.

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