

# Care of adults with developmental disabilities

## Effects of a continuing education course for primary care providers

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### Abstract

**Objective** To evaluate the effects of an interdisciplinary, guideline-based continuing education course on measures related to the care of adults with developmental disabilities (DD).

**Design** Before-and-after study with a control group.

**Setting** Ontario.

**Participants** Forty-seven primary care providers (physicians, registered nurses, and nurse practitioners).

**Intervention** Participants either only received reference material about primary care of people with DD (control group) or participated in a continuing education course on primary care of people with DD in addition to receiving the reference material (intervention group).

**Main outcome measures** Participants reported on 5 key measures related to care of adults with DD: frequency of using guidelines, frequency of performing periodic health examinations, frequency of assessing patients who present with behaviour changes, level of comfort while caring for adults with DD, and knowledge of primary care related to adults with DD.

**Results** Over time, the intervention group showed significant increases in 4 of the 5 key measures of care compared with the control group: the frequency of guideline use ( $P < .001$ ), frequency of assessment of patients' behaviour change ( $P = .03$ ), comfort level in caring for people with DD ( $P = .01$ ), and knowledge of primary care related to adults with DD ( $P = .01$ ).

**Conclusion** A continuing education course on primary care of adults with DD is a useful interdisciplinary model to train health professionals who provide primary care services to these patients.

### EDITOR'S KEY POINTS

- Adults with developmental disabilities (DD) experience more mental and physical health conditions compared with the general population and have difficulty accessing primary care that meets their needs. Published guidelines assist primary care providers with managing patients with DD; however, the availability of guidelines and other reference material alone does not mean that their recommendations will be applied in practice.
- This study found that primary care providers who participated in a continuing education course about care of adults with DD reported improvements in key areas related to the health care of these patients; these improvements suggest that it is worthwhile to invest in an interdisciplinary, guideline-based continuing education course to train primary care providers on how to provide care to this vulnerable population.
- Continued support for the education of primary care providers could improve health outcomes of adults with DD; there is a need for more research using direct measures of health outcomes.

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# Soins requis par les adultes souffrant de déficience développementale

Effets d'un cours de formation continue à l'intention des soignants de première ligne

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## Résumé

**Objectif** Déterminer quels effets peut avoir un cours de formation continue basé sur des directives sur certains paramètres liés au traitement des adultes souffrant de déficiences développementales (DD).

**Type d'étude** Étude avant-après avec groupe témoin.

**Contexte** L'Ontario.

**Participants** Quarante-sept soignants de première ligne (médecins, infirmières diplômées et infirmières praticiennes).

**Intervention** Certains participants ont reçu seulement des documents de référence sur le traitement des personnes souffrant de déficience développementale (groupe témoin) alors que d'autres ont suivi un cours de formation continue sur le même sujet en plus de recevoir les mêmes documents de référence (groupe d'intervention).

### POINTS DE REPÈRE DU RÉDACTEUR

- Par rapport à la population générale, les adultes souffrant de déficience développementale (DD) ont plus de problèmes de santé physique et mentale et ont plus de difficulté à obtenir les soins primaires dont ils ont besoin. Les directives existantes peuvent aider les soignants de première ligne à répondre à leurs besoins; toutefois, la disponibilité de ces directives et d'autres sources de référence ne signifie pas nécessairement que leurs recommandations sont appliquées en pratique.
- Cette étude a constaté qu'après avoir suivi un cours de formation continue sur les soins aux adultes souffrant de DD, des soignants de première ligne ont rapporté des améliorations dans des domaines clés liés aux soins de santé de ces patients; cela permet de croire qu'il vaut la peine d'investir dans un cours de formation continue interdisciplinaire portant sur ces directives afin que ces intervenants soient plus en mesure de soigner cette population vulnérable.
- Assurer un soutien continu permettant de former les soignants de première ligne pourrait améliorer les issues des adultes souffrant de DD; il serait nécessaire de réaliser d'autres études mesurant directement ces issues.

**Principaux paramètres à l'étude** Les participants devaient évaluer 5 paramètres clés liés au traitement des adultes souffrant de DD : la fréquence d'utilisation des directives, des examens de santé périodiques effectués et des évaluations de patients présentant des changements de comportement, leur niveau de confort lorsqu'ils traitent les personnes avec DD et leur connaissance des soins primaires requis par ces patients.

**Résultats** Par rapport au groupe témoin, le groupe d'intervention a montré avec le temps des augmentations significatives dans 4 des 5 paramètres clés relatifs aux soins des patients souffrant de DD : la fréquence d'utilisation des directives ( $P < ,001$ ), la fréquence d'évaluation des changements de comportement de ces patients ( $P = ,03$ ), leur niveau de confort lorsqu'ils les traitent ( $P = ,01$ ) et leurs connaissances des soins qu'ils requièrent ( $P = ,01$ ).

**Conclusion** Un cours de formation continue sur les soins des adultes souffrant de DD est un modèle interdisciplinaire utile pour les professionnels de la santé qui dispensent des soins de santé primaires à ces patients.

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Developmental disabilities (DD) are characterized by lifelong limitations in intellectual and adaptive functioning first manifested before the age of 18. They include conditions such as Down syndrome and fragile X syndrome.<sup>1</sup> Persons with DD experience more physical and mental health problems<sup>2-4</sup> than those without DD do, and there is evidence that they have difficulty accessing primary care that meets their needs.<sup>5</sup> Disparities in health and health service outcomes between Canadians with and without DD have been reported, and improvements in primary care could play a role in decreasing these disparities.<sup>1</sup>

To improve the health outcomes of adults with DD, the “Canadian Consensus Guidelines”<sup>6</sup> (hereafter referred to as the *Guidelines*) and the supporting book *Tools for the Primary Care of People with Developmental Disabilities*<sup>7</sup> (hereafter referred to as the *Tools Book*) for the primary care of adults with DD were developed through extensive consultation with primary care providers. The Guidelines stress the need to perform comprehensive preventive care assessments annually and, when patients with DD present with changes in behaviour, they encourage the use of appropriate assessments to identify the underlying cause of the behaviour changes. The Tools Book includes strategies and checklists to facilitate follow-through on recommendations. Hard copies of the Guidelines and the Tools Book were distributed to every family physician in Canada in 2011 and are readily available for primary care providers to access online in French and English.<sup>8</sup>

Research in the area of guideline use has noted that distribution alone is not sufficient to ensure that guidelines are applied in practice.<sup>9</sup> As workshops and other forms of continuing medical education have shown promise in supporting the adoption of guideline recommendations,<sup>10</sup> they might be one way to encourage the use of the Guidelines and Tools Book. However, little research has looked at the effectiveness of this type of intervention among primary care professionals working with persons with DD.

To our knowledge, only one study has examined the effects of continuing education-related interventions on primary care providers who work with people with DD. Using a before-and-after study design, Melville et al<sup>11</sup> found that nurses who received both training and literature on the health needs of people with DD had increased knowledge of and improved comfort levels in caring for these patients in contrast to comparison groups. Our study adds to the existing literature by studying both primary care physicians and nurses, and by evaluating outcomes that relate to a Canadian context in which primary care is increasingly being implemented using interdisciplinary models of care and in which the national consensus Guidelines have been

introduced. The educational strategy under study also uses an innovative mix of face-to-face and online formats. Our study aimed to evaluate the effects of an interdisciplinary, guideline-based continuing education course on measures related to the practice of primary care among physicians and nurses whose case loads include adults with DD.

## METHODS

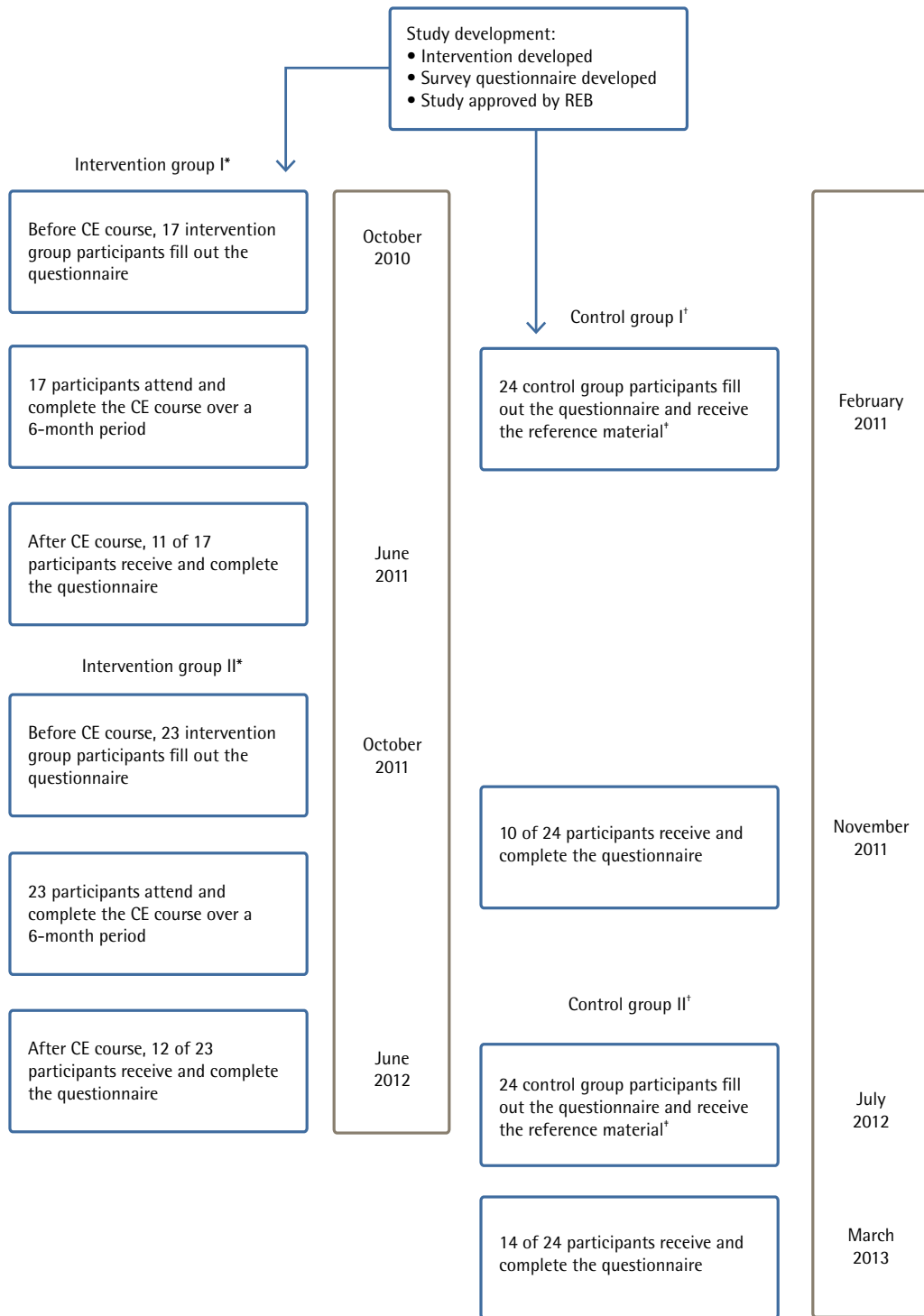
We conducted a before-and-after intervention study with a control group. Individuals in the intervention group participated in a 6-month continuing education course and received reference material on primary care for persons with DD, while the control group received only the reference material. The study progression is described in **Figure 1**.<sup>6,7,12,13</sup> The study took place in Ontario over a 2.5-year period (October 2010 to March 2013).

Nurses, nurse practitioners, and physicians who enrolled and took part in the Primary Care of Persons with DD continuing education course were invited to participate in the study. Course participants who agreed and consented to participate were considered part of the intervention group. Participants in the control group were recruited through referral or snowball sampling, in which existing study participants recruited other participants from among colleagues and by e-mail communications with professional groups. To be included in the study, health care providers were required to have adult patients with DD in their case loads. Clinicians such as psychiatrists, rehabilitation therapists, social workers, and psychologists were participants in the continuing education course; however, they were excluded from our analysis because some of the outcomes we measured were not applicable to these professions. The study received approval from the Surrey Place Centre Research Ethics Board.

## Intervention

The continuing education course was structured around case scenarios and consisted of 3 online modules; there were also 2 face-to-face, all-day workshops (1 workshop at the beginning and 1 at the end of the course). The introductory workshop familiarized the participants with the Guidelines, the Tools Book, and the methods of the continuing education course and included a case scenario. The content of the online modules was made available asynchronously to participants through learning management software. The modules revolved around 3 specifically designed cases that were discussed in interdisciplinary small groups led by trained facilitators. Key issues in the primary care of adults with DD including assessment and treatment approaches were elaborated on using discussion

Figure 1. Flowchart of study activities



CE—continuing education, DD—developmental disabilities, REB—research ethics board.

\*Intervention group participants attended a CE course on primary care of adults with DD in addition to receiving reference material.

†Control group participants only received reference material about primary care of adults with DD.

‡Reference material included the Guidelines,<sup>6</sup> Tools Book,<sup>7</sup> and 2 resource books.<sup>12,13</sup>

boards. Each module lasted approximately 1 month and the entire course term lasted 6 months. The final workshop addressed issues flagged during the online case studies (eg, sexuality and the appropriate use of medication for mental disorders and behavioural problems) and also reviewed community-based resources available to support persons with DD and their caregivers. The Guidelines stress that interdisciplinary health care is effective in addressing the complex needs of people with DD. To encourage this approach, the continuing education course included participants from various professional backgrounds involved in primary care (eg, physicians, nurses, nurse practitioners, social workers, rehabilitation therapists, and psychologists); however, only physicians and nurses were included in the study analysis. In addition, the course curriculum included interdisciplinary work and discussions.

Both the intervention and control groups received the same reference material, including the Guidelines, Tools Book, and 2 resource books<sup>12,13</sup> that address specific issues and challenges regarding the primary care of adults with DD.

### Measurement

The intervention group participants completed an online survey before and after the intervention periods, while the control group participants completed the survey before and after receiving the reference material. For both the intervention and control groups, there was 9 to 10 months between the “before” period (when the participants received the initial survey) and the “after” period (when the participants received the follow-up survey) (Figure 1<sup>6,7,12,13</sup>). The survey was created by a committee that included researchers and family physicians. The committee identified constructs that should change with training; the constructs were translated into questions that were categorized into 5 key measures that address specific objectives of the continuing education course curriculum. The 5 key measures included questions on frequency of use of the Guidelines and Tools Book, frequency of performing periodic health examinations, frequency of performing assessments of patients who present with behaviour changes, level of comfort while caring for adults with DD, and knowledge of primary care related to adults with DD (Table 1). Reliability analysis indicated high internal consistency of the questions within each of the key measures (Chronbach  $\alpha$  range .78 to .89). The survey also included questions on study participants’ demographic characteristics (age, sex, profession, urban or rural practice) (Table 2). The survey was pilot-tested with 4 physicians and revised based on feedback. A copy of the “Survey of Practice Patterns, Behaviours, Comfort Level and Knowledge” is available from the authors upon request.

### Statistical analysis

Descriptive statistics were computed for participant demographic variables (age, sex, and profession); these characteristics, as well as the key measures, were compared at baseline to evaluate if significant differences existed. Separate 2×2 repeated-measures ANOVA (analysis of variance) tests were conducted to examine differences in scores on the key measures between the training and comparison groups, as well as between time periods (before and after intervention). The  $\alpha$  level for determining significance was set at  $P < .05$  for all tests, and all analyses were calculated using SPSS, version 18.0.

## RESULTS

A total of 47 primary care providers participated in the study. Of these primary care providers, 23 completed the continuing education course and received the reference material, while 24 only received the reference material. Many participants were women (72.3%) and the sample had an overall mean (SD) age of 46.4 (9.3) years. The participants consisted of physicians (59.6%), nurse practitioners (21.3%), and registered nurses (19.1%) who had a mean (SD) of 13.6 (11.3) years in practice. Most participants served urban populations (70.2%), with a smaller percentage serving rural populations (17.0%), geographically isolated or remote areas (2.1%), or a combination of urban and rural areas (10.6%). No significant differences were found for any demographic variables or key measures between the intervention group and the control group participants at baseline (Tables 2 and 3).

Statistically significant group-by-time interactions were found for 4 of the 5 key measures. Between the before-and-after study periods, there was a significantly greater increase in reported frequency regarding the use of the Guidelines and Tools Book ( $P < .001$ ) and assessment of behaviour change ( $P = .03$ ) among the intervention group compared with the control group. In addition, comfort levels with providing primary care to adults with DD increased for both groups over time, but there was a significantly greater increase for the participants in the intervention group ( $P = .01$ ). Finally, over time, the intervention group participants showed significantly increased knowledge of primary care related to adults with DD ( $P = .01$ ) compared with the knowledge scores in the control group. No significant main effects or interactions were identified for the measure of frequency of performing periodic health examinations.

A subanalysis was conducted examining before-and-after changes in the above measures among the 28 physicians only. Results from this analysis paralleled those identified in the full sample with the exception that the group-by-time interaction for the level-of-comfort measure was no longer statistically significant. As in the full

**Table 1. Description of 5 key measures used in questionnaires**

KEY MEASURES	NO. OF QUESTIONS	RESPONSE FORMAT (SCORING)	EXAMPLES
Frequency of use of the Guidelines and Tools Book	3	5-point Likert scale (never = 1, rarely = 2, sometimes = 3, usually = 4, always = 5) (values summated)	"Indicate the frequency [with which] you used the 'Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities'"
Frequency of performing periodic health examinations	11	5-point Likert scale (never = 1, rarely = 2, sometimes = 3, usually = 4, always = 5) (values summated)	"Estimate how often you assessed for cerumen impaction"
Frequency of performing assessments when a patient presents with a behaviour change	7	5-point Likert scale (never = 1, rarely = 2, sometimes = 3, usually = 4, always = 5) (values summated)	"Estimate how often you assessed for physical, verbal and nonverbal cues of pain and distress"
Level of comfort while caring for adults with DD	8	5-point Likert scale (strongly disagree = 1, somewhat disagree = 2, neutral = 3, agree somewhat = 4, strongly agree = 5) (values summated)	"To what extent do you agree/disagree with the statement: 'I feel I have the necessary skills and training to care for a patient with a DD'"
Knowledge of primary care related to adults with DD	4	Multiple choice in response to vignette (no. of correct answers out of 4)	"In assessing the cause of mild DD for this patient, which of the following statements are TRUE"

DD—developmental disabilities.

sample, significant group-by-time interactions were identified for use of the Guidelines and Tools Book [ $F_{1,20}=23.41$ ,  $P=.004$ ], assessment of behaviour change [ $F_{1,24}=9.60$ ,  $P=.01$ ], and knowledge of primary care related to adults with DD [ $F_{1,20}=4.81$ ,  $P=.04$ ] (but not for the measure of performing periodic health examinations).

## DISCUSSION

This study investigated the effects of a continuing education course on the care delivered to adults with DD as reported by primary care providers. Results indicated that compared with a group of primary care providers who did not take the course, those providers who did take the continuing education course had improved outcomes in 4

out of 5 key measures: frequency of use of Guidelines and Tools Book, frequency of performing assessments when a patient presents with a behaviour change, level of comfort while caring for adults with DD, and knowledge of primary care related to adults with DD.

Our results parallel those from Melville and colleagues' study<sup>11</sup> on the effects of a training program on nurses' knowledge and self-efficacy. They found statistically significant improvements in knowledge and self-efficacy among the nurses who participated in a training event compared with the nurses who only received a training pack with information on the health needs of individuals with DD. Our study adds to the existing literature, as it provides data from a Canadian context, includes physicians, uses an interdisciplinary continuing education intervention, and measures self-reported behaviour in addition to comfort levels (similar to self-efficacy) and knowledge.

The creation of primary care guidelines was an important step in encouraging the adoption of evidence-based practice among primary care providers caring for adults with DD. However, consistent with research on successful guideline implementation, our study found that guidelines and other reference material alone are less likely to engender best practices for this vulnerable population. Without context and encouragement to practise, primary care providers might not apply the content of the Guidelines and Tools Book. The reported improvements in the intervention group suggest that it is a worthwhile investment to train primary care providers using an interdisciplinary, guideline-based continuing education course that includes face-to-face workshops and online modules.

**Table 2. Demographic characteristics of study participants**

CHARACTERISTICS	INTERVENTION GROUP (N=23)	CONTROL GROUP (N=24)	P VALUE
Female sex, n (%)	16 (69.6)	18 (75.0)	.68
Mean (SD) age, y	47.1 (9.0)	46.1 (9.7)	.73
Mean (SD) duration of practice, y	12.2 (10.7)	14.9 (12.0)	.43
Profession, n (%)			.68
• Physicians	13 (56.5)	15 (62.5)	
• Registered nurses or nurse practitioners	10 (43.5)	9 (37.5)	

**Table 3. Repeated-measures ANOVA results of the key measures comparing the intervention group and the control group before and after the study period**

KEY MEASURES	GROUP	BEFORE STUDY PERIOD, MEAN (SD)	AFTER STUDY PERIOD, MEAN (SD)	REPEATED-MEASURES ANOVA RESULTS		
				GROUP-BY-TIME INTERACTIONS	TIME INTERACTIONS	GROUP INTERACTIONS
Frequency of use of the Guidelines and Tools Book	Control	7.7 (4.2)	7.8 (3.4)	$F = 17.2, P < .001$	$F = 18.4, P < .001$	$F = 3.7, P = .07$
	Intervention	7.8 (3.2)	12.8 (3.5)			
Frequency of performing periodic health examinations	Control	31.8 (10.5)	32.5 (10.9)	$F = 0.63, P = .43$	$F = 2.5, P = .13$	$F = 1.9, P = .18$
	Intervention	34.9 (7.2)	37.2 (10.9)			
Frequency of performing assessments when a patient presents with a behaviour change	Control	24.6 (5.7)	23.6 (5.8)	$F = 5.3, P = .03$	$F = 1.5, P = .23$	$F = 1.2, P = .28$
	Intervention	24.2 (6.0)	27.5 (7.1)			
Level of comfort while caring for adults with DD	Control	21.5 (4.9)	22.4 (6.6)	$F = 6.9, P = .01$	$F = 14.7, P = .001$	$F = 0.95, P = .34$
	Intervention	21.3 (6.1)	26.2 (6.0)			
Knowledge of primary care related to adults with DD	Control	2.6 (1.1)	2.3 (1.1)	$F = 7.9, P = .01$	$F = 0.27, P = .61$	$F = 2.2, P = .15$
	Intervention	2.6 (0.7)	3.1 (0.6)			

ANOVA—analysis of variance, DD—developmental disabilities.

The issue of lack of training in health care provision to persons with DD at the undergraduate and post-graduate levels is consistently stressed by clinicians and researchers.<sup>14</sup> In a study from the United States, clinicians attributed the feeling of discomfort when caring for people with DD to a lack of training<sup>15</sup>; our study showed that training after being licensed to practise could indeed have a positive effect on comfort levels when caring for patients with DD.

### Strengths and limitations

A strength of the study is that it included physicians, nurse practitioners, and registered nurses, reflecting a range of primary care providers whom adults with DD might have encounters with in Ontario’s varied models of care. Approximately 20% of adults with DD in Ontario are associated with a family health team,<sup>16</sup> in which they might see a family physician, registered nurse, or nurse practitioner. Further, the Guidelines underscore the importance of interprofessional care for adults with DD.<sup>6</sup> Our study showed the benefits of a continuing education course that integrates key aspects of the Guidelines; future training initiatives should consider including aspects of our curriculum and approach in their own programs. While the continuing education course was developed for professionals already in practice, some components would likely fit in undergraduate settings as well.

The study was limited in that it did not include a direct measure of clinical behaviour change, a common issue in studies evaluating the effect of education interventions.<sup>17</sup>

Our key measures relied upon participants’ perceptions of how they engage with patients. Future research should include both perceptual and objective measures of practice change in order to gain a more complete understanding of how educational interventions affect the health of adults with DD. Future research should also consider randomizing participants to study groups, an approach that was not feasible for our study.

### Conclusion

This study described a continuing education course intervention that improved self-reported outcomes for 4 out of 5 key measures. To our knowledge, this study is the first to examine the effects of an interdisciplinary, guideline-based continuing education course on measures related to the effective care of adults with DD. It has thus added to the limited research on this topic and provides a starting point for designing future interventions. It also provides a successful course model that could be replicated in other jurisdictions.

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#### Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

#### Competing interests

None declared

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