



Educational Perspective

# Development of educational modules for MRTs to better support patients with intellectual and developmental disabilities undergoing imaging procedures: A collaborative patient-oriented initiative

Muhammad Irfan Jiwa<sup>a</sup>, Shafeeq Armstrong<sup>b</sup>, YiWen Shao<sup>b</sup> and Yona Lunsky<sup>a\*</sup>

<sup>a</sup> Azrieli Adult Neurodevelopmental Centre, Centre for Addiction and Mental Health

<sup>b</sup> Special Olympics Ontario

## ABSTRACT

**Background:** Patients with intellectual and developmental disabilities (IDD) experience increased anxiety when undergoing medical imaging procedures for a variety of reasons including sensory overload, comprehension difficulty, and meeting unfamiliar people. There are several strategies that medical radiation technologists (MRTs) can apply to improve the imaging process. The purpose of this project was to work together with patients to develop educational modules and resources for MRTs on how to best support patients with IDD during medical imaging procedures.

**Development process and findings:** The project team used a four stage process to (1) determine the educational needs of MRTs around imaging procedures for people with IDD and (2) develop a series of online case-based video modules of challenges and improved practices with accompanying digital resources. First, the project team created and distributed a needs assessment survey to MRTs to identify their educational needs, experience, and interest in learning more about how to best support patients with IDD. The results from this needs assessment underscored that developing skills to better support patients with IDD was an area of interest and need amongst OAMRS members, which led to the formation of a working group whose goal was to identify priority topics and how to best teach these topics. Second, we conducted a focus group with adults with IDD, who had experience with imaging procedures,

to ensure the lived experience of people with IDD was a pillar of the modules. Third, we developed a set of video scripts and educational slides, informed by the needs assessment with MRTs and the focus group with adults with IDD. The video scripts focused on four scenarios: (1) Waiting for an imaging procedure, (2) & (3) the imaging process (MRI and PET), and (4) the exit interview. Each of these videos focused on common practice errors made during these scenarios, followed by strategies to address those errors. The educational slides focused on: (1) an introduction to people with IDD (2) Communication and (3) Triggers and Strategies. The fourth and final phase focused on filming the teaching videos with actors with IDD and finalizing the educational slides. Together, the set of educational slides and videos formed the modules for MRTs that will be published online.

**Lessons learned:** Undertaking this process to develop educational modules for MRTs on working with people with IDD taught us that people with IDD have lived experiences which should inform the development of educational material; they must be treated as partners during this development process; and a partnered process takes time to carry out.

**Conclusion:** The process that was undertaken allowed the team to develop resources, which can be used by MRTs. Evaluation of the educational modules can inform further refinement and improvement.

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**Ethical approval:** Given that this was not a research study, REB approval for this undertaking was not necessary.

\* Corresponding author. CAMH – Centre for Addiction and Mental Health, Azrieli Adult Neurodevelopmental Centre, 1001 Queen St W, Unit 4 -372, Toronto, ON M6J 1H4.

E-mail address: [Yona.lunsky@camh.ca](mailto:Yona.lunsky@camh.ca) (Y. Lunsky).

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## RÉSUMÉ

**Contexte :** Pour différentes raisons, notamment la surcharge sensorielle, les difficultés de compréhension et la rencontre de personnes qui ne leur sont pas familières, les patients présentant des déficiences intellectuelles et développementales (DID) ressentent une plus grande anxiété lorsqu'ils doivent se soumettre à des procédures d'imagerie médicales. Il existe plusieurs stratégies que les techniciens en radiation médicale (TRM) peuvent utiliser pour améliorer le processus d'imagerie. Le but de ce projet était de travailler avec les patients pour développer des modules éducatifs et des ressources pour les TRM sur la meilleure façon de soutenir les patients présentant des DID durant les procédures d'imagerie médicale.

**Processus de développement et constatations :** L'équipe de projet a eu recours à un processus en quatre étapes pour 1) déterminer les besoins éducatifs des TRM en ce qui a trait aux procédures d'imagerie médicale pour les personnes avec des DID, 2) développer une série de modules vidéo en ligne fondés sur des cas réels de difficultés et d'amélioration de la pratique, avec des ressources d'accompagnement numériques. Dans un premier temps, l'équipe de projet a créé et distribué aux TRM un sondage d'évaluation des besoins afin d'établir leurs besoins de formation, leur expérience et leur intérêt à en apprendre davantage sur la façon de mieux soutenir les patients avec une DID. Les résultats de l'étude des besoins ont démontré que le développement de compétences permettant de mieux soutenir les patients avec une DID était un intérêt et un besoin chez les membres de l'OAMRS, ce qui a conduit à la formation d'un groupe de travail dont le but était de recenser les sujets prioritaires et de déterminer la meilleure façon d'enseigner ces sujets. Dans un deuxième temps,

nous avons tenu un groupe de discussion avec des adultes ayant une DID et ayant fait l'objet de procédures d'imagerie médicale, afin de nous assurer que l'expérience vécue des patients ayant une DID soit un pilier des modules. Troisièmement, nous avons produit une série de scénarios de vidéos et de diapositives éducatives, avec l'éclairage assuré par l'évaluation des besoins des TRM et les résultats du groupe de discussion avec les patients adultes ayant une DID. Les scénarios mettaient l'accent sur quatre situations: 1) l'attente d'une procédure d'imagerie, 2) et 3) la procédure d'imagerie (IRM et TEP) et 4) l'entrevue de sortie. Chacune des vidéos met l'accent sur les erreurs courantes faites dans ces situations, suivies par les stratégies permettant de corriger ces erreurs. Les diapositives éducatives mettent l'accent sur: 1) une introduction aux personnes ayant une DID, 2) la communication, et 3) les déclencheurs et les stratégies. La quatrième et dernière phase est le tournage des vidéos avec des acteurs ayant une DID et la préparation des versions finales des diapositives éducatives. Ensemble, les diapositives et les vidéos forment les modules destinés aux TRM qui seront publiés en ligne.

**Leçons apprises :** Le processus de développement de modules éducatifs pour les TRM sur la façon de travailler avec les personnes ayant une DID nous a appris que ces personnes ont vécu des expériences qui devraient éclairer le développement du matériel éducatif; elles doivent être traitées comme des partenaires dans ce processus de développement, et un processus mené en partenariat demande du temps.

**Conclusion :** Le processus entrepris a permis à l'équipe de produire des ressources qui peuvent être utilisées par les TRM. L'évaluation des modules éducatifs permettra d'y apporter des améliorations.

*Keywords:* Intellectual disability; Developmental disability; Imaging; MRI; PET; Accommodations

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## Introduction

Managing people with IDD during the imaging process can be challenging, with many patients unable to complete an imaging procedure because of high anxiety and stress, without accommodations. Understanding how to support patients with IDD is not heavily emphasized in current imaging training. People with IDD may have a hard time understanding instructions, being able to keep still in a confined space, remaining calm in a sterile and unfamiliar environment – sometimes with loud and unpredictable sounds, and interacting with people they do not know. These difficulties have been previously documented among people with Down syndrome<sup>1</sup> as well as autistic spectrum disorder.<sup>2</sup> A systematic review by Zhong et al.<sup>1</sup> noted a number of considerations during imaging procedures for patients with Down syndrome, namely requiring more time, the importance of warm communication strategies and rapport building, and allowing for the presence of support people. Perry et al.<sup>3</sup> highlighted the increased anxiety faced by people with autistic spectrum disorder or IDD when undergoing imaging procedures, such as sensory triggers faced during the procedure (including noises, being on a cold table, IV line related discomfort) as

well as interacting with unfamiliar people.<sup>3</sup> To reduce this anxiety, they recommended various accommodations for people with IDD including reducing the number of staff interacting with a patient during a visit, using clear and slow verbal communication, and the use of images to aid explanation prior to visits to the imaging facility.

In order to help people with IDD safely participate in imaging procedures, it is important that the MRTs facilitating the procedure have some familiarity with people with IDD and are able to apply patient-centred strategies to help patients feel calm and cope before, during and after the procedure. It is important to consider how we undertake the process of teaching these interpersonal skills and strategies as it relates to caring for people with IDD. Research with other health professionals has shown that simply reading about IDD does not translate into practice changes.<sup>4</sup> Learning directly from people with IDD is important, and capturing scenarios that are likely to happen, and challenging to navigate, are also valuable. Herein, we describe the process that we applied to (1) determine what was needed in a teaching intervention for MRTs for how to best support people with IDD during imaging procedures; (2) develop this teaching intervention by involving various organizations and key stakeholders:

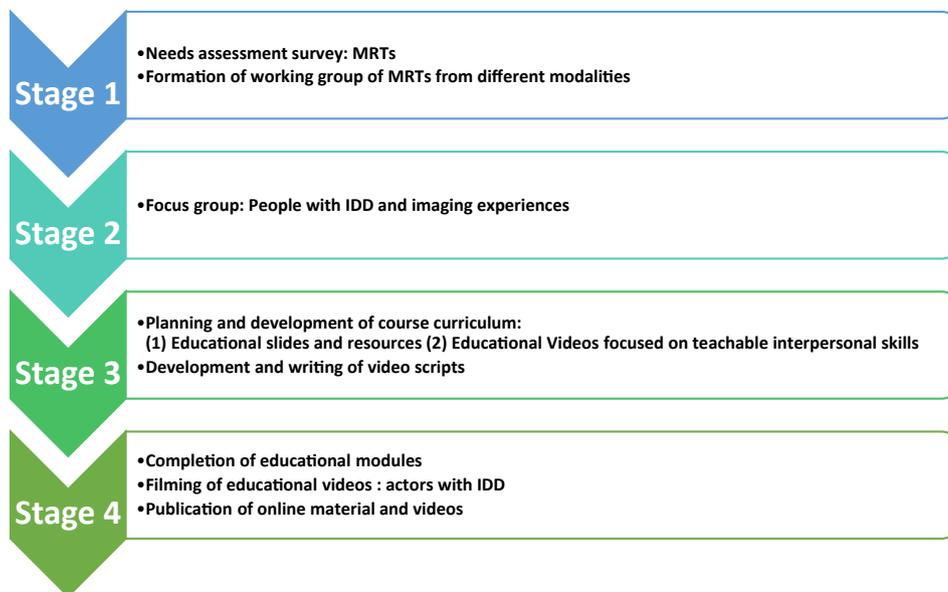


Fig. 1. Overview of the staged process we employed to develop educational material for MRTs to better support people with IDD.

people with IDD, an IDD sport and health advocacy organization (Special Olympics Ontario), a medical radiation professional association (Ontario Association for Medical Radiation Sciences), an IDD research team (Health Care Access and Research in Developmental Disabilities) and a teaching hospital (Centre for Addiction and Mental Health). The purpose of this collaborative project was to work together with patients to develop online case-based course consisting of video modules of challenges and improved practices with accompanying digital resources for MRTs. This paper highlights lessons learned as we undertook this process.

### Development process and findings

We used four stages to develop the modules. Stages 1 and 2 involved information gathering while Stages 3 and 4 involved the creation of the educational modules (see Fig. 1).

#### Stage 1

Through their Healthy Communities program, Special Olympics Ontario has been working to improve access to healthcare for people with intellectual disabilities and to improve the health equity of people with IDD. A large part of these efforts includes working with health professional associations to improve their members' capacity to care for people with IDD.

In 2018, Special Olympics Ontario (SOO) and the Ontario Association of Medical Radiation Sciences (OAMRS) conducted a needs assessment among OAMRS members, to understand (1) the education, training and experience they had received on how to provide care to people with IDD, and (2) if they would be interested in receiving further training to improve their capacity to care for people with IDD. The results from the needs assessment, based on 147 members, highlighted the following, 79% disagreed with

the statement: my professional degree included training or education specific to working with people with intellectual disabilities; 75% agreed that communication difficulties are often barriers to high quality healthcare for patients with IDD; 78% agreed that if a training course was provided, including outlining key concepts of effective communication with those who have IDD, they would be interested in taking it.

Based on this needs assessment, SOO and OAMRS established a working group, comprised of MRTs from different modalities (X-ray, CT, Mammography, Sonography), as well as health care professionals with significant experience providing care to people with IDD. The purpose of this working group was to develop a comprehensive course to assist OAMRS members in adapting their care for people with IDD.

#### Stage 2

While the needs assessment provided important information as to what specific concerns MRTs regularly experienced when working with people with IDD and what they wanted addressed in the course, the working group recognized they needed to hear directly from people with IDD to understand more about common barriers and challenges experienced by people with IDD, but also, successful strategies that people with IDD identified themselves.

To do this, SOO and the OAMRS invited adults with IDD from a self-advocacy group based in Toronto who had a recent imaging experience to participate in a focus group discussion about the procedure. This discussion was facilitated by members of the working group, with a support person present from the self advocacy group and participants received an honorarium for their time. While this was not considered to be an extensive review of all potential barriers and facilitators

to imaging procedures, the stories varied in terms of the type of imaging that occurred and the quality of experiences. This rich discussion with five people provided the project working group with a framework to develop the course. Hearing the stories of these adults with IDD both validated the experience of people with IDD, and provided examples that could be used as case studies.

The topics addressed in the focus group were organized into six themes: (1) Accessibility – one size doesn't fit all (2) Patients are experts of their own body (3) Role of caregivers (4) Communication (5) Respect and (6) Tips on comforting patients. Some of the key themes and representative quotes as they pertain to imaging procedures for people with IDD are further outlined below.

People with IDD highlighted that they should be the focus of the interaction and that communication should be directed to them and not their caregiver or support person.

“And honestly, if I bring people to the MRI or whatever test I'm doing, they talk to the person (caregiver) instead of me.”  
... “I'm the patient, he's not!”

Furthermore, people with IDD also identified the need for clear communication strategies and how the type of communication used has a large impact on how the imaging procedure goes for them.

“And he was taking an X-ray. ‘I don't want to hurt you, I'm just going to move your ankle over or leg over so’ Oh, it was a breath of fresh air.”

“I had a really good technologist explain everything to me, not my mom, not anyone else in the room. He put everything else out in the room ... He didn't notice anyone else besides me.”

### Stage 3

We used several pieces of data to design the outline of the course: “Caring for People with Intellectual Disabilities”, including the needs assessment, existing literature, expertise of

the working group and the lived experiences of people with IDD. Using this data, the working group developed a set of modules that focused on three key topics: (1) Introduction to people with IDD (2) Communication (3) Triggers and Strategies.

To complement the modules, the working group also developed a set of educational videos across different modalities, which highlighted (1) common practice errors and (2) strategies to address those common practice errors. These videos were organized by key moments or interactions during the imaging process: Waiting for imaging, the imaging process (MRI and PET), and the exit interview. Script development was an iterative and time-intensive process, which included input from people with IDD, families, health experts and medical radiation technologists from the OAMRS and CAMH.

A key part of this stage was applying the themes and learnings from the focus groups to develop a list of teachable interpersonal skills. This list, in turn, informed and guided the creation of the educational videos and practice improvement modules. These interpersonal skills are summarized in [Table 1](#).

### Stage 4

An important piece highlighted by the needs assessment and the working group were the benefits of videos as learning tools. To develop an effective set of teaching videos that would complement the course modules, the working group hired a director and videographer who had extensive experience working with adults with IDD. They edited and further refined the scenarios while creating a plan for the videos. Actors with IDD who had acted in prior educational videos through the Health Care Access for People with Developmental Disabilities (H-CARDD) program were hired both to develop the scripts and to act in the scenes. Prior to the filming of each scene, these actors provided feedback on the scripts, and familiarized themselves with the situations and also adapted them to be as consistent as possible to how they might experience the situations.

Table 1  
List of interpersonal skills.

Interpersonal skill	Description
Rapport building	Using open and warm communication (verbal and non-verbal) Trauma-informed lens: patients may have had negative encounters with healthcare professionals Taking the time to familiarize yourself with the patient before beginning the procedure
Explanation of processes	Clearly communicating the various steps that will be taken in the imaging procedure as well as what to expect Use communication aids such as images, diagrams Ensure that the patient has understood the various steps and provide a space to ask questions or clarify Maintain a comforting environment, being attentive to patient needs After the procedure, debrief procedure and follow up instructions including next steps to be taken and how to access results
Working with caregivers	Ensure you are always speaking to the patient and using the caregiver as a support Take the time to facilitate the presence of caregiver with the patient to reduce anxiety. This may require some adaptations to the standard procedure (e.g., caregiver in the imaging room)
Supporting non-verbal patients	Communicate directly with patients - they understand more than they are able to express Ask caregivers for tips on how to best communicate, or to facilitate communication with the patient

The videos were filmed at CAMH and at Special Olympics Ontario. The scenes were filmed over two days and were supported by experts in imaging technology as well as experts in health care in IDD. The editing process occurred over three months, and videos were shared with team members, including people with IDD, to make sure they accurately reflected their experiences.

In 2020, the OAMRS will make this course available to their membership. The videos will also be available via Special Olympics Ontario and the H-CARDD YouTube channel.

### Lessons learned

Team members learned several lessons by taking a staged process to develop course modules and design videos to effectively teach interpersonal skills:

1. The lived experiences of people with IDD are invaluable and provide an essential framework for designing effective education.
2. People with IDD must be treated as equal partners throughout the process. They need time and a safe space to provide feedback.
3. People with IDD provide valuable information and expertise. They should be appropriately compensated for their time and efforts.
4. Developing quality content takes time and patience. This process, from start to finish, took almost two years.

Clinical team members learned a great deal from the self advocates with IDD involved in the project. Additionally, the actors with IDD who were involved in the educational videos emphasized the educational importance of these videos and the need for understanding the patient perspective in these scenarios. They also identified what value they saw in participating in this initiative to be able to bring about changes for people with IDD in clinical encounters.

“it was important ... to participate in this important message to healthcare specialists - recognize and understand what may seem like a simple medical test ... can be traumatic for the patient. Speaking in simple and gentle terms can calm someone's fears and make the situation a tolerable one.”

“I participated in *making* these videos because I love advocating for people with disabilities ...”

“Making these videos was important so that health care professionals can see some of the ways people with disabilities

experience medical visits, and some simple changes they can make to make things more positive.”

### Conclusion

We used a multi-organizational collaborative and inclusive process to determine the educational needs surrounding caring for people with IDD for MRTs and develop a series of educational modules aimed at teaching several key interpersonal skills to improve clinical practices. People with IDD were involved at various stages including the development of ideas as well as educational material. The process allowed the team to develop resources for MRTs. A formal evaluation of the educational modules is necessary to determine further refinement and improvement.

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