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Résumé de l'article

Au cours des dernières années, un nombre grandissant d'initiatives de formation destinées à des professionnels actuels et futurs ont misé sur l'engagement actif des patients ou des usagers. Les recensions des écrits publiées dans les dernières années décrivent différentes composantes de ces initiatives. Or, elles ne permettent pas d'établir de distinctions entre l'engagement de personnes présentant des incapacités et celui d'individus vivant avec une autre condition. Cette recension met en exergue les principales composantes d'initiatives de formation dans le domaine de l'éducation, de la santé et des sciences sociales, qui ont recours à l'engagement actif de personnes présentant des incapacités. Notre approche systémique a favorisé l'identification de 20 projets. Nos analyses nous ont permis de circonscrire leur nature, les acteurs impliqués et leurs retombées. Cette recension met en lumière que l'engagement des personnes ayant des incapacités dans la formation doit se faire en utilisant une diversité de stratégies pédagogiques et viser des apprenants de plusieurs disciplines pour contribuer au développement de pratiques et de services de meilleure qualité. Des recommandations pour implanter de telles initiatives sont aussi proposées.

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Active Involvement of People with Disabilities in Education: A Literature Review*

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Abstract

In recent years, a growing number of educational initiatives designed for current and future professionals have sought the active involvement of patients and users. Recent reviews have explored different aspects of these initiatives. However, they do not distinguish between the involvement of people with disabilities and that of other users. This review describes the main features of educational initiatives in the fields of education, health and social sciences that actively seek the involvement of people with disabilities. Our systematic approach identified 20 projects. We analyzed their nature, the actors involved, and their documented outcomes. This review shows that to improve professional practice and the quality of services given to people with disabilities, it is important to seek their active participation in educational initiatives targeting learners from a range of disciplines and to use a diversity of teaching strategies. Recommendations to consider when implementing such initiatives are also discussed.

Keywords: disability, education, service user involvement, patient involvement, participation

Résumé

Au cours des dernières années, un nombre grandissant d'initiatives de formation destinées à des professionnels actuels et futurs ont misé sur l'engagement actif des patients ou des usagers. Les recensions des écrits publiées dans les dernières années décrivent différentes composantes de ces initiatives. Or, elles ne permettent pas d'établir de distinctions entre l'engagement de personnes présentant des incapacités et celui d'individus vivant avec une autre condition. Cette recension met en exergue les principales composantes d'initiatives de formation dans le domaine de l'éducation, de la santé et des sciences sociales, qui ont recours à l'engagement actif de personnes présentant des incapacités. Notre approche systémique a favorisé l'identification de 20 projets. Nos analyses nous ont permis de circonscrire leur nature, les acteurs impliqués et leurs retombées. Cette recension met en lumière que l'engagement des personnes ayant des incapacités dans la formation doit se faire en utilisant une diversité de stratégies pédagogiques et viser des apprenants de plusieurs disciplines pour contribuer au développement de pratiques et de services de meilleure qualité. Des recommandations pour implanter de telles initiatives sont aussi proposées.

Mots-clés : incapacité, éducation, formation engagement actif, participation

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Introduction

A growing number of student training and professional development initiatives have sought to have people receiving care and services play a role than the one traditionally ascribed to them: that of passive actor (e.g., simulated patient) or absent witness (e.g., in written case studies or video reports). Today, they now serve as experts who are actively engaged in teaching, curriculum development and assessment (Jha, Quinton, Bekker, & Roberts, 2009; Towle et al., 2010; Towle & Godolphin, 2011, 2013). The popularity of this new form of partnership in education is based on a recognition of their unique expertise, acquired through their experiences of health, illness, disability, or the effects of the social determinants of health (Towle et al., 2010). Recent reviews have explored aspects of patient¹ involvement (ex. practical, theoretical) mainly in healthcare professional education (Jha et al., 2009; Morgan & Jones, 2009; Repper & Breeze, 2004; Spencer et al., 2000; Towle et al., 2010; Wykurz & Kelly, 2002). These reviews do not distinguish between the involvement of people with disabilities and other patients. While there are certainly commonalities between these two groups of service users, there are also important differences: people with disabilities often cope with social stigma; they usually require treatments and services throughout their lives; transitions they go through can be challenging; barriers to communication and social interaction can hinder their relationships in various contexts; etc. (World Health Organization [WHO], 2011). Since their needs and experiences are distinct, current and future practitioners have much to learn from them (Iezzoni & Long-Bellil, 2012).

To understand educational initiatives involving people with intellectual, developmental, senso-

ry or physical disabilities, we have conducted a literature review.

Methods

- Design: Literature review method

We conducted a literature review of educational initiatives involving people with disabilities in order to draw useful lessons for guiding similar projects.

- Identification of the research question

The literature review was designed to answer one main question: What are the characteristics of educational initiatives that actively involve people with disabilities and that are intended for current or future professionals in the fields of education, health and social sciences?

- Systematic search of the literature

The papers upon which this review is based were systematically collected as in figure 1. They were found following a comprehensive search in relevant databases in education (ERIC, FRANCIS), social sciences (Social Sciences Full Texts, PsycINFO) and medicine (MEDLINE). We used various combinations of keywords and thesaurus search terms, which have been validated by a research synthesis expert. They were used alone and in combination, and referred to four themes (1) education/teaching/learning; (2) service users/patients; (3) disability; (4) involvement/partnership.

- Systematic selection of relevant articles: Inclusion and exclusion criteria

We prioritised the papers that referred to any educational initiative that sought active involvement of people with disabilities, as reported in peer-reviewed scholarly papers and grey literature. The following criteria, presented at Table 1, were applied to identify papers in scope.

- Collection and mapping of the data

The data was extracted from 19 texts and organized in a table. The extraction criteria were

¹ Some authors use the term 'patient', for the sake of brevity, to include people receiving healthcare, their carers (including parents and families) and healthy people (eg: community members, lay people, etc.). Towle et al. (2010) believe that the term "patient" may seem controversial, but no single alternative seems more acceptable.



broken down into three main categories: (A) educational initiatives, (B) people actively engaged, and (C) outcomes. Subcategories are presented in Table 2 below.

FIGURE 1: SYSTEMATIC SEARCH OF THE LITERATURE

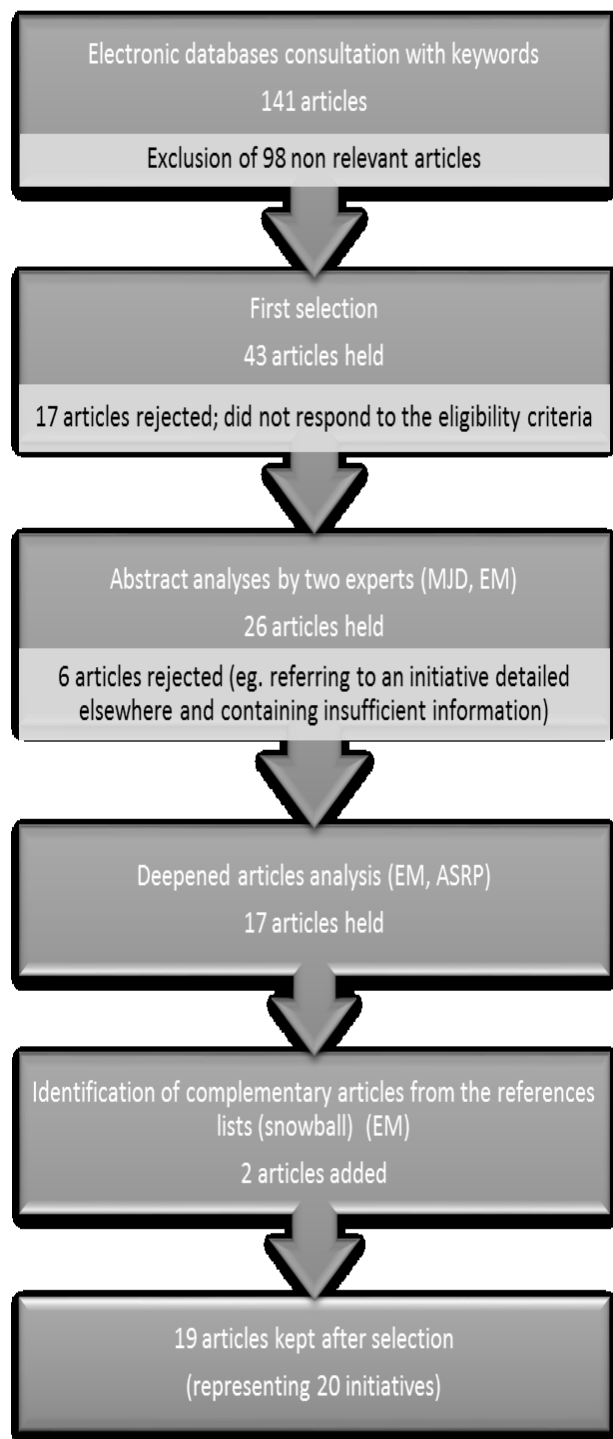


TABLE 1: INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria	Papers must: • Refer to people with disabilities actively engaged in teaching or in an educational role; • Refer to undergraduate or graduate learners or practitioners of any educational, social or healthcare professions; • Have been published since 2000; • Are written in English or French.
Exclusion criteria	Papers must not: • Refer to mental health service users actively engaged in teaching or in an educational role; • Refer to a discussion on the topic (ex. opinion paper); • Be a conference abstract.

- Collating, summarizing, and reporting results

The educational initiative itself is the unit of analysis. In the case of the text describing three initiatives (Jorgenson, Bates, Frechette, Sonnenmeier, & Curtin, 2011), each one was analyzed separately. Only the initiative involving people with disabilities in the article by Novak, Murray, Scheuermann, & Curran (2009) was examined. Fifteen other texts each described a single initiative, and the last text (Towle et al., 2014) described an activity as part of an overall report (The Social Planning and Research Council of BC [TSPRCBC], 2011). Therefore, we referred mainly to the text by Towle et al. (2014) to understand this initiative.

The results are presented in three parts, based on the extraction criteria above. The first part, discusses the initiatives' distinctive characteristics, learners, objectives, reference frameworks, and teaching strategies. The second part, concerns the people with disabilities, their

characteristics, the recruitment methods, their preparatory training, and the distinctive aspects of their involvement. The third part concerns the initiatives' outcomes, the obstacles encountered, the facilitators, and the recommendations proposed by the authors of the texts.

TABLE 2: EXTRACTION CRITERIA

Criteria	Subcategory
(A) Educational initiatives	A.1) Format (e.g., number of hours, session frequency, etc.) A.2) Learners targeted A.3) Objectives of the educational initiative A.4) Reference framework(s) underlying the initiative A.5) Teaching or learning strategies used
(B) People actively engaged	B.1) Characteristics of the population involved (e.g.: age, number, types of disabilities, etc.) B.2) Criteria used to select participants B.3) Recruitment methods B.4) Participants' degree of involvement
(C) Outcomes	B.1) Outcomes B.2) Obstacles encountered B.3) Recommendations

Results

1. Educational initiatives

1.1 An overview

Four **large-scale interventions** include the creation of a national framework for nurse education (Mathieson, 2002), an undergraduate intellectual disabilities² nursing program (Bol-

lard, Lahiff, & Parkes, 2012), and two extended interdisciplinary learning experiences (Doucet, Andrews, Godden-Webster, Lauckner, & Nasser, 2012; Towle et al., 2014).

In five other initiatives, people with disabilities were involved in **university courses** of a semester or more. Two were integrated within an undergraduate program (Muwana & Gaffney, 2010; Sadao & Robinson, 2002) and another, within a graduate program (Jorgensen et al., 2011). Two others were offered within the context of an advanced certification (Jorgensen et al., 2011). While four of these initiatives used interactive and innovative in-class co-teaching methods, the fifth relied heavily on partnerships with four community disability agencies (Muwana & Gaffney, 2010). Students were called upon to collaborate with these partners on and off campus.

Finally, eleven initiatives consisted of **brief interventions** (e.g., workshops) within a larger educational or professional setting. Of these, seven involved a single, interactive on-campus session within an undergraduate, (Maestri-Banks, 2013; McClimens & Scott, 2007; Tracy & Iacono, 2008; Zirkle et al., 2008) graduate (Terry, 2012) or postgraduate professional development program (Heneage, Morris, & Dhanjal, 2010; Martin & Hoy, 2013; Terry, 2012). Four other initiatives were spread out over two or more sessions on campus (Kroll, Groah, Gilmore, & Neri, 2008) or off-campus (Novak et al., 2009; Siebens et al., 2004; Smith, Anderson, & Thorpe, 2006). Community groups (e.g., a theatre group comprising people with disabilities) or agencies (e.g., local clinics, hospitals) were directly involved in three of these initiatives (McClimens & Scott, 2007; Novak et al., 2009; Smith et al., 2006), while pairing of students with a person with disabilities took place within two of them (Siebens et al., 2004; Smith et al., 2006).

² The terms "learning disabilities," used mainly in the United Kingdom, and "intellectual disabilities" were both

chosen by the authors of the selected texts to refer to the same condition. For the sake of consistency, we used the term "intellectual disabilities" in this article.



1.2 Learners targeted

The learners targeted were varied and spanned all levels of post-secondary education. Unfortunately, the number of learners reached is not always specified and varies from one initiative to another.

Ten single discipline designs were aimed at nursing (Bollard et al., 2012; Kroll et al., 2008; Maestri-Banks, 2013; Martin & Hoy, 2013; Mathieson, 2002; McClimens & Scott, 2007; Terry, 2012) or medical (Siebens et al., 2004; Tracy et al., 2008; Zirkle et al., 2008) students or professionals. Most of these were conducted in the United Kingdom. Four other initiatives targeted students or professionals in education (Jorgensen et al., 2011; Muwana & Gaffney, 2010; Novak et al., 2009), while another initiative was geared towards students in rehabilitation/communication (i.e., future speech pathologists) (Jorgensen et al., 2011). All of these were run in the United States. The five remaining initiatives were interdisciplinary (Doucet et al., 2012; Heneage et al., 2010; Sadao & Robinson, 2002; Towle et al., 2014; Smith et al., 2006), including both Canadian initiatives.

1.3 Objectives

All the initiatives had a common objective—to improve professional practice with people with disabilities, and by extension, the quality of care and services offered. However, more specific objectives were also listed or implied by the choice of teaching activities and assessment methods. These objectives, which concern the training environment, knowledge, skills, and learner dispositions, are described in Table 3 below.

1.4 Reference frameworks and teaching or learning strategies

Three primary frameworks emerge from our analysis: person- or community-focused, experiential and interprofessional education. In addition, three secondary frameworks have been identified: service learning, intergroup contact theory, and reflective practice. Teaching strategies are chosen in light of these frameworks.

Sixteen initiatives referred to **person- or community-focused learning** and/or practice. The most prevalent person-focused teaching strategies include collaborative teaching (an educator and a person with disabilities teach conjointly) (Heneage et al., 2010; Jorgensen et al., 2011; Kroll et al., 2008; Martin & Hoy, 2013), mentoring (pairing of students with a person with disabilities) (Doucet et al., 2012; Siebens et al., 2004; Smith et al., 2006; TSPRCBC, 2011), and inviting guest speakers to share their experiences and knowledge (Terry, 2012; TSPRCBC, 2011; Zirkle et al., 2008).

Among the four remaining initiatives, two of them make extensive use of the **service learning** approach, which combines community service with academic studies (Muwana & Gaffney, 2010; Novak et al., 2009). While **experiential learning** is extensively implied in these two service learning initiatives, it is alluded to in three others (Kroll et al., 2008; Tracy et al., 2008; Siebens et al., 2004). Experiential learning is based on the assumption that students learn through personal experience. In addition to mentoring and community service learning, project-based learning (Sadao & Robinson, 2002; Smith et al., 2006), as well as action learning (Kroll et al., 2008; McClimens & Scott, 2007; Tracy & Iacono, 2008) are popular experiential learning/teaching strategies. Much like service learning, **intergroup contact theory**, which postulates that learning occurs when different groups interact with one another, is mentioned in two initiatives (Heneage et al., 2010; Tracy & Iacono, 2008). Furthermore, **interprofessional education**, which promotes learning through collaboration between students from various fields of study, is discussed in three initiatives (Doucet et al., 2012; Smith et al., 2006; TSPRCBC, 2011). Lastly, while only two initiatives wove **reflective practice** theory into their framework (Doucet et al., 2012; McClimens & Scott, 2007), a total of five incorporated an explicit self-reflection component (e.g., journaling), which encourages students to examine their experiences, attitudes, and behaviours (Doucet et al., 2012; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Towle et al., 2014). Similarly, implicit self-reflection opportunities (e.g., oral debrief

TABLE 3: OBJECTIVES

Type of objective	Description	Number of Initiatives
Training environment	General objectives related mainly to the explicit desire to improve the quality and relevance of the training provided, especially by establishing durable partnerships and conducting learning activities to prepare students for practice	5 ³
Knowledge development	Concern the acquisition of evidence-based theoretical and factual knowledge (definitions, diagnostics, etiology, and assessment methods)	14 ⁴
Skills development	Refer to the acquisition of practical knowledge (e.g., mastering person-focused interprofessional team work, adopting a reflective approach, etc.)	15 ⁵
Dispositions	Aim to shape learners' attitudes through awareness activities to help them develop new insights and challenge their own attitudes (e.g., foster empathy)	15 ⁶

³ (Bollard et al., 2012; Mathieson, 2002; McClimens & Scott, 2007; Terry, 2012; TSPRCBC, 2011)

⁴ (Bollard et al., 2012; Doucet et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Kroll et al., 2008; Muwana & Gaffney, 2010; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; Tracy et al., 2008; Towle et al., 2014; Zirkle et al., 2008)

⁵ (Bollard et al., 2012; Doucet et al., 2012; Jorgensen et al., 2011; Kroll et al., 2008; Martin & Hoy, 2013; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; Tracy & Ianoco, 2008; Towle et al., 2014)

⁶ (Bollard et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Kroll et al., 2008; Maestri-Banks, 2013; Martin & Hoy, 2013; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Smith et al., 2006; Siebens et al., 2004; Terry, 2012; Towle et al., 2014; Tracy & Ianoco, 2008; Zirkle et al., 2008).



ing sessions or ongoing post-intervention on-line conversation) were built into two other initiatives (Martin & Hoy, 2013; Terry, 2012).

2. Actors Involved

2.1 Characteristics

Fifteen of twenty initiatives sought the active involvement of people with disabilities.⁷ Only one project involved high school students (Novak et al., 2009). In the other five the active participation of individuals with knowledge of particular disabilities (e.g., representatives of community organizations) were also used, although the focus was on the expertise of the individuals with disabilities.

Of the initiatives where the type of disability is mentioned, five referred to people with physical disabilities (Jorgensen et al., 2011; Kroll et al., 2008; Sieben et al., 2004; Terry, 2012; Zirkle et al., 2008) and five sought the participation of people with intellectual disabilities (Bollard et al., 2012; Heneage et al., 2010; Maestri-Banks, 2013; Mathieson, 2002; Tracy & Iacono, 2008) or autism spectrum disorder (Jorgensen et al., 2011).

Of the five initiatives that sought the involvement of individuals with knowledge of specific disabilities, three referred to family members (Jorgensen et al., 2011; Muwana & Gaffney, 2010; Sadao & Robinson, 2002) and two to informal caregivers (Martin & Hoy, 2013; Smith et al., 2006). The initiative of Muwana and Gaffney (2010) also refers to the participation of six representatives of community organiza-

tions, including two with disabilities, as well as that of professionals and family members.

2.2 Recruitment and selection

Nine of twenty initiatives synthesized discussed how people with disabilities were recruited and selected, which depended mainly on the training environment (e.g., type of institution, number of learners). They also described the type of disability sought (e.g., physical vs. intellectual), which varied according to the learners' needs. In five initiatives, people with disabilities were selected based on their community involvement or membership in a community organization (Heneage et al., 2010; Siebens et al., 2004; Towle et al., 2004; Tracy & Iacono, 2008; Zirke et al., 2008). They were described as having knowledge about their condition or a certain expertise acquired through contact with health professionals. In three initiatives (Kroll et al., 2008; Terry, 2012; Towle et al., 2004), the people recruited had to be able to articulately convey their expertise and experience in public. Selecting these participants involved judgement and an aptitude for the type of teaching/communication required.

2.3 Preparation and training

Five of the twenty initiatives that involved people with disabilities mentioned that tangible resources (e.g., technological support, training manual) (Jorgensen et al., 2011; Kroll et al., 2008) or training was offered to make sure they develop the skills needed to fulfill their roles (Bollard et al., 2012; Jorgensen et al., 2011; Kroll et al., 2008).

2.4 Type of involvement

Six types of involvement are described: personal accounts of real life situations, consultation, course development, formal teaching, informal teaching, and assessment (formative or summative).

Personal accounts by individuals with experiential expertise were mainly a matter of sharing personal experiences, particularly with regard to their disabilities, to the adaptations they

⁷ The article by Jorgensen, Bates, Frechette, Sonnenmeier, & Curtin (2011) briefly mentions the involvement of other specially invited people with disabilities, families, or professionals, without describing the nature of their participation (e.g., active or passive). Since in the case of three initiatives the authors focused mainly on the active participation of four people, we limited our analysis to their contribution. The articles by Mathieson (2002) and Zirkle et al. (2008) also examined the involvement of people with disabilities in initiatives in which other players participated. Since the articles focus on the involvement of people with disabilities, we analyzed only their contribution to the initiatives concerned.

need and to social, educational and medical services they require. In eighteen initiatives, one or more people with disabilities or representatives helped draw up, develop, plan, or organize a project, program, strategy, curriculum, or training environment. Of all the forms of active participation in local initiatives (apart from personal accounts), teaching was the most common: 18 initiatives involved one or more people with disabilities in formal or informal teaching (i.e., arising from interaction with learners). Apart from these types of involvement, the initiative conducted by Bollard et al. (2012) also sought the participation of people with disabilities in marketing and publicizing the training program and hiring teaching staff (recruitment and admission).

3. Outcomes

According to the 17 texts listing outcomes⁸, 18 initiatives had positive ones, not only from the learners' perspective, but also in the eyes of people with disabilities, community partners, the proponents of the initiatives, and the authors. They relate to the training environment, acquired knowledge and skills, dispositions, and identity.

The outcomes related to the **training environment** mainly consisted of participant satisfaction with their learning or teaching experience and the scope of the methods used.

With regard to learners, the acquisition of durable **knowledge** is implied or mentioned in 14 of the 17 texts discussing outcomes (Bollard et al., 2012; Doucet et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Martin & Hoy, 2013; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; TSPRCBC, 2011; Towle et al., 2014; Tracy & Iacono, 2008; Zirkle et al., 2008). The knowledge acquired concerned: (a) people with disabilities and their needs; (b) the power relations they must deal with; (c) required adaptations and support; (d) the roles of informal and pro-

fessional caregivers, (e) available community resources, (f) person-focused practice, (g) the disabilities themselves, and (i) related concepts and theories. In one initiative, representatives of community organizations mentioned having learned more about other community programs (TSPRCBC, 2011). A number of learners acquired new **skills** in the areas of person-focused interprofessional collaboration, partnerships with people with disabilities, teamwork, individual intervention, and reflective practice (Doucet et al., 2012; Heneage et al., 2010; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Smith et al., 2006; Terry, 2012; Towle et al., 2014). Other texts referred to the ability of learners to apply what they learned to their practice (Bollard et al., 2012). With regard to people with disabilities, the authors indicated an improvement in their teaching skills (Jorgensen et al., 2011; TSPRCBC, 2011). The initiative involving teens with disabilities enabled the latter to acquire professional experience and job search skills (Novak et al., 2009).

Outcomes regarding learners' **dispositions** refer more specifically to their values, perceptions, and attitudes. Some authors indicate that when the initiatives came to an end, learners were more aware and respectful of people with disabilities' expertise and conscious and critical of their own assumptions and stereotypes. The same authors also observed greater empathy, compassion, and openness to others and greater ease in their interactions with people with disabilities (Bollard et al., 2012; Martin & Hoy, 2013; McClimens & Scott, 2007; Muwana & Gaffney, 2010; Novak et al., 2009; Sadao & Robinson, 2002; Siebens et al., 2004; Smith et al., 2006; Terry, 2012; TSPRCBC, 2011; Towle et al., 2014; Tracy & Iacono, 2008; Zirkle et al., 2008).

Impacts on **identity**, or how participants felt about themselves, are also measured as outcomes. This included of a feeling of confidence and professional competence (Heneage et al., 2010; Novak et al., 2009; Towle et al., 2014; Zirkle et al., 2008). In participants with disabilities, they refer to a greater sense of confi-

⁸ Outcomes were not listed in the texts by Maestri-Banks (2013) and Mathieson (2002).



dence, pride, self-worth, liberation, empowerment and accomplishment (Bollard et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Smith et al., 2006; Terry, 2012; Towle et al., 2014; TSPRCBC, 2011).

4. Obstacles

Eight initiatives listed the obstacles encountered, including individual, logistical and financial. The **individual** obstacles concerned mainly people with disabilities, especially with regard to their selection (e.g., ensuring that a range of disabilities was represented, finding people who were articulate and available, etc.) (Terry, 2012) or to their level of confidence (e.g., first encounter with learners, insecurities about the quality and benefits of their involvement, etc.) (Towle et al., 2014).

The main **logistical** obstacles related to transportation (e.g., travel time and cost), technology (e.g., people unfamiliar with technology), time management (e.g., heavy workload outside class time, preparation of clinical sites, etc.), and scheduling (Jorgensen et al., 2011; Muwana & Gaffney, 2010; Smith et al., 2006; Terry, 2012).

The active involvement of people with disabilities requires prior consultation, ongoing collaboration with external resources, and a longer preparation period, which increases costs and the necessary organizational investment, thus potentially undermining the feasibility of this type of initiative (Bollard et al., 2012).

5. Facilitating factors and recommendations

The texts identified facilitating factors and recommendations in favour of conducting similar initiatives. They mainly refer to the active involvement of people with disabilities, reference frameworks and teaching/ learning strategies.

5.1 Involvement of people with disabilities

It is generally recommended that people with disabilities be involved, or more involved, in training of current or future professionals, in order to enrich the learning experience. This

approach tends to involve learners emotionally and spur their interest in issues and resources that can affect the quality of care and services available to people with disabilities (Zirkle et al., 2008). However, to maximize the impact of this involvement and ensure a positive experience for all, certain conditions must be met. For example, it is better to recruit individuals who are capable of self-reflection and have appropriate personal and/or professional expertise with respect to the material to be conveyed, as well as the teaching skills required to convey it. It is also recommended that teaching tasks be assigned based on their skills, interests, and personal aspirations.

To ensure that people with disabilities are considered by all as partners in the initiative, proponents should: (a) make sure that everyone has a hand in planning, teaching, and assessment; (b) check to what extent people with disabilities wish to participate in the transfer of scientific knowledge and adapt their involvement accordingly; (c) assign tasks, set the number of sessions, and explore the possibility of future collaboration in advance; (d) agree on a vision of the initiative and its objectives and clearly conveyed to learners; (e) insist on the complementary nature of professional and experiential expertise to learners throughout the initiative (Bollard et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Maestri-Banks, 2013; Martin & Hoy, 2013; Sadao & Robinson, 2002). Issues of confidentiality as well as copyright and subsequent use of written documents or videos must be negotiated before the initiative begins (Terry, 2012).

Regardless of the level of involvement of people with disabilities, it is important to make sure that they are suitably prepared for their assigned tasks. Initiative proponents must therefore: (a) offer training in line with individual needs (organization's policies, discursive norms in the classroom, assessment, scientific knowledge, or use of online platforms and software applications); (b) provide the required material resources (e.g., ICT equipment, software); (c) make sure that the place where the initiative is carried out is accessible to people with disabilities; (d) plan and implement appro-

priate support mechanisms when sensitive or stressful issues are raised (Doucet et al., 2012; Heneage et al., 2010; Jorgensen et al., 2011; Martin & Hoy, 2013). Several authors stressed the importance of tangibly recognizing the contributions people with disabilities make to the training initiative (e.g., financial compensation) (Doucet et al., 2012; Martin & Hoy, 2013; Towle et al., 2014). A means of ongoing communication should be established to inform them of how the initiative is progressing and of new opportunities for getting involved (TSPRCBC, 2011). It was suggested that opportunities for interacting with learners be put in place once an initiative is over so that participants could strengthen the ties they have forged and discuss the outcomes of the initiative if they wished to (TSPRCBC, 2011).

5.2 Reference frameworks and teaching/learning strategies

The authors champion the involvement of people with disabilities in undergraduate education and professional training initiatives. Some suggest promoting interprofessional teaching and learning (Sadao & Robinson, 2002; Smith et al., 2006; TSPRCBC, 2011), integrating a community service component (Muwana & Gaffney, 2010; Novak et al., 2009), focusing on experiential learning (Zirkle et al., 2008), or using forum theatre (McClimens & Scott, 2007) or the arts in general (TSPRCBC, 2011). All these aspects aim to apply theory to practice. Regardless of the reference framework chosen, all training initiatives should use teaching and learning strategies that are consistent with professional practice (Bollard et al., 2012).

During team activities, initiative proponents should play a secondary role or act as mediators with learners, or between experiential experts and learners, in order to raise awareness of the etiquette of communicating with people with disabilities, facilitate communication, support learning, and intervene as needed (Muwana & Gaffney, 2010; Siebens et al., 2004; Towle et al., 2014). They also must clearly understand and use various ways to help learners and other participants feel comfortable interacting (Terry, 2012).

Discussion

As all the initiatives of this literature review highlight, active involvement of people with disabilities in education gives rise to the creation of mutual dynamic relationships uniting people receiving care and learners from various fields of study. In doing so, students learn **from** and **with** these people, instead of just learning **about** them from a teacher who has a theoretical comprehension of their reality (Bleakley & Bligh, 2008). Towle and Godolphin (2011, p. 500) believe that “patient-led education sends an important message to students about the value of patients’ expertise [...] in which professionals and patients are ‘co-producers of health’”. Experiential experts can share what they consider to be important that future professionals learn, paving the path towards true person-centered care and services. Moreover, putting the person at the center of an educational intervention creates quite a different learning environment and inevitably brings with it a shift in power, role and meaning from the relationship between current or future professionals and people receiving services, in a way that maintains their authentic and autonomous voice (Bleakley & Bligh, 2008).

However, in order for this shift in power, role and meaning to truly occur, all kinds of people with all types of disabilities and from various ethnic and cultural backgrounds should be perceived as potential equal partners (with the help of their carers or family members if needed). For example, while it is understandable that initiative developers aspire to recruit guest lecturers or trainers who are experienced and/or gifted in articulate public speaking and teaching, there is a risk of reinforcing a socially constructed dichotomy between people who have so-called acceptable or relatable disabilities versus people whose disabilities are seen as overly disruptive of social interaction norms and communication protocols. Because people with disabilities are people first and foremost with an array of distinct characteristics, practitioners must be made aware of the subtleties experienced by those whose identities are subject to the forces of oppression inhabiting intersections of gender, sexual orientation, class,



ethnicity, and so on (Yuval-Davis, 2006). It is rather encouraged to work with a wide range of people with disabilities, with respect to their potential, in order to avoid perpetuating negative social perceptions, ignorance-based discomfort and inequalities.

With the notion of equal partnership comes that of equitable involvement and compensation. If we are to include people with disabilities in the education of students and professionals, we must create the conditions and opportunities within which they may contribute further to all aspects of said education: consultation, planning, marketing and publicity, student admissions, hiring of staff, teaching and evaluation. However, this literature review has pointed out that of all active involvement strategies, giving personal accounts of real life situation and teaching remain the most popular. Likewise, recruiting, selecting and soliciting people's expertise in training should always be accompanied by offering them appropriate compensation. Payment for involvement, for example, is sometimes associated with increased formal recognition and status. While certain people prefer other forms of compensation (ex. co-writing an article and being published, presenting at a conference, etc.) (Towle & Godolphin, 2013) they should still be given a choice in the matter.

Finally, it is recommended in most of the initiatives in this study that public and institutional educational policies be reviewed in order to support the active involvement of people with disabilities in large-scale training initiatives. While small-scale initiatives can be beneficial to learners, national and institutional championing of large-scale initiatives would increase the visibility, credibility, and legitimacy of educational patient/community-professional partnerships, impacting on their ability to boost their resources), ensuring their growth and enhancing their capacity to reach an exponentially greater number of students.

Although our comprehension of the issues discussed in this article stems from a highly rigorous process, we should not overlook the limits of our literature review. Unfortunately,

only twenty initiatives fit our selection criteria, which demonstrates the novelty of these initiatives, but limits the scope of our review. This could also be attributed to the diversity of terms used within the literature when speaking of educational initiatives involving people with disabilities. While our research was thorough, we may have missed certain initiatives as a result of this abundance of terminology. Furthermore, certain articles contained scarce information, which made it difficult for us to gain insight on who was involved, how they were involved and how their involvement influenced the learners implicated.

Conclusion

The initiatives studied in this review show that to improve professional practice and the quality of services given to people with disabilities, it is important to seek their active participation in educational initiatives targeting learners from a range of disciplines and using a diversity of teaching strategies. In light of our analysis of these initiatives, however, we believe that more effort should be invested in ensuring that people with disabilities contribute to the entire process of creating educational initiatives, from content selection to learner assessment.

Although we focused on initiatives that actively involved people with disabilities, we recommend a similar review of initiatives involving informal caregivers and family members. We would also like to point out that not all outcomes of the referenced initiatives have been thoroughly evaluated. And for the initiatives that were the subject of research projects, only short-term outcomes were studied. Further research should include longitudinal studies in order to better assess the long-term benefits of such initiatives (Spencer et al., 2011).

Finally, the more we know about what is being done, how it is being done as well as if, how and to what extent it is or isn't beneficial for all those involved, the better equipped we will be as researchers, professors, practitioners and members of an inclusive society to work and evolve side by side with people who have disabilities.

References

- BLEAKLEY, A., & BLIGH, J. (2008). Students learning from patients: Let's get real in medical education. *Advances in Health Sciences Education*, 13(1), 89-107. doi: 10.1007/s10459-006-9028-0
- BOLLARD, M., LAHIFF, J., & PARKES, N. (2012). Involving people with learning disabilities in Nurse Education: Towards an inclusive approach. *Nurse Education Today*, 32(2), 173-177. doi: 10.1016/j.nedt.2011.10.002
- DOUCET, S., ANDREWS, C., GODDEN-WEBSTER, A. L., LAUCKNER, H., & NASSER, S. (2012). The Dalhousie Health Mentors Program: Introducing students to collaborative patient/client-centered practice. *Journal of Interprofessional Care*, 26(4), 336-338. doi: 10.3109/13561820.2012.680631
- HENEAGE, C., MORRIS, D., & DHANJAL, K. (2010). Nothing about us without us: Combining professional knowledge with service user experience in training about mental health and learning disabilities. *Mental Health and Learning Disabilities Research and Practice*, 7(2), 119-129.
- LEZZONI, L. I., & LONG-BELLIL, L. M. (2012). Training physicians about caring for persons with disabilities: "Nothing about us without us!". *Disability and Health Journal*, 5(3), 136-139. doi: 10.1016/j.dhjo.2012.03.003
- JHA, V., QUINTON, N. D., BEKKER, H. L., & ROBERTS, T. E. (2009). Strategies and interventions for the involvement of real patients in medical education: A systematic review. *Medical Education*, 43(1), 10-20. doi: 10.1111/j.1365-2923.2008.03244.x
- JORGENSEN, C. M., BATES, K., FRECHETTE, A. H., SONNENMEIER, R. M., & CURTIN, J. (2011). "Nothing about Us without Us:" Including people with disabilities as teaching partners in university courses. *International Journal of Whole Schooling*, 7(2), 109-126.
- KROLL, T., GROAH, S., GILMORE, B., & NERI, M. (2008). Consumer-directed teaching of health care professionals involved in the care of people with spinal cord injury: The Consumer-Professional Partnership Program. *Journal of Continuing Education in Nursing*, 39(5), 228-234. doi: 10.3928/00220124-20080501-05
- MAESTRI-BANKS, A. (2013). Learning disability, education and empowerment: Learning from individuals who live with a learning disability. *Health and Social Care Education*, 2(1), 21-24. doi: 10.11120/hsce.2013.00022
- MARTIN, D., & HOY, L. (2013). Service user and carer participation in an endoscopy nursing programme. *British Journal of Nursing*, 22(18), 1051-1055.
- MATHIESON, A. (2002). The real deal: Involving Scots with learning disabilities in the creation of a national framework for nurse education was a masterstroke. *Learning Disability Practice*, 8(8), 6-7.
- MCCLIMENS, A., & SCOTT, R. (2007). Lights, camera, education! The potentials of forum theatre in a learning disability nursing program. *Nurse Education Today*, 27(3), 203-209. doi: 10.1016/j.nedt.2006.04.009
- MORGAN, A., & JONES, D. (2009). Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: A literature review. *Medical Teacher*, 31(2), 82-95. doi: 10.1080/01421590802526946
- MUWANA, F. C., & GAFFNEY, J. S. (2010). Service-learning experiences of college freshmen, community partners, and consumers with disabilities. *Teacher Education and Special Education: The Journal of the Teacher Education Division of the Council for Exceptional Children*, 34(1), 21-36. doi: 10.1177/0888406410371354
- NOVAK, J., MURRAY, M., SCHEUERMANN, A., & CURRAN, E. (2009). Enhancing the preparation of special educators through service learning: Evidence from two preservice courses. *International Journal of Special Education*, 24(1), 32-44.
- REPPER, J., & BREEZE, J. (2007). User and carer involvement in the training and education of health professionals: A review of the literature. *International Journal of Nursing Studies*, 44(3), 511-519. doi: 10.1016/j.ijnurstu.2006.05.013
- SADAO, K., & ROBINSON, N. B. (2002). Teaching the culture of collaboration: The validity of a case-based, interactive teaching methodology in higher education. Retrieved from <http://eric.ed.gov/?id=ED466447>
- SIEBENS, H., CAIRNS, K., SCHALICK, W. O., FONDULIS, D., CORCORAN, P., & BARTELS, E. (2004). PoWER Program: People with disabilities educating residents. *American Journal of Physical Medicine & Rehabilitation*, 83(3), 203-209. doi: 10.1097/01.phm.0000113407.47657.46
- SMITH, R., ANDERSON, L., & THORPE, L. (2006). SWAP report: Interprofessional Education. Southampton, UK: Higher Education Academy. Subject Centre for Social Policy and Social Work.
- SPENCER, J., BLACKMORE, D., HEARD, S., MCCROIRIE, P., MCHAFFIE, D., SCHERPBIE, A., . . . SOUTHGATE, L. (2000). Patient-oriented learning: A review of the role of the patient in the education of medical students. *Medical Education*, 34(10), 851-857. doi: 10.1046/j.1365-2923.2000.00779.x
- SPENCER, J., GODOLPHIN, W., KARPENKO, N., & TOWLE, A. (2011). *Can patients be teachers? Involving patients and service users in healthcare professionals' education*. Newcastle, UK: The Health Foundation.
- TERRY, L. M. (2012). Service user involvement in nurse education: a report on using online discussions with a service user to augment his digital story. *Nurse Education Today*, 32(2), 161-166. doi: 10.1016/j.nedt.2011.06.006
- THE SOCIAL PLANNING AND RESEARCH COUNCIL OF BC (TSPRCBC) (2011). An external review of patient and community voices in health professional education: Final report. Retrieved from <http://meetingofexperts.org/files/2011/10/PCV-External-Review-Final-report.pdf>
- TOWLE, A., BAINBRIDGE, L., GODOLPHIN, W., KATZ, A., KLINE, C., LOWN, B., MADULARU, I., SOLOMON, P., & THISTLETHWAITE, J. (2010). Active patient involvement in the educa-



tion of health professionals. *Medical Education*, 44(1), 64-74. doi: 10.1111/j.1365-2923.2009.03530.x

TOWLE, A., & GODOLPHIN, W. (2011). A meeting of experts: The emerging roles of non-professionals in the education of health professionals. *Teaching in Higher Education*, 16(5), 495-504. doi: 10.1080/13562517.2011.570442

TOWLE, A., & GODOLPHIN, W. (2013). Patient involvement in medical education In K. Walsh (Ed.), *The Oxford Textbook of Medical Education* (pp. 311-322). Oxford, UK.: Oxford University Press.

TOWLE, A., BROWN, H., HOFLEY, C., KERSTON, R. P., LYONS, H., & WALSH, C. (2014). The expert patient as teacher: An interprofessional health mentors programme. *The Clinical Teacher*, 11(4), 301-306. doi: 10.1111/tct.12222

TRACY, J., & IACONO, T. (2008). People with developmental disabilities teaching medical students : Does it make a difference? *Journal of Intellectual and Developmental Disability*, 33(4), 345-348. doi: 10.1080/13668250802478633

WORLD HEALTH ORGANIZATION (WHO) (2011). World report on Disability. Retrieved on http://www.who.int/disabilities/world_report/2011/en/

WYKURZ, G., & KELLY, D. (2002). Developing the role of patients as teachers: Literature review. *British Medical Journal*, 325(7368), 818-821. doi: 10.1136/bmj.325.7368.818

YUVAL-DAVIS, N. (2006). Intersectionality and feminist politics. *European Journal of Women's Studies*, 13(3), 193-209. doi: 10.1177/1350506806065752

ZIRKLE, D., WILLIAMS, K., HERZOG, K., SIDELINGER, D., CONNELLY, C., & REZNIK, V. (2008). Incorporating the experiences of youth with traumatic injury into the training of health professionals. *American Journal of Preventive Medicine*, 34(3 Suppl), S62-66. doi: 10.1016/j.amepre.2007.12.012