

## Identifying Priorities for Pre-licensure Nursing Curriculum to Care for People With Intellectual and Developmental Disabilities: A Delphi Study

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## Cover Page Footnote | Note de page couverture

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People with intellectual and developmental disabilities (IDD) experience a higher prevalence of illnesses than people without IDD, which is reflective of inequities (Cooper et al., 2015; Ouellette-Kuntz et al., 2015; Trollor et al., 2017). Despite increased contact with the health care system, people with IDD experience significant barriers to accessing health care and poorer health care outcomes (Ouellette-Kuntz et al., 2015; Shooshtari et al., 2017). The World Health Organization (WHO) World Report on Disability (2011) noted that people with disabilities were four times more likely to be mistreated by health care providers and three times more likely to be denied health care compared to people without disabilities. Hosking et al. (2016) reported that people with IDD were six times more likely to die from causes “amenable to health care” (p. 1488).

Despite the WHO (2022) call for nursing curriculum to develop disability-inclusive competencies, research continually identifies that student nurses receive inadequate, if any, education about people with IDD (Edwards et al., 2022; Trollor et al., 2016; Warshawski, 2025). Student and practising nurses frequently report feeling uncomfortable about and unprepared for caring for people with IDD (Cashin et al., 2022).

## Background

Barriers to implementing nursing curriculum about people with IDD include the lack of expertise and time among faculty, of curriculum space, and of nursing guidelines and resources (Ankam et al., 2019; Ilkhani et al., 2016; Smeltzer et al., 2010). Entry-to-practice nursing competencies to care for people with IDD are needed. Havercamp et al. (2021) and Kronk et al. (2020) identified competencies for American health professionals and for nursing, respectively, about care for people with all disabilities. Kronk et al. consulted faculty and stakeholders with unspecified disabilities, while Havercamp et al. consulted health professionals, including nurses, and people with unspecified disabilities. Howie et al. (2022) identified standards of practice for Australian nurses who specialize in care for people IDD based on expert opinion of practising nurses in this area. The combined results of these three Delphi studies reflect commonalities in identified competencies and content priorities about person-centred care, communication, legal and ethical considerations, collaboration, disability-specific knowledge, clinical skills, and care across the lifespan and health states. The voices of people with IDD are absent within this research. Competencies about people with IDD for pre-licensure general nurses are less obvious.

Don et al. (2025) conducted a scoping review to map, in part, global pre-licensure nursing education content about people with IDD. The review included articles published between 2006 and 2024, with inclusion criteria of pre-licensure student nurses as the population, people with IDD as the concept, and nursing education as the context. A total of 135 articles were included; 45.9% were student reflections, 45.2% were primary research, and 8.9% were discussion papers. Six content categories were identified: person-centred care, communication, advocacy, health conditions and diagnoses, collaboration, and decision-making. People with IDD were rarely included in the development of nursing curriculum. The identified content categories are thus largely devoid of their perspectives. This review found that student nurses learned about diverse topics in caring for people with IDD, often through opportune clinical exposure and incidental lectures not explicitly linked to nursing curriculum learning objectives. Only four of the 135 included articles were from Canada, indicating a regional gap.

Within a post-structuralist paradigm, we take the epistemological stance that participant opinions are socially constructed; thus, consensus, or agreement, does not equate with identified truth but, instead, convergence of opinion on an important health issue at one point in time (Jünger, 2023). Non-consensus is welcomed and provides information about differing perspectives. Foucault’s (1978,

1998) theory of resistance guided the present study's design, to disrupt hierarchical speaking positions with nuanced co-constructive collaborations to create change.

In this Delphi study, we asked the following question: What are priorities for pre-licensure nursing curriculum about caring for people with IDD? We aimed to counter exclusive research methods and nursing curriculum development by including people with IDD as experiential experts with equal speaking positions to nurses who often care for people with IDD. Further, we aimed to contextualize curriculum priorities according to experts within a Canadian context.

## Methods

### Ethics

The Algonquin College Research Ethics Board provided ethical approval for this study (Protocol # 2024-MAY-DON). We developed a study information and consent form for nurse participants and an easy-read version for people with IDD, using plain language accompanied by Picture Exchange Communication System® (PECS) images (Frankena et al., 2019). PECS is a communication system developed in 1984 by Frost and Bondy that uses pictures to represent words (National Autism Resources, n.d.). Participants with IDD had the choice to express informed consent or dissent using a consent picture board, verbal or body language, or a communication tool (Dee-Price, 2020).

### Design

We conducted a three-round mixed-methods modified-Delphi study, synergized with inclusive health research methodology (IHRM). We reported our results using the Recommendations for Conducting and REporting DELphi Studies (CREDES) (Jünger et al., 2017).

IHRM broadly aims to include people with IDD in research study design and as participants guided by the ethos of human rights, respect, flexibility, cultural safety, and collaboration (Frankena et al., 2019). People with IDD may participate in the research team through consultation, collaboration, or leading the study (Smith-Merry, 2017). Our team included the lead researcher, two research advisors with IDD, and four student nurse research assistants, each receiving an equal rate of pay. The research advisors collaborated on the easy-read design and culturally safe language of all study tools and options for people with IDD to participate and be compensated.

The Delphi method was determined to be the best fit to address the research question and aims, given the heterogeneity of extant research about nursing curriculum about people with IDD. The long-standing nursing knowledge gap, particularly in Canada, and associated health inequities experienced by people with IDD justify the urgent need for identifying priorities for nursing curriculum content (Jünger, 2023; Nasa et al., 2021).

Delphi method conducts survey rounds with participants, considered experts about the studied topic, to identify if the group agrees, reaches consensus, or disagrees about survey items (Keeney et al., 2011). The participants, referred to as *panellists*, remain anonymous to one another to promote individual responses and reduce the risk of group think. Panellists are provided controlled feedback from previous rounds to consider in subsequent surveys. The research team determines the criteria that define “an expert” and “consensus,” the type of controlled feedback, and a survey design consistent with the epistemic stance taken and the research objectives (Jünger, 2023). Sample sizes of 25 to 30 are ideal for generating new ideas (Chalmers & Armour, 2019). Attrition rates of 20% to 30% associated with survey rounds often pose a challenge for Delphi studies (Chalmers & Armour, 2019). The target sample size for

this study was 15 people with IDD and 15 nurses for a total of 30 participants. This sample size is consistent with other Delphi studies with similar participants (Bonell et al., 2012; de Kuijper et al., 2023).

## Participants

We recruited panellists using purposeful sampling techniques, including the definitions of expert, specified in the inclusion criteria and recruitment strategies (Campbell, 2020; Keeney et al., 2011; McPherson et al., 2018). The inclusion criteria for panellists with people with IDD were being 18 years of age or older; having received nursing care; being able to understand verbal or written English, supported with pictures; and being able to communicate through verbal or written English, pictures, gestures, or a communication device. The inclusion criteria for nurses were being a practising or retired nurse in Ontario with 2 or more years' experience in caring for people with IDD, and being able to understand and communicate in written English. The duration of nurses' experience was informed by two previous Delphi studies defining nurse experience as expertise (Gok Metin & Yildiz, 2023; Rasmussen et al., 2023).

Panellists with IDD were recruited through an Ontario developmental service agency. Nurse panellists were recruited through social media (Facebook nursing and academic institutional groups and targeted advertising in Ontario), IDD nursing interest group, and agencies employing nurses to care for people with IDD.

## Compensation

Nurse panellists received a \$30 gift card at the conclusion of data collection, regardless of the number of surveys completed. Panellists with IDD were provided a \$25 gift card at the start each survey meeting. Panellists with IDD received greater compensation because they invested increased time to meet with the lead researcher to complete the surveys and allow for the lead researcher to adapt to the panellists' language and understanding (Dee-Price, 2020).

## Data Collection

Data were collected between September 2024 and January 2025. Three survey rounds were completed with the same panellists. The lead researcher administered the surveys in person to panellists with IDD to support potential questions, literacy differences, rephrasing needs, and panellists who communicate non-verbally (Corby & Sweeney, 2017; Dee-Price, 2020). Panellists scheduled meetings at their convenience, choosing either their home or a private office at a developmental service agency, with the option to have a trusted person or persons present (Dee-Price, 2020). The lead researcher explained to the panellists and trusted persons that only the panellists should provide answers. Trusted persons did not attempt to answer for panellists, nor did panellists defer to trusted persons to answer the survey questions. Nurse panellists received an email via SurveyMonkey with a unique link to each survey round as well as email reminders 1, 2, and 3 weeks following the initial email if they had not yet completed it. If a nurse panellist had not responded following the third reminder, they were not invited to subsequent survey rounds.

We modified the classically unstructured first round of Delphi design by composing Survey 1 with the six content themes and 28 Likert-style items developed from a scoping review (Don et al., 2025; Jünger et al., 2017). We collaborated with the research advisors to design and pilot the survey in an easy-read format (Frankena et al., 2019; Kidney & McDonald, 2014). Panellists were asked to rate the importance of each survey item for inclusion in pre-licensure nursing education by selecting one of five Likert points: *not at all important*, *less important*, *I don't know*, *important*, and *very important*. Six optional open-ended questions were included for panellists to identify additional priorities.

The *a priori* closing criteria was to terminate the Delphi process following three survey rounds. Three rounds are often sufficient to identify consensus on survey items; further rounds may increase participant attrition and burden (Chalmers & Armour, 2019; Veugelers et al., 2020). The *a priori* procedure for inclusion and exclusion of survey questions across the three survey rounds was to return survey questions without consensus on any Likert point to subsequent survey rounds for re-rating and to remove and not re-rate questions that met consensus on any Likert point (Jünger et al., 2017). Panellists received controlled feedback in the form of a copy of their responses following each survey. Survey 2 included eight returning Survey 1 questions requiring re-rating, with itemized controlled feedback of a pie chart totalling panellist rating frequency counts and percentages for each Likert point. Optional open textboxes were included under returning questions for participants to provide feedback about them. Survey 2 also included 10 new survey Likert items, developed from the content analysis of the open-ended questions from Survey 1. These new survey questions were designed in an easy-read format with the research advisors. Survey 2 retained optional open-ended questions to provide panellists continued opportunity to give semi-unstructured feedback.

Survey 3 included six items requiring re-rating from Survey 2, with associated controlled feedback of descriptive statistics as in Survey 2, and anonymized comments representing the diversity of responses that panellists made in Survey 2 (Nasa et al., 2021).

## Data Analysis

Following each survey, the Likert responses of all panellists were combined and analyzed together to promote panellists' heterarchical influence on one another in co-constructing identified priorities. This approach resists "normative expectations" or hegemonic beliefs potentially held by panellists with IDD or nurses about authority and value of contribution, which could be reinforced if panellists' responses were separated, with identified speaker positions (Jünger et al., 2017, p. 57). Consensus was set at  $\geq 75\%$  panellist rating agreement on any Likert point for each survey question, measured according to frequency counts and percentages (Jünger et al., 2017; Keeney et al., 2011). This consensus sets a meaningful agreement criterion, welcoming some variance (McPherson et al., 2018), and is comparable to similar studies (Bonell et al., 2012; de Kuijper et al., 2023; Salgado et al., 2018). A consensus of  $\geq 75\%$  with a sample of 30 (15 per panel) ensures that if the lowest threshold of consensus for a question were met (75%), the greatest degree of disagreement between the two participant groups would not exceed 100% of one group and 50% of the other. Responses to open-ended questions in Surveys 1 and 2 were analyzed following the seven procedural stages of inductive manifest content analysis to generate new Likert items (Bengtsson, 2016; Nicmanis, 2024). The lead researcher and research assistants separately analyzed the data and then discussed their results to obtain consensus, as a method of triangulation to promote the credibility and fulsomeness of the analysis (Bengtsson, 2016).

Panellists' open-textbox feedback on Survey 2 questions that required re-rating from Survey 1 was combined into narrative controlled feedback that was then provided alongside the six items that returned in Survey 3. The narrative controlled feedback about specific survey items was anonymized and presented in short form, with the most articulate quotes selected (Nasa et al., 2021). The research team included quotes representing the spectrum and diversity of comments in the controlled feedback to provide further perspective about how some participants interpreted the questions, as panellists rated these questions for a final time (Nasa et al., 2021). The lead researcher and research assistants reviewed the selected quotes for the controlled narrative feedback and reached consensus about its representativeness, establishing the confirmability of the findings (Jünger, 2023). The final Likert results of Survey 3 were assessed for consensus.

## Trustworthiness

We adhered to Lincoln and Guba's (1985) criteria of credibility, confirmability, dependability, and transferability to establish and demonstrate trustworthiness of the study (Jünger, 2023; Keeney et al., 2011; McPherson et al., 2018). The credibility of the study was supported through inclusion of different voices in the research team, collaborative methodological decisions, and two stakeholder groups included as expert panellists. The goal of the study findings was not to force consensus but to locate where consensus is and is not (Chalmers & Armour, 2019; Veugelers et al., 2020). To promote transparency, we completed an audit trail to inform the detailed description of our methodological decisions. We promoted triangulation between diverse panellists through the compilation of the anonymous survey responses within controlled feedback. The criterion of consensus promoted the dependability of the collected data. The confirmability of the study was demonstrated through the design of Survey 1 based on a scoping review, consensus and iterative survey rounds, and peer review for publication. The reader can determine the transferability of the findings because of the detailed description of the methods and findings in accordance with CREDES guidelines (Jünger et al., 2017).

## Results/Findings

### Participants

All panellists had the ability to provide informed consent. Panellists with IDD completed the surveys with differing levels of support: one panellist independently completed the surveys, two panellists required some support to input survey responses, and 13 panellists required the lead researcher to read aloud the survey questions and record their responses. Nurse panellists included eight registered nurses and eight registered practical nurses, all currently practising. A total of 16 panellists with IDD and 16 nurse panellists completed Survey 1. A total of 13 panellists with IDD and 15 nurse panellists completed Surveys 2 and 3. The duration of the first survey round was the longest of the rounds because it included recruitment of and scheduling and meeting with panellists with IDD. The duration of Surveys 2 and 3 were shorter because of quick panellist response time and scheduling. Nurse panellists completed Surveys 1, 2, and 3 in approximately 10, 16, and 2 minutes, respectively. Panellists with IDD completed Surveys 1, 2, and 3 in approximately 31, 30, and 5 minutes, respectively. Panellists completed Survey 3 quickly because it included only six questions requiring re-rating. Figure 1 outlines the flow of the project.

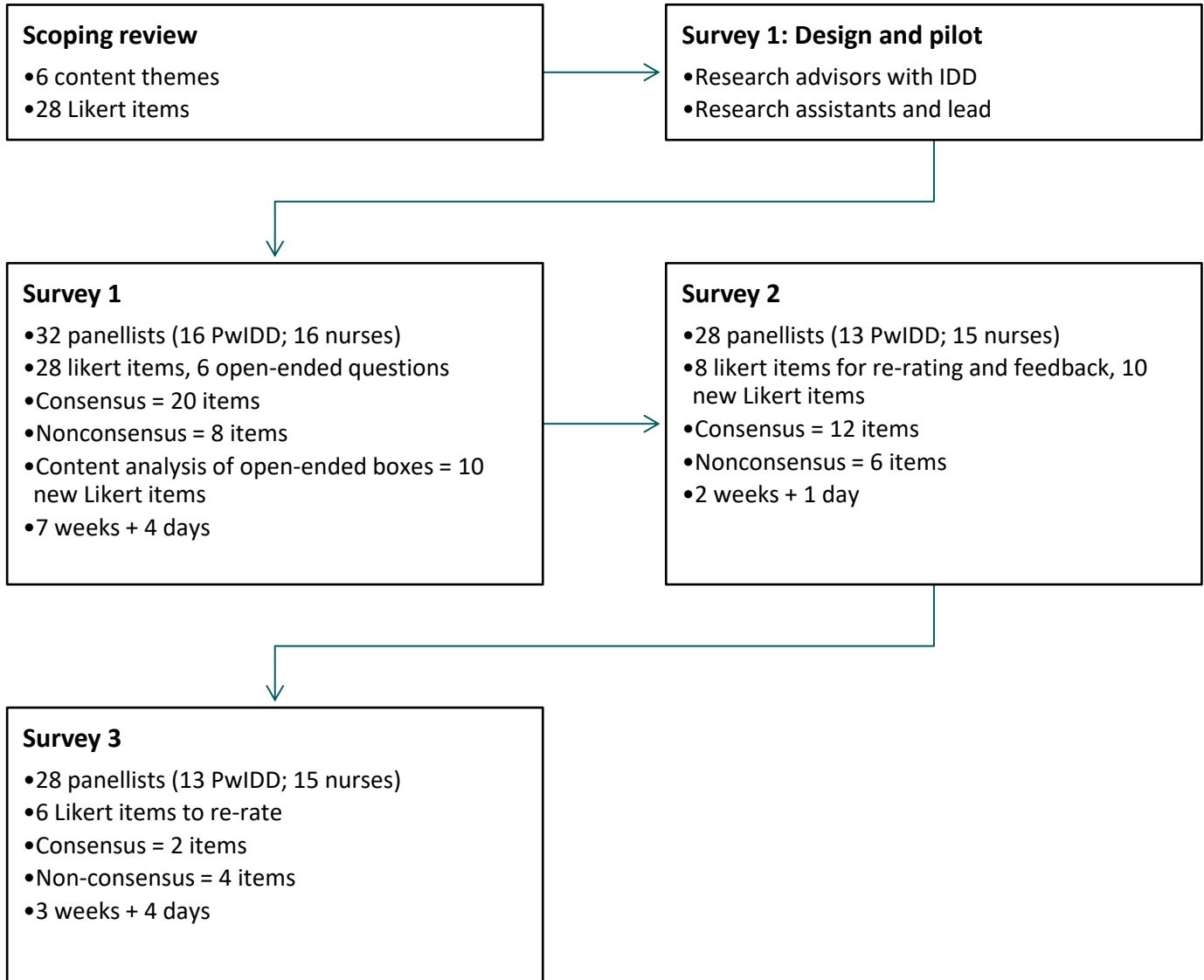
### Surveys 1–3 Delphi Results

At the conclusion of three survey rounds, consensus was met on 34 out of 38 proposed priorities for nursing education, each rated as *very important*. Survey 1 included 28 Likert questions developed from a scoping review and six open-ended questions. A total of 20 Likert questions met consensus and thus were not included in Survey 2. Eight Likert questions did not meet consensus and thus were included in Survey 2. The subthemes identified from the content analysis of the open-ended questions generated 10 additional Likert questions with companion open textboxes, included in Survey 2. Survey 2 comprised 18 Likert questions and six open-ended questions. A total of 12 Likert questions met consensus: 10 questions generated from content analysis and two re-rated questions. Six questions did not meet consensus. Analysis of the open feedback in Survey 2 did not generate new Likert items, only further narrative data aligning with the previously identified subthemes from content-analyzed open-ended questions in Survey 1. Survey 3 included six questions for re-rating; two met consensus and four did not. Table 1 presents the frequency counts and percentages of panellists' Likert-scale ratings for Survey 1 questions. Table 2 presents the frequency counts and percentages of Likert-scale ratings for questions in Surveys 2

and 3; questions generated from content analysis are identified with an asterisk. The categories, subthemes, codes, and exemplar quotes identified from content analysis are found in Appendix A.

Figure 1

*Flow Diagram Delphi Method Process*



*Note.* IDD = intellectual and development disabilities; PwIDD = people with intellectual and developmental disabilities.

*Person-Centred Care*

A total of 13 Likert items about person-centred care were rated for importance; 10 items met consensus, each rated as *very important*. Six person-centred care priorities, originating from the literature, met consensus: 1) legal and ethical issues; 2) the importance of getting to know people with IDD and their wishes; 3) adapting care environments to promote people with IDD to feel safe and included; 4) health



information exchange (e.g., health passports); 5) learning about individual experiences of living with IDD; and 6) health teaching to people with IDD about health check-up procedures and treatments. The content analysis of open-ended question feedback in Survey 1 generated four new questions, rated in Survey 2; each met consensus: 1) prioritizing talking *with* people with IDD; 2) implementing trauma awareness and trauma-informed approaches; 3) understanding people with IDD as individuals with unique needs; and 4) treating people with IDD with equal respect to people without IDD.

Consensus was not met for any Likert point for the questions about student nurse proficiency to educate people with IDD about sexual health, physical fitness, and nutrition or to support routines. In Survey 2, panellists' open feedback about sexual health education ranged from questioning the relevance of this education for people with greater IDD-related limitations to acknowledging stereotypical assumptions that people with IDD are asexual:

[Sexual health education] is very important for most people, [but] less important for people with profound level of IDD.

People often assume individuals with disabilities aren't sexually active.

Other panellists recognized that educational approaches differ and should be adjusted for accessibility:

Often [people with IDD do] not receive sexual health education at the same level as traditional classes.

Some people need it taught in an easier way.

Panellists also identified the importance of educating the individual about their body and strategies for health promotion and harm prevention:

If we don't get [sexual health teaching,] we won't know. No one else knows how you are feeling inside your body.

Everyone needs to learn how to keep themselves safe from harm or pregnancy or disease.

In Survey 3, 88.9% of all panellists rated sexual health teaching as either *very important* (63%) or *important* (25.9%), without consensus on one Likert point. The speaker position of responders was reviewed to determine the composition of the disagreement on the Likert points. A total of 84.5% of panellists with IDD rated this item as either *important* ( $n = 3$ ; 23.0%) or *very important* ( $n = 8$ ; 61.5%), while 86.6% of nurse panellists rated this item as *important* ( $n = 4$ ; 26.6%) or *very important* ( $n = 9$ ; 60.0%). Therefore, there was consensus within and between the panellist groups about prioritizing sexual health for nursing curriculum, but there was not agreement within or between groups about the degree of its importance.

Panellists' open feedback about education on physical exercise and nutrition differed in Survey 2. One panellist reported that the topic was irrelevant for their nursing practice: "Never used it yet in my career." Another highlighted the importance of individualized, accessible information: "How—hands on, videos/pictures, incorporate life skills, field trip to market? Consult with other professionals, dietitians." Other panellists also cautioned that people with IDD should have the opportunity and choice to learn about physical health:

It's up to the person if they want that or not. Sometimes it feels like it's being forced.

If we don't know we can't do anything about it.

In Survey 3, 84.5% of panellists with IDD rated the item as *important* ( $n = 3$ ; 23.0%) or *very important* ( $n = 8$ ; 61.5%), and 93.3% of nurse panellists rated it as *important* ( $n = 2$ ; 13.8%) or *very important* ( $n = 12$ ; 80.0%). There was consensus within and between panellist groups that this item was a priority for nursing curriculum. There was no agreement between groups or between panellists with IDD on the specific degree of importance. There was consensus within the nurse panellist group that this item was *very important*.

Panellists' comments in Survey 2 about student nurses learning to support people with IDD in their daily routines included specifying the relevance of this support for home care nurses, considering the connection between lack of routine, anxiety, and anxiolytics; and recognizing individual variation in the importance of routine and ways of doing:

If [the nurse is] in direct, in-home care [learning about daily routines would be important].

Lack of routines/structure can result in anxiety of the unknown.... Many people are treated with medications for anxiety and yet their daily "routines" have no structure.

Some depend on a routine. Others can deal with change. Know the individual and figure out how it will work.

[Nurses] need to know we [people with IDD] might do stuff slower, but we get it done.

In Survey 3, 88.9% of panellists rated this item as *important* or *very important*, without reaching consensus on either Likert point. Panellists with IDD rated this item as *important* ( $n = 5$ ; 38.5%) or *very important* ( $n = 8$ ; 61.5%), and 86.7% of nurse panellists rated this item as either *important* ( $n = 2$ ; 13.4%) or *very important* ( $n = 11$ ; 73.3%). There was no consensus within groups as to the degree of importance.

### Communication

Panellists met consensus on all six Likert questions about communication, each rated as *very important* for pre-licensure nursing education. Four communication topics that met consensus originated from the literature: 1) recognizing behaviour as a form of communication of personal expression and need; 2) developing communication competencies to support people with IDD who are experiencing distress or self injury; 3) enhancing awareness of diverse communication methods that people with IDD may use; and 4) developing nursing competencies in alternative communication approaches (e.g., sign language, pictures). Two communication priorities were developed from Survey 1 open-ended responses: 1) assessing individual communication approaches and adapt nursing communication accordingly, evaluating patient understanding; and 2) "talking nicely, not down to" people with IDD.

### Advocacy

Panellists reached consensus on five advocacy topics developed from the literature, all rated as *very important* priorities. Panellists agreed that student nurses should learn about the 1) historical treatment and nursing care of people with IDD; 2) disability discourses; 3) advocacy actions of student nurses with and for people with IDD for fair treatment; 4) advocacy for people with IDD to be heard and respected; and 5) the promotion of people with IDD to have autonomy in choices and self-determination.

### Health Issues and Diagnoses

Seven questions about health issues and specific diagnoses were rated, with six reaching consensus as *very important*. Six of these questions were developed from the literature, with five meeting consensus: 1) understanding manifestations of specific developmental disabilities (e.g., Autism, Down

syndrome, fetal alcohol spectrum disorder, Prader-Willi syndrome); 2) increasing awareness, prevention, identification of, and interventions for common conditions that people with IDD experience (e.g., epilepsy, mental illness, choking); 3) understanding pain assessment and intervention for people with IDD; 4) offering palliative care of people with IDD; and 5) providing accessible health education for people with IDD. One prioritized item was developed from the Survey 1 open-ended responses: nurses must “do their job right” by upholding nursing standards when caring for people with IDD.

The question about grief and bereavement support for people with IDD did not reach consensus on any Likert point. The spectrum of panellist comments about this topic in Survey 2 included recognition that people with IDD experience many unique losses: “They lose workers ... and friends over and over again.... Family breakdown and adoption, and then placements....” Some panellists emphasized that grief experienced by people with IDD should be recognized and supported. A panellist cautioned how expressions of grief by people with IDD can be misunderstood: “The labels *difficult* or *non-compliant* are too quickly used when we choose not to understand.” In Survey 3, 89.3% of panellists rated this topic as either *important* or *very important*. All panellists with IDD rated this item as either *important* ( $n = 2$ ; 15.4%) or *very important* ( $n = 11$ ; 84.6%), and 80% of nurse panellists rated this item as *important* ( $n = 4$ ; 26.7%) or *very important* ( $n = 8$ ; 53.3%). Thus, there was agreement between the panellist that this item was important, but not agreement on the degree of importance. Panellists with IDD met consensus, rating this item as *very important*.

### *Collaboration*

Four items about collaboration met consensus, rated as *very important* priorities. Two prioritized topics originated from the literature: 1) collaborative approaches with people with IDD and their families; and 2) awareness of services and supports for people with IDD. Two priorities originated from the open-ended questions: 1) awareness of interprofessional providers and their roles; and 2) inclusion of direct support professionals.

### *Decision-Making*

Panellists met consensus on three items about decision-making, all rated as *very important* priorities for nursing curriculum. Two priorities derived from the literature: 1) support for people with IDD in decision-making; and 2) nursing knowledge about elements of consent and substitute decision-makers. The third curriculum item derived from the open-ended feedback was respect for the choices made by people with IDD.

Table 1

*Survey 1: Priority Ratings on a Five-Point Likert Scale for Pre-licensure Nursing Education Content Topics About Care of People With IDD*

How important is it for student nurses to learn about PwIDD and the following topic?	# of panellists answered	# of panellists skipped	Likert-scale response				
			Not at all important	Less important	I don't know	Important	Very important
<b>Person-centred care</b>							
Legal/ethical issues	32	-	-	-	-	12.50%	<b>87.50%</b>
Getting to know PwIDD	32	-	-	3.13%	-	15.63%	<b>81.25%</b>
Feeling safe/included in care	32	-	-	3.13%	-	6.25%	<b>90.63%</b>
Health information exchange	32	-	-	3.13%	3.13%	12.50%	<b>81.25%</b>
What life is like for PwIDD	32	-	-	3.13%	12.50%	9.38%	<b>75.00%</b>
Educating PwIDD about sexual health	30	2	10.00%	-	13.33%	10.00%	66.67%
Educating PwIDD about healthy food and exercise	32	-	3.13%	12.50%	3.13%	12.50%	68.75%
Supporting PwIDD in routines	32	-	3.13%	3.13%	12.50%	12.50%	68.75%
Health check-up and treatment teaching	32	-	3.12%	-	-	18.75%	<b>78.13%</b>
<b>Communication</b>							
Understanding behaviours of PwIDD	32	-	-	-	-	18.75%	<b>81.25%</b>
Different forms of communication	32	-	3.13%	-	3.13%	15.63%	<b>78.13%</b>
How to communicate differently	32	-	-	-	6.25%	25.00%	68.75%
How to support PwIDD in distress	32	-	-	3.13%	3.13%	6.25%	<b>87.50%</b>
<b>Advocacy</b>							
Historic treatment towards PwIDD	31	1	3.23%	3.23%	6.45%	19.35%	67.74%
Ways disability is understood	32	-	-	3.13%	3.13%	15.63%	<b>78.13%</b>
Ensuring fair treatment	32	-	-	-	-	15.63%	<b>84.38%</b>
Making sure the voices of PwIDD are heard	32	-	-	-	3.13%	8.38%	<b>87.50%</b>
Allow PwIDD to make their own choices	32	-	-	3.13%	3.13%	18.75%	<b>75.00%</b>

<b>Specific diagnoses and health problems</b>							
Specific diagnoses	32	-	3.13%	-	-	15.63%	<b>81.25%</b>
Common health problems	32	-	-	-	3.13%	6.25%	<b>90.63%</b>
Easy ways to teach health	31	1	-	3.23%	3.23%	16.13%	<b>77.42%</b>
How to know if someone is in pain	31	1	-	3.23%	-	16.13%	<b>80.65%</b>
Supporting those who are dying	30	2	-	3.33%	-	20.00%	<b>76.67%</b>
Grief and bereavement support for PwIDD	30	2	-	6.67%	3.33%	16.67%	73.33%
<b>Collaboration – working together</b>							
How to work with PwIDD and their families	29	3	-	3.45%	-	17.24%	<b>79.31%</b>
Available services/supports for PwIDD	30	2	-	6.67%	3.33%	16.67%	73.33%
<b>Decision-making</b>							
Supporting PwIDD to make choices	30	2	-	3.33%	-	26.67%	70.00%
How to know if PwIDD can give consent	30	2	-	3.33%	-	13.33%	<b>83.33%</b>

Note. Bolded items met or exceeded consensus criteria of  $\geq 75\%$ . PwIDD = people with intellectual and developmental disabilities.

Table 2

*Survey 2: Priority Ratings on a Five-Point Likert Scale for Pre-Licensure Nursing Education Content Topics About Care of People With IDD*

How important is it for student nurses to learn about PwIDD and the following topic?	# of panellists answered	# of panellists skipped	Likert-scale response				
			Not at all important	Less important	I don't know	Important	Very important
<b>Person-centred care</b>							
Talking to PwIDD*	28	-	3.57%	-	-	10.71%	<b>85.71%</b>
Each PwIDD is unique and has unique needs*	28	-	-	2.57%	-	17.86%	<b>78.57%</b>
Awareness of possible trauma/negative health care experience*	28	-	-	7.14%	3.57%	14.29%	<b>75.00%</b>
Treat PwIDD with equal respect as others*	28	-	-	-	-	17.86%	<b>82.14%</b>
Educate PwIDD about sexual health	26	2	-	3.85%	15.38%	23.08%	57.69%
Educate PwIDD about healthy food and exercise	27	1	-	7.41%	3.70%	29.63%	59.26%
Supporting PwIDD in routines	28	-	-	3.57%	3.57%	21.43%	71.43%
<b>Communication</b>							
Adapting communication for PwIDD*	28	-	-	-	-	14.29%	<b>85.71%</b>
Talking nicely/not talking down to PwIDD*	28	-	-	-	-	17.86%	<b>82.14%</b>
Different ways to communicate	27	1	-	3.70%	3.70%	33.33%	59.26%
<b>Advocacy</b>							
Historical treatment of PwIDD	27	1	3.70%	-	-	18.52%	<b>77.78%</b>
<b>Specific diagnoses and health problems</b>							
Upholding nursing standards with PwIDD*	28	-	-	-	-	14.29%	<b>85.71%</b>
Grief and bereavement support for PwIDD	28	-	-	3.57%	-	25.00%	71.43%
<b>Collaboration – working together</b>							
Talk to families/support workers*	28	-	-	-	-	14.29%	<b>85.71%</b>
Different service providers and their role*	28	-	-	3.57%	3.57%	17.86%	<b>75.00%</b>
Available services/supports for PwIDD	28	-	-	3.57%	-	28.57%	67.86%

<b>Decision-making</b>							
Respecting the choices of PwIDD*	28	-	3.57%	-	-	7.14%	<b>89.29%</b>
Supporting PwIDD to make choices	28	-	-	-	-	21.43%	<b>78.57%</b>

Note. Bolded items met or exceeded consensus criteria of ≥ 75%. Asterisk indicates new Likert item generated from open-ended questions in Survey 1. PwIDD = people with intellectual and developmental disabilities.

Table 3

Survey 3: Priority Ratings on a Five-Point Likert Scale for Pre-licensure Nursing Education Content Topics About Care of People With IDD

How important is it for student nurses to learn about PwIDD and the following topic?	# of panellists answered	# of panellists skipped	Likert-scale response				
			Not at all important	Less important	I don't know	Important	Very important
<b>Person-centred care</b>							
Educate PwIDD about sexual health*	27	1	7.41%	-	3.70%	25.93%	62.96%
Educate PwIDD about healthy food and exercise*	28	-	3.57%	3.57%	3.57%	17.86%	71.43%
Supporting PwIDD in their daily routine*	28	-	-	3.57%	3.57%	25.00%	67.86%
<b>Communication</b>							
Adapting communication	28	-	-	3.57%	-	7.14%	<b>89.29%</b>
<b>Specific diagnoses and health problems</b>							
Grief and bereavement support for PwIDD*	28	-	-	7.14%	3.57%	21.43%	67.86%
<b>Collaboration – working together</b>							
Services and supports for PwIDD	28	-	-	3.57%	-	14.29%	<b>82.14%</b>

Note. Bolded items met or exceeded consensus criteria of ≥ 75%. Asterisk indicates question with no consensus at the closing of the study. PwIDD = people with intellectual and developmental disabilities.

## Discussion

In this inclusive Delphi study, we aimed to identify priorities for pre-licensure curriculum about nursing care of people with IDD by surveying people with IDD and nurses who often work with this population. Of the 38 curriculum content items that were rated, 28 items were developed from a scoping review, with 24 meeting consensus and four not, and 10 were generated from open-ended questions, all meeting consensus. Although consensus was set to panellists' rating agreement on any Likert point, all items meeting consensus were rated as *very important* priorities for nursing education. The 24 consensus items generated from the scoping review provide stakeholder validation and prioritization, which were previously largely absent, aligning with findings of Don et al.'s (2025) scoping review about this topic.

The topics of sexual health education, physical and nutrition education, nursing support of individuals' routines, and bereavement and grief nursing care did not reach consensus, therefore diverging from literature themes. The combined scores of *important* and *very important* for each item, together with panellist feedback, indicate that these topics should be prioritized with specific considerations. Nurse educators should emphasize that student nurses assess and challenge unconscious bias that would deem aspects of holistic care irrelevant for people with IDD or for nursing practice, particularly involving sexual health. Nursing stigma about the sexual health of people with IDD is well documented, and panellist feedback highlights its persistence (Pelleboer-Gunnink et al., 2017). Student nurses must learn to continually reflect on power relations between themselves and people with IDD when providing physical and nutritional health information, avoiding paternalistic approaches. Instead, they must develop person-centred collaborations, adapting to individual priorities and needs. These implications advance Martin et al.'s (2021) study, wherein clinical nurse specialists delivered an educational module of accessible information for people with IDD about nutrition and physical health, promoting self-determination rather than a diet or weight outcome.

While panellists with IDD conclusively rated bereavement and grief support as *very important*, nurse panellists did not. Whuczek (2025) identified the following barriers for people with IDD: stereotypes about grieving ability, overprotection, and lack of competencies among health professionals to address this abstract topic in an accessible way. These barriers identify points to include in nursing education.

The panellist-generated questions reflect nuanced findings about nursing curriculum priorities. Pre-licensure nursing curriculum should include explicit approaches to communicating with people with IDD that convey a respect of individuality; a commitment to facilitating speaking on their own behalf; and curiosity, patience, and humility to learn ways that individuals communicate and to adapt nursing communication to ensure it is accessible and understood by the recipient with IDD. These findings provide new insights about how to shift from away the ableist privileging of verbal communication and situates nurses and people with IDD as "equal partners in the communication needs situation" (Dee-Price, 2020, p. 133).

Panellists shared stories about experiencing or witnessing nursing care that was condescending and patronizing, deprioritizing of people with IDD, and not in accordance with general nursing practice standards. Pre-licensure curriculum should include content about negative and traumatic experiences that people with IDD commonly experience in receiving nursing care to better understand how to promote culturally safer care. Stakeholder responses to the issue paper of Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2019) about health care abuses experienced by this population proposed that health care worker stereotypes about disabilities contributed to the devaluing of people with IDD, unequal treatment, and harmful care. Panellists similarly prioritized equal respect in this study. The ethos of respect enables nurses to perceive all people as having



equal worth and value, while individualizing nursing care so as not to “treat everyone the same” with no consideration of IDD.

Finally, student nurses should be exposed to interprofessional education opportunities to develop their understanding of the role of developmental service workers and how to navigate this collaboration. The identification of developmental service workers as interprofessional collaborators with nurses is unresearched and expands beyond traditional interprofessional education between nursing and medicine, rehabilitation, and social work (Ailey et al., 2024).

To our knowledge, this study is the first to identify priorities for Canadian nursing curriculum about people with IDD, including the voices of Canadian nurses with practice experience in caring for people with IDD. This study is also, globally, the first that we are aware of to include people with IDD in identifying priorities for content topics in nursing education about people with IDD. The identified priorities of this study break the silence within the nursing profession about people with IDD, using the voices of people with IDD and leading nursing action.

## Limitations

Demographic data were not collected in this study to protect panellists’ privacy and reduce the risk of panellists with IDD not participating. Though not required in Delphi design, the representativeness of the sample is thus unspecified (Keeney et al., 2011). The inclusion criteria of a minimum age of 18 precluded younger people with IDD from participating. People with IDD who cannot provide informed consent and those who do not use verbal language were not represented in this study. Inadequacy of nursing education about people with IDD is a national issue, but the perspectives of only Ontario panellists were represented. Open-ended questions and comment completion to generate new Likert items was optional and skipped by many panellists. Thus, the comprehensiveness of generated Likert items may be incomplete. Because of constrained time between survey rounds, research advisors did not participate in data analysis.

## Conclusion

The identified curriculum content priorities provide direction for nurse educators and faculty to develop disability-inclusive nursing curriculum relevant to the care needs of people with IDD. The findings of this study provide stakeholder validation of extant global literature that has yet to be consistently recognized or adopted. Further, panellist-generated topics and feedback inform nurse educators about current non-therapeutic approaches and biases that people with IDD commonly experience, and identify key approaches to communication, reflection, clinical practice, and collaboration to counter them. This study identifies adaptive skills that student nurses require to provide individualized accessible care.

The findings will inform a nurse educator toolkit, pairing priorities with available resources. Nurse educators can incorporate priorities by decentering non-disabled patients as the tacitly assumed standard patient, broadening considerations of general nursing practice standards within curriculum to explicitly include people with IDD. To support the implementation of these priorities into nursing curriculum, further research focused on teaching and learning methods, designed collaboratively with people with IDD, is needed.

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## Appendix A: Categories, Subthemes, Codes, and Exemplar Quotes Identified From Content Analysis

Category: Person-centred care		
Subcategory; created survey item	Code	Exemplar quotes
<p>How important is it for student nurses to learn to...</p> <ul style="list-style-type: none"> <li>talk to people with intellectual and developmental disabilities (IDD)?</li> </ul>	<p>“Learn about me... Talk to me.”</p> <ul style="list-style-type: none"> <li>Collaborate with people with IDD to learn about their priorities.</li> </ul>	<p>“Identifying and understanding the person’s priorities.... What is essential to the individual?” —N5</p> <p>“It is important for the nurses to learn about me and help me out.” —P11</p> <p>“If they don’t know what you need, they can’t help.” —P14</p>
<p>How important is it for student nurses to know that...</p> <ul style="list-style-type: none"> <li>people with IDD may have had bad experiences with nurses or hospitals?</li> <li>some things might make people with IDD nervous?</li> </ul>	<p>Trauma-informed care.</p>	<p>“You are always the last one. They always look after other people first. It makes you feel sad and mad. I would like to be seen first. They forget you.” —P9</p> <p>“I always get nervous when I go to a health check-up because I don’t know what they are going to do.... I feel uncomfortable.... It’s a bit scary.” —P15</p> <p>“How to recognize when there is trauma and appreciate this can change the response to seeking care/treatment.” —N14</p>
<p>How important is it for student nurses to learn that...</p> <ul style="list-style-type: none"> <li>every person with IDD is unique and has different needs?</li> </ul>	<p>“Depends on who.” —P14</p> <ul style="list-style-type: none"> <li>Nurses should consider the individual’s ability and adapt approach accordingly.</li> <li>Every person is unique.</li> </ul>	<p>“Question 6 (sexual health teaching) would be dependent on the severity of the patient’s intellectual disability—would need to be appropriate for their level—and based specifically on that individual not a one teaching model for all.” —N1</p> <p>“Understand that every person is different in their ability.” —N13</p> <p>“[Nurses] need to explain more. They need to be patient. I know that my doctor, I move a lot and they tried to put a [blood pressure] machine on me and they are very patient [with] me so why not everyone else?” —P14</p>

<p>How important is it for student nurses to...</p> <ul style="list-style-type: none"> <li>treat people with IDD with the same respect as they do everyone else?</li> </ul>	<p>“Treat us like equals.” —P12 “Treat me fairly” (equity).</p>	<p>“Treat us like equals. Make sure we are heard.” —P12 “Everyone has equal worth in every area of life.” —N3 “Treat [people with IDD] fair and square like everybody else.” —P15</p>
<b>Category: Decision-making</b>		
Subcategory	Code	Exemplar quotes
<p>How important is it for student nurses to respect the following of people with IDD:</p> <ul style="list-style-type: none"> <li>choices?</li> <li>rules?</li> <li>when they say “yes” or “no”?</li> </ul>	<ul style="list-style-type: none"> <li>Informed consent—establishing boundaries.</li> <li>My body, my choice.</li> </ul>	<p>“I’m a pop-aholic and my support person may suggest waiting. And it’s my choice.” —P1 “The nurse is not allowed to touch you.” —P6 “[Nurses] need to ask first the individual before talking to the family because [the individual] might not want them talking to the family.” —P16</p>
<b>Category: Communication</b>		
Subcategory	Code	Exemplar quotes
<p>How important is it for student nurses to...</p> <ul style="list-style-type: none"> <li>learn how each person with IDD communicates?</li> <li>make sure the person with IDD understands what the nurse is saying?</li> </ul>	<p>Adapting to individual communication.</p>	<p>“Knowing to ask if [the person with IDD does] have any communication needs and using outside supports to support conversations.” —N6 “Non-verbal cues as well as learning the way [people with IDD] communicate[, such as] sweating, facial grimacing, or cries.” —N3 “[Nurses] need to be patient. We are slower than a normal person and we might ask again too to explain it better.” —P14 “Many people in our care are non-verbal or have minimal verbal skills—learning how to observe, what to observe for.” —N4</p>

<p>How important is it for student nurses to...</p> <ul style="list-style-type: none"> <li>• talk to people with IDD nicely?</li> <li>• not talk down to people with IDD?</li> </ul>	<p>“Talk to me nicely, ... not down to me.”</p> <p>Nursing approach to interactions with people with IDD.</p>	<p>“Nurses, let them talk to me [like] normal, like a human being[,] not as a child. As long as they don’t talk down to me, it’s fine. I understand most things.” —P15</p> <p>“Talk to individuals with disabilities without making them feel stupid or different.” —N9</p> <p>“Talk to me nicely.” —P11</p> <p>“Keep it positive and professional.” —N11</p>
<p><b>Category: Specific diagnoses and health problems</b></p>		
Subcategory	Code	Exemplar quotes
<p>How important is it for student nurses to...</p> <ul style="list-style-type: none"> <li>• do their job right when they care for people with IDD (uphold nursing standards)?</li> </ul>	<p>“Do their job right.” —P12</p> <p>Maintain nursing standards.</p>	<p>“Understanding communication impacts on crucial health care processes like informed consent/assent.” —N6</p> <p>“Learn how to comfort those with intellectual disabilities when they are scared about procedures.” —N3</p> <p>“If you have client with management tools for medical situations know ... and understand [the tools] before you meet [the client] if possible.” —P3</p> <p>“[It is] important that [nurses] learn how to administer the meds, facilitate the meds... Many people in the house have different needs, a neighbour has [chronic obstructive pulmonary disease]. Every client is different on their meds. If they don’t learn about the meds and something goes wrong....” —P1</p> <p>“Providing adequate orientation for the nurse before working independently with a client to ensure that a client receives the best possible relationship with those entrusted with their care.” —N11</p>



Category: Collaboration		
Subcategory	Code	Exemplar quote
<p>How important is it for student nurses to learn about...</p> <ul style="list-style-type: none"> <li>• different types of service providers?</li> <li>• how they can support people with IDD?</li> </ul>	<p>Nursing awareness of interprofessional resources for people with IDD</p>	<p>“Connect with members of the community so they can get the resources they need—family [doctor, nurse practitioner, speech–language pathologist, occupational therapist, physiotherapist].” —N14</p> <p>“Nurses should learn about behavioural programs. Nurses should come to advoca[cy] groups.” —P1</p> <p>“Resources and navigating them is difficult so understanding where to go, who to ask and what services can be provided is very important.” —N8</p>
<p>How important is it for student nurses to talk to...</p> <ul style="list-style-type: none"> <li>• the family of a person with IDD?</li> <li>• support workers for a person with IDD?</li> </ul> <p>Note: If the person with IDD wants the student nurses to do so.</p>	<p>“If they don’t understand us, they should pull someone who would understand us.” —P14</p> <p>Learning from staff/people in the person’s support team/in their life.</p>	<p>“Understanding how a support worker, family member, &amp; power of attorney works with the client.” —N8</p> <p>“If they don’t understand us they should pull someone who would understand us.” —P14</p> <p>“How strained and knowledgeable families are—working with them and understanding their fears &amp; concerns &amp; impact of previous negative experience, communicating with families to keep them informed and gather information and get input on care plans.... [L]ack of services means that families carry a huge burden, siblings as caregivers, senior/aging parents as caregivers.... [W]ork with families from a place of compassion and empathy and in a supportive way, listen to and respect families.” —N16</p> <p>“Talk to the person’s support worker because they know the person very well.” —P1</p> <p>“Learn to have someone on hand that understands/knows the person[']s way of communicating.” —N4</p>