"This Is about My Health": Partnering with Patients and Families to Share Knowledge and Tools about Healthcare Communication for Adults with Intellectual and Developmental Disabilities

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Abstract

This project involved patients with intellectual and developmental disabilities and a family caregiver as advisors on a knowledge translation (KT) effort on healthcare communication. The project demonstrated that with the right supports, patient and family advisors can effectively share their experiences and add a powerful voice to KT activities. Lessons learned included the importance of being creative, responsive and flexible to support the advisors, of recognizing their expertise and of building capacity in multiple advisors to allow for diverse voices and greater flexibility. This work requires adequate time and funding, which needs to be factored into planning.

Key Points

- People with intellectual and developmental disabilities (IDD) and their families are not always included in patient engagement and knowledge translation initiatives. However, this project demonstrates how they can be involved in an authentic, meaningful and collaborative way.
- Supporting the inclusion of IDD patients and family advisors requires creativity, responsivity and flexibility to support them; recognition of their expertise in the power of sharing their lived experience; and expanding capacity by involving multiple advisors.
- With the right supports, patient and family advisors can effectively leverage and communicate their experience to their peers and others and share their expertise.

Introduction

Context and original research

Adults with intellectual and developmental disabilities (IDDs) receive problematic healthcare in Ontario, across Canada and internationally. Population-based research in Ontario and elsewhere shows that poor health combined with poor healthcare puts adults with IDDs at greater risk for repeated emergency department visits and hospitalizations, delayed discharges and premature mortality (Lin et al. 2019). Among contributors to inadequate healthcare are providers feeling ill-equipped to adapt care to the needs of these individuals (Selick et al. 2018) and patients with IDD and caregivers (e.g.,

P = Patient or family advisor.

family or paid support workers) not feeling empowered or prepared to effectively manage healthcare interactions (Boyd et al. 2018; Spassiani et al. 2017). The COVID-19 pandemic and related restrictions have made it even more difficult for people with IDD to obtain needed healthcare – for example, attending in-person appointments, managing virtual appointments and including caregivers in the visits (Grier et al. 2020; Lunsky et al. 2021).

The mandate of the Health Care Access Research and Developmental Disabilities Program (H-CARDD; www.hcardd.ca) is to work with healthcare and social service providers, adults with IDD and caregivers to identify healthcare gaps and develop strategies to improve healthcare. In 2017, H-CARDD partnered with Vita Community Living Services and the Developmental Disabilities Primary Care Program on the "About My Health" study of patient-oriented healthcare communication tools (https://nutsandbolts.ddtoolkits.com/). This project was conducted together with people with IDD, caregivers and health and social care providers. Two tools were created as a result and were made available online: one tool introduces the patient generally to the provider (About My Health [https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/]) (Figure 1) and the second one helps the patient (and caregiver) in preparing for and documenting what occurs during an appointment (My Healthcare Visit [https://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/]) (Figure 2). The tools are intended to be completed by or with extensive input from the person

FIGURE 1.
A screenshot showing part of the "About My Health" tool, filled out with details of a hypothetical patient

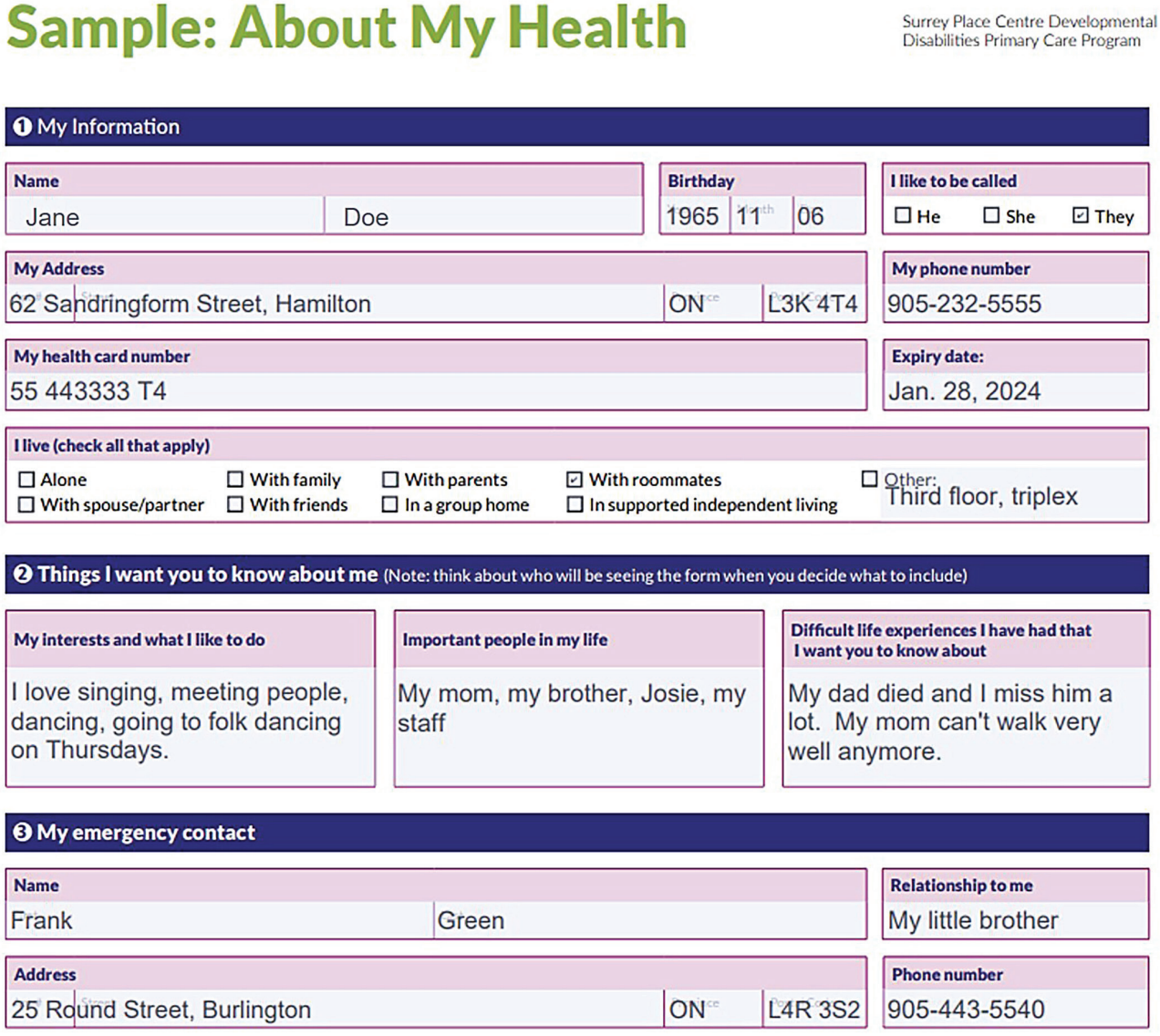
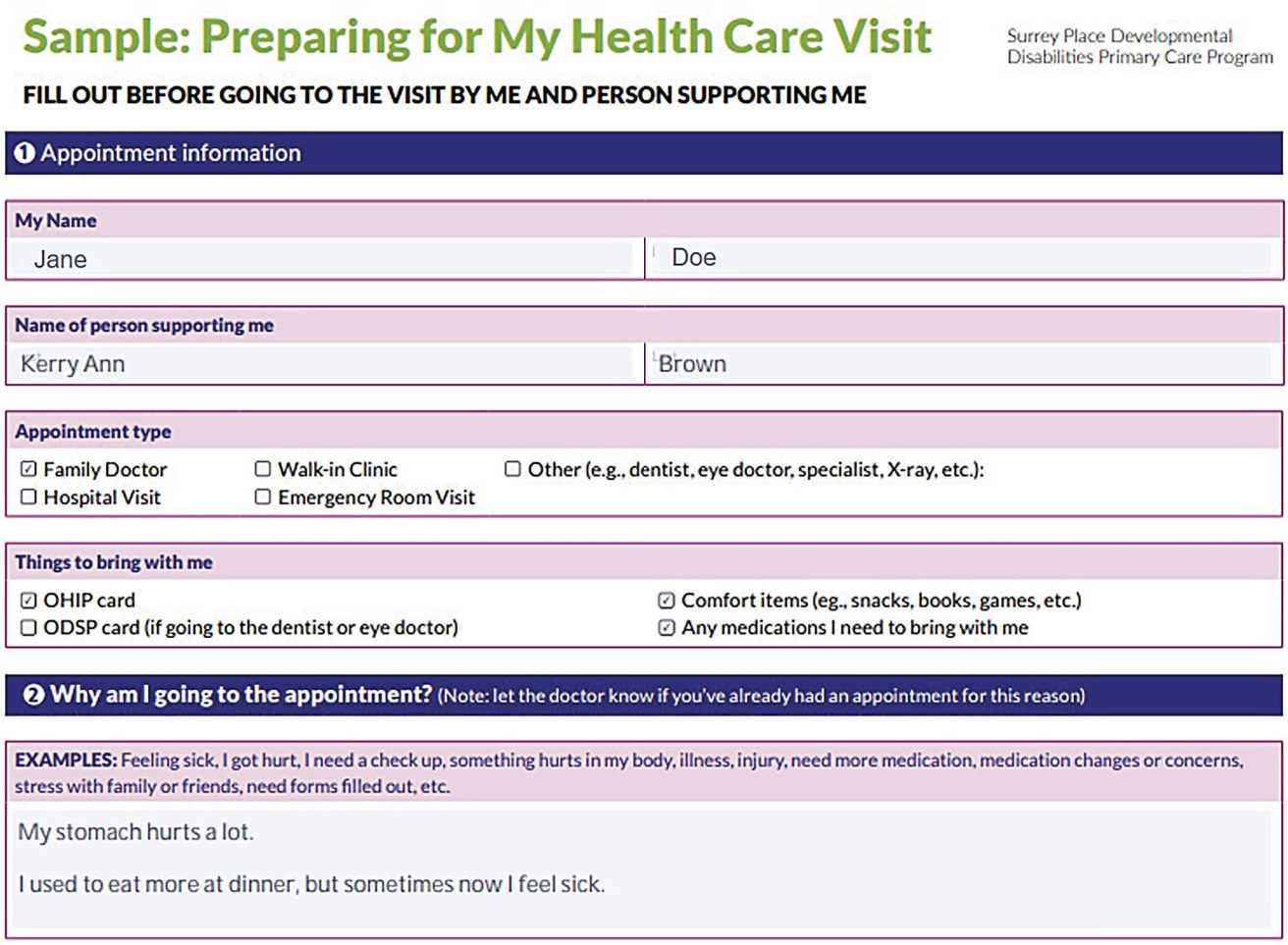


FIGURE 2.
A screenshot showing part of the "My Health Care Visit" tool, filled out with details of a hypothetical patient



Sample: Preparing for My Health Care Visit

Surrey Place Developmental Disabilities Primary Care Program

FILL OUT BEFORE GOING TO THE VISIT BY ME AND PERSON SUPPORTING ME

❶ Appointment information

My Name
Jane | Doe

Name of person supporting me
Kerry Ann | Brown

Appointment type
☑ Family Doctor ☐ Walk-in Clinic ☐ Other (e.g., dentist, eye doctor, specialist, X-ray, etc.):
☐ Hospital Visit ☐ Emergency Room Visit

Things to bring with me
☑ OHIP card ☑ Comfort items (eg., snacks, books, games, etc.)
☐ ODSP card (if going to the dentist or eye doctor) ☑ Any medications I need to bring with me

❷ Why am I going to the appointment? (Note: let the doctor know if you've already had an appointment for this reason)

EXAMPLES: Feeling sick, I got hurt, I need a check up, something hurts in my body, illness, injury, need more medication, medication changes or concerns, stress with family or friends, need forms filled out, etc.

My stomach hurts a lot.

I used to eat more at dinner, but sometimes now I feel sick.

with IDD and provide a shared communication resource (Selick et al. 2022).

The Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach (EMPOWER) grant funding allowed for a scale-up of the availability, awareness and use of these communication tools across Ontario and other parts of Canada. All knowledge translation (KT) activities were performed in partnership with persons with IDD and caregivers. The core EMPOWER team included two patient advisors and one family advisor, with other patient and family advisors joining the team for specific KT activities. These individuals had been working on other H-CARDD projects in an advisory capacity prior to joining the EMPOWER team. The project originally ran from October 2019 to March 2020, but was extended to August 2020 due to the pandemic.

Approach

The initial KT plan included in-person and virtual sharing of the About My Health and My Health Care Visit communication tools at conferences and H-CARDD–hosted events, targeting health and social service professionals, persons with IDD and families. Patient and family advisors actively participated at these events by presenting the tools to persons with IDD and their families, staffing exhibition booths at professional conferences and teaching clinical providers and support workers about healthcare communication. They also contributed to developing and delivering a telemedicine interprofessional continuing education program and a family education series.

At the onset of the COVID-19 pandemic in March 2019, the project pivoted to virtual-only KT activities and, with additional funding from the Canadian Institutes of Health

Research, later expanded the virtual education programs to reach families, people with IDD and providers across Canada. The courses covered general and COVID-19–specific topics that resonated with patients and families (e.g., mental health during the COVID-19 pandemic), and the communication tools were embedded as part of the curriculum. Patient and family advisors participated in virtual teaching to share their perspectives on the value of the tools. They were also involved in the development of a video (https://www.youtube.com/watch?v=AOKJKBSAFWA) explaining the use of the tools in a virtual healthcare environment.

Through these various KT strategies, the tools reached broad audiences. As of January 2022, the healthcare communication tools have had a total of over 6,400 views.

What the Team Learned along the Way

Be creative, responsive and flexible while supporting patient and family advisors

During this EMPOWER-funded KT project, the strategies used to support the patient and family advisors evolved. Coaching was always a key strategy. This included in-person and later online coaching on how to use the communication tools and how to talk about them with others. We also instituted weekly small-group coaching/support sessions to co-develop the presentations/resources and discuss delivery for different audiences, including other people with IDD, as well as healthcare providers. A key (and unanticipated) issue was helping the patient and family advisors learn how to integrate their personal experiences into their presentations while maintaining privacy and boundaries on how much information to share.

> I think having a family member share their personal experience is impactful to other caregivers. I was able to give real-life examples of the benefits and challenges we encountered. Dr. Lunsky helped me refine my wording as in my first presentation I realized I was disclosing too much information that my son may not have appreciated me sharing publicly. I was grateful for the sensitivity she provided in helping me craft a useful but less personal sharing for future presentations. (Family advisor)

When our team shifted to remote-only working, we adopted several additional strategies. During presentations, we provided "off-camera" coaching through text, direct chat messaging or phone calls for instances where patient advisors had questions, needed prompts to recall speaking notes or reminders when they veered off topic. We found that we needed to have a variety of communication methods to accommodate their individual abilities and skill sets, as well as backup options in the event of technical difficulties such as Internet and software troubles. We also learned that it was critical to debrief after events as a team to learn, reflect and provide feedback. However, this preparation and debriefing could add two to three hours to each hour of active presentation/meeting, and required prior planning.

The power of sharing personal experiences

By sharing their personal experience using the communication tools, the patient and family advisors demonstrated their expertise both about how to apply the tools in healthcare settings and their personal value.

> I use the tools before the healthcare visit. I fill it out and turn it in to the doctor. How I use the tool [is that] I would use it as a prompt [for] what I need to say. A lot of [the] times what I'm saying doesn't come out too clearly, so having it written down works for me. A lot of [the] times we tend to forget what we need to say. (Patient advisor)

> When I completed these forms with my own son, the tools empowered us to think about essential health information ahead of time, while we were both calm. We discussed information and strategies that should be shared with healthcare providers. Capturing this information in one place helped to record a lot of the information that I hold in my mind as my son's primary caregiver. The information was recorded in a succinct format in one document that could be located at his doctor's office, [in] the emergency department, or [at] new healthcare providers. In addition, the forms provided a place where recommendations from the healthcare provider could be captured accurately, avoiding confusion or misunderstanding of [the] next steps. (Family advisor)

Although it took time and hard work for the advisors to be able to understand the tools and craft their story, this approach was incredibly powerful. One example of this was when one of the patient advisors was promoting the tools in an exhibition booth at a physician conference. About 60 physicians stopped by, and the patient advisor engaged with nearly every visitor, sharing his personal experience about going to the doctor.

> This doctor said, "Why would I need the tools?" But when I explained, from my point of view – the patient's point of view – I explained it to him, and it really changed his perspective on what the tools actually

> mean, like what the tools actually are good for. They are good for people with disabilities who are scared of going to the doctor, or even people who are mute and going to the doctor for the first time.

The staff facilitator working with the patient advisor at the booth noted a visible shift in the physician's attitude from skeptical to understanding. In speaking about this experience afterward, the patient advisor described feeling empowered to make a difference:

> To be able to change a person's perspective was really amazing for me because I can never change a person's mind.

Respect and amplify the expertise of the patient and family advisors

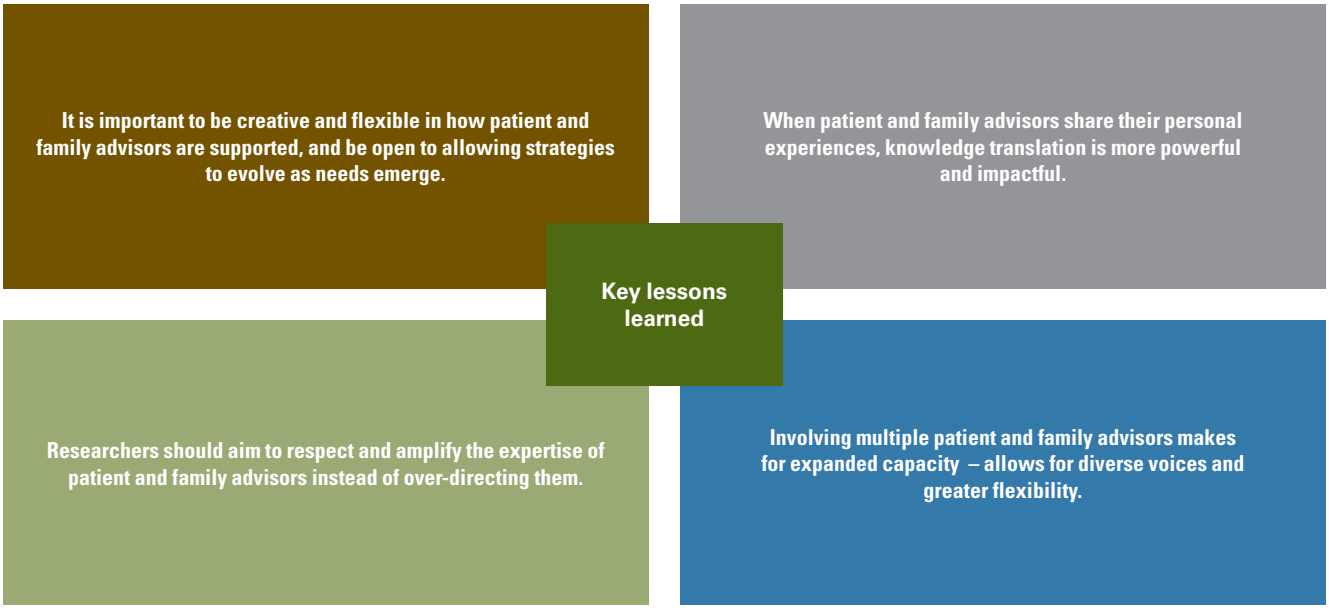
It took some practice for the academic members of the team to appreciate the unique expertise of all the members. This included respecting all voices and amplifying the lived experience of patient and family advisors instead of taking the lead or instructing them on what to do. This meant being aware of pre-existing power dynamics and being open to the advisors' styles of speaking about their experience, even if it did not always match preconceived ideas of how things should go.

> I realized rather quickly that we would have to be very flexible with how we did our KT activities to amplify their expertise and not over-direct our patient advisors. For example, while preparing for a webinar, they expressed how instead of having prepared speeches to read out, they would much rather have me ask them questions on a panel as a way of sharing their experiences and understanding of the tools. (Academic team member)

Expanding capacity by involving multiple patient and family advisors

A small group of patient and family advisors were active participants on the research team, and they were not always available for all activities, particularly when personal circumstances, health concerns or family issues arose. While this can be an issue for any team member, without a broader roster of patients and families to draw on, some activities had to proceed without their participation or had to be rescheduled. Additionally, they described in different ways the pressure or burden of representing the patient or family voice when they were the only patient/family advisor involved in a specific activity. This is not unique to projects involving patients with IDD but it does need to be addressed. Our team respected and supported everyone to participate as best they could, given the circumstances. Having an expanded roster of patient and family advisors would provide a richer sharing of experiences and include individuals with a variety of lived experiences of not only disability but also other intersectional identities, such as race, gender, age, sexual orientation, etc. A larger team of advisors would also provide greater flexibility so that the work could be maintained while accommodating the various needs and availability within the team. This requires funding to support multiple people in similar roles and investment in ongoing capacity building. See Figure 3 for key lessons learned.

FIGURE 3.
Key lessons learned



Discussion

This project demonstrated the feasibility and value of meaningful collaboration with people with IDD and family members. The EMPOWER grant has allowed us to not only disseminate communication tools to address an important gap in healthcare for adults with IDD and reach stakeholders nationally, but also to build capacity and develop processes to integrate patients and families into the project team. The lessons learned from this project, summarized in Figure 3, are informing our current work and can help others engage people with IDD and families in research and KT initiatives. Among these were the importance of being flexible and adapting in real time to advisor needs. For example, we incorporated additional coaching and debriefing time to our support approach (e.g., an extra two hours to help advisors prepare for presentations and to debrief), and we took direction from the patient advisors on their preferred presentation formats (e.g., delivering information through a structured panel question and answer session over a more open didactic format). We also invested effort to increase the number of patient advisors on the team to reduce the demands on any one individual and to bring more perspectives forward.

This work also demonstrated the relevance of being flexible and of individualizing the coaching and support we provide to patient advisors with IDD and family advisors. Beginning projects with an exploration of learning styles, communication preferences and individual strengths and then planning KT activities around this was key. Still, we needed to be iterative and quickly evolve our KT plans based on how situations and needs unfolded. The advisors learned in different ways and at different paces. It is important to know individual abilities, strengths and skills and match them to tasks accordingly. It is also crucial to be able to provide extra time and support to accommodate each advisor's unique needs and provide the right support to build their capacity and confidence to take on new roles. We found that by using a collaborative, strengths-based approach to designing KT events, we were able to develop more accessible products and deliver targeted inclusive presentations.

Additionally, this project showed that "experts" should include people with IDD, and not just the families or paid workers supporting them. This is an important message for academic researchers who may not think to include this group because of traditional research hierarchies and/or perceived barriers, including overcoming difficulties comprehending verbal and written communication and challenges related to expressing their thoughts verbally and in writing. Accommodations – such as simplifying information to be used by patient advisors, providing it in a range of formats (written, with pictures, recordings, etc.) and offering more time for individual coaching debriefs – might help multiple groups but are particularly important for including people with IDD.

We are continuing to expand our roster of advisors, drawing on the lessons learned in this project. We have achieved some success, and our learning on how to effectively engage and support continues to evolve. However, this work does require having adequate time and sufficient funding (to pay advisors for their time, including preparation and debrief; and provide dedicated staff support). This cost and time need to be factored into planning. It also requires flexibility to authentically engage and support people with IDD to fully participate in the initiative. When such strategies and accommodations are made, we all benefit from the inclusion of diverse voices and perspectives.

Conclusion

The efforts undertaken in this initial smaller-scale end-of-grant KT project demonstrate several lessons learned to facilitate authentic, non-tokenistic, patient engagement for people with IDD and their families. With the right supports, patient and family advisors can effectively leverage and communicate their experience to their peers and others and share their expertise as part of end-of-grant KT activities. Although this project only included a small group of patient and family partners, with more funding, resources and staff support, the strategies developed could be scaled to involve larger groups of adults with IDD and family caregivers in KT and research, more broadly. Based on the lessons learned in this project, we have started working with additional patient and family advisors to prepare them for future KT efforts, while allotting the necessary time and staffing to properly support their roles as teachers and champions. HQ

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