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INTELLECTUAL DISABILITY (R CONDILLAC AND P BURNHAM RIOSA, SECTION EDITORS)

Key Considerations for Providing Self-Management Support to Adults with Intellectual and Developmental Disabilities

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Abstract

Purpose of Review The aim of this review is to identify key considerations for health providers delivering self-management support to adults with intellectual and developmental disabilities (IDD) living with chronic health conditions.

Recent Findings There is an emerging body of evidence to inform the delivery of self-management support for adults with IDD living with chronic health conditions. The most extensive research on this topic relates to diabetes self-management, with a small number of studies on general chronic disease self-management. Three over-arching themes were identified: (1) acknowledging autonomy, responsibility, and risk; (2) building the capacity of caregivers, and (3) attending to emotional needs and psychosocial factors.

Summary To facilitate wellness, it is critical that health providers are equipped with the knowledge and resources required to provide appropriately tailored self-management supports for people with IDD living with a range of chronic health conditions. This review extends our current understanding of this approach and identifies both unique considerations and tensions that exist for this population and their caregivers.

Keywords Intellectual disability · Developmental disability · Self-management · Supported self-management

Introduction

Self-management support (SMS) is a recognized health service approach that aims to build a person's capacity to participate in valued roles and activities, and live well with chronic conditions [1, 2]. SMS interventions have been specifically developed to increase a person's skills and confidence to manage the medical, life, and emotional demands associated with living with chronic conditions [2, 3]. The provision of SMS has been shown to improve health outcomes in people living with health conditions such as diabetes, arthritis, chronic pain, and asthma [2, 4, 5]. The extent to which individuals with intellectual and developmental disabilities (IDD) are included in, and benefit from, mainstream SMS interventions is largely unknown. Research specifically focused on the provision SMS for adults with IDD is growing [6•, 7•, 8••, 9•]. It is important to understand the unique SMS needs of this population as they experience high rates of chronic physical and mental health conditions, as well as poorer health outcomes than adults without IDD (e.g., lower rates of preventative health screening; higher rates of obesity, premature mortality, hospital use, and early admission to long-term care facilities) [10–13].

Providing comprehensive health care that includes attention to health promotion, chronic disease prevention, and management early in the health trajectory of adults with IDD has been identified as critical to improve the health of this population across the lifespan [13–15]. Chronic health conditions known to be prevalent among adults with IDD include the following: congestive heart failure, chronic obstructive pulmonary disease, diabetes, epilepsy, osteoporosis, and mental illness (e.g., depression, schizophrenia, bipolar disorder) [16–19]. High rates of multimorbidity (having more than one chronic condition) are also common, and can result in

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increasing care and health management complexity, as well as risks for frailty [20, 21]. Despite a recognized need, many adults with IDD continue to face barriers in receiving high-quality, accessible care for their chronic conditions [14, 15, 19]. To reduce health service inequities and support this population in general practice, it is essential to increase awareness and capacity to provide tailored SMS interventions.

General Principles and Processes: Self-Management and SMS

Self-management is a complex and multi-faceted concept. For the purposes of this review, self-management was defined as "the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management, and emotional management" [1 p57]. Core skills involved in self-management include the following: problem solving, decision making, using resources, forming health care partnerships, and taking action [2].

SMS interventions are person-centered and designed around the priorities and concerns identified by the patient (versus health provider) [2]. Two critical processes in SMS interventions involve (1) establishing collaborative partnerships, and (2) utilizing educational strategies and techniques to support behavior change [22]. Individual and group SMS interventions aim to increase self-efficacy, as well as develop skills, and incorporate techniques such as learning to interpret symptoms, modeling, performance mastery, and social persuasion [2]. Battersby and colleagues further identified 12 evidence-based principles for implementing SMS in primary care that can be used to integrate SMS into routine primary care practice [23]. These principles include a focus on use of a non-judgmental approach, self-efficacy, shared-decision making, collaborative problem solving, and multifaceted interventions provided in diverse formats [23].

SMS and People with IDD

A preliminary search of the literature was conducted and found a small body of work pertaining to SMS and adults with IDD. The most extensive research on this topic relates to diabetes self-management [24, 25], and a few studies focus on more general chronic disease self-management [9•, 26•]; cardiovascular disease [8•]; and epilepsy self-management [6•] for people with IDD. These studies raise common concerns around the high prevalence of chronic conditions in this population and the need to understand ways in which SMS can be adapted to accommodate the unique communication, learning, and support needs of people with IDD.

Taggart and colleagues' review [7•] examined two diabetes self-management education programs adapted for individuals with IDD (i.e., DESMOND-ID [27]; OK-Diabetes [25]) and one diabetes prevention program (STOP [28]). The programs were co-developed with stakeholders, theoretically informed (e.g., Theory of Planned Behavior and Reasoned Action, Leventhal's Common-Sense Theory, Dual Process Theory, and Social Learning Theory), and evaluated. Common SMS modifications included the following: acknowledging caregivers' roles and needs, adapting materials, and providing a range of inclusive educational opportunities (e.g., using concrete kinesthetic and/or observational methods). Taggart and colleagues [7•] identified that all programs included a focus on engaging caregivers and helping them to identify their role in supporting health and fostering behavior change in people with IDD. In the STOP and DESMOND-ID programs, an initial session with caregivers was offered to review the program, answer questions, and explore the role of caregivers in supporting self-management [7•, 27, 28]. In the OK-Diabetes program, caregivers were engaged in supporting a patient-identified goal and provided with written information to support goal attainment [7•, 25]. Authors note that lessons learned from these programs, especially in regard to the modifications for cognitive and communication needs, are highly transferable to the self-management of other health conditions [7•].

Two feasibility studies were completed to evaluate modified versions of general chronic disease self-management programs (CDSMP) [9•, 26•]. In the United Kingdom, a CDSMP for adults with IDD focused on building self-care skills and included adaptations such as: longer course duration (i.e., 2 weeks longer), communication adaptations, and increased facilitation and caregiver support [26•]. In Ferretti and McCallion's United States-based study [9•], individuals with moderate IDD attended an integrated CDSMP along with participants without IDD. In this study, a range of stakeholder focus groups (e.g., people with IDD, paid staff, nurses, administrators, and family caregivers) were conducted to inform the development of supplementary material to accompany the standard CDSMP manual [9•]. Major components of the content remained intact and modifications were made to: (1) tailor messages to first and second grade reading levels, (2) add elements (e.g. graphics and checklists) to support understanding, and (3) reorder elements to facilitate an easy read approach [9•].

Studies examining the experiences of people with IDD, caregivers, and health providers highlight several important considerations [8••, 29••, 30••, 31••, 32••, 33••]. Participating in self-management can be challenging for people with IDD. Adults with IDD have unique learning, communication, and support needs in relation to their cognitive and/or adaptive functioning skills and capabilities. They may have had limited opportunities to develop problem solving or self-care skills and/or, many not have control over many daily lifestyle choices (e.g., meal planning/preparation, opportunities to exercise), which may impact their self-efficacy and ability to take-action [29••, 30••, 31••]. Importantly, people with IDD have expressed that they experience many medical, functional, and emotional consequences as a result of living with chronic health conditions and can participate in self-management given time, practice, and support [29••, 30••, 34••]. Many people with IDD rely on caregivers to assist them in their activities of daily living (e.g., medication monitoring) [32••, 33••]. Caregivers report a range of competencies and confidence related to supporting health and wellness which can have implications on the health and access to health services for people with IDD [32••, 33••].

Aim

Concerningly, many of the self-management programs currently endorsed by governments do not actively engage family and caregivers, or consider accommodations for low literacy, different learning styles, cognitive, or communication difficulties [7•, 9•]. Many individuals with IDD can be involved in managing their health and it is critical to understand the ways in which SMS can be tailored to foster health, and meet the needs of this complex and vulnerable population. Although there is evidence for modified SMS approaches for this population, there remains a gap in our understanding of best practices that can inform the provision of SMS, foster collaborative partnerships, and facilitate behavior change across chronic health conditions. The aim of this paper is to extend our current understanding of SMS adaptations for people with IDD, and identify key considerations for health providers working with people with IDD to support self-management of chronic conditions and facilitate wellness.

Approach to This Review

This review was guided by a rapid review methodology [35]. It is acknowledged that this review focused on peer-reviewed literature and did not include an exhaustive search strategy of gray literature or a critical appraisal. The preliminary question was developed by the primary author (NB) and reviewed by co-authors (YL, YH). Initial search terms and a search strategy were developed by the primary author with consultation from a librarian and co-authors (YH). A systematic search of four databases CINAHL, MEDLINE, EMBASE, and PsycINFO was completed using the keywords: self-management, supported self-management, education self-management programs, intervention, intellectual disability, and developmental disability. There were no limitations placed on the search strategy (e.g., timeframe, language) and 390 references were identified. References were de-duplicated and included in the review if they identified the provision of SMS for individuals with IDD in adulthood, and focused on either the provision of SMS or experience of self-management (i.e., general management or specific skills for managing health conditions e.g., diabetes, cardiovascular disease, epilepsy). Reference lists of identified papers were reviewed to locate any additional papers not identified in the database searches. A total of 17 papers were included in the final review and co-author (YH) randomly reviewed 6 of 17 papers to ensure that they met the inclusion criteria for the review. A data extraction form was developed and used to gather information pertaining to considerations and/or strategies specifically related to supporting SMS for people with IDD. Results were synthesized by the primary author (NB) and reviewed by co-authors (YL, YH). The themes were discussed and further revised to ensure conceptual clarity. Inter-observer agreement was not calculated for this review as per the rapid review methodology used [35]; however, to increase reliability, the research team aimed for investigator-triangulation at key points during the study. To achieve this, authors met frequently during the study to review the research question, search strategy, included studies, initial themes, and final results.

Results

Three over-arching themes were identified that address important considerations for the provision of SMS for adults with IDD; these include: (1) acknowledging autonomy, responsibility, and risk; (2) building the capacity of caregivers; and (3) attending to emotional needs and psychosocial factors.

Addressing Autonomy, Responsibility, and Risk

Issues of autonomy shared responsibility and risk feature prominently in the literature on self-management and SMS for people with IDD. Autonomy in this review refers to an individual's capacity to govern their lives and make decisions about their health [31••]. Autonomy is a central component of self-determination, independence, and social inclusion for people with disabilities [31••]. There is considerable heterogeneity among people with IDD in regard to their capabilities (i.e., cognitive and adaptive functioning), needs, and supports [36]. As a result of these personal and contextual factors, individuals will vary significantly in their experiences of autonomy, especially in regard to making decisions about their health. Autonomy in relation to the self-management of health should not be seen as the "ultimate goal" for people with IDD, and a lack of experience or skill in decision making should not be assumed as a lack of motivation or capability to participate in self-management tasks [30••].

People with IDD have their own beliefs and knowledge about their health conditions and management [30••] and understanding this should be explored early on when establishing a collaborative relationship. In addition to understanding beliefs and knowledge related to health, it is important to understand both an individual's capabilities to take on medical, life, and emotional roles and whether there is anyone else sharing those responsibilities. Rouse and Finlay [34••]

examined the concept of responsibility in diabetes self-management and found that both people with IDD ($N = 7$) and caregivers ($N = 7$) described individuals with IDD as competent self-managers, notwithstanding the key role of others in supporting daily health management tasks.

To establish a strong collaborative relationship, it is also critical to understand the person with IDD's unique social and contextual factors. Specifically, when people with IDD are supported by disability organizations, health providers need to understand where paid caregivers and these organizations stand in relation to accountability and risk [34••]. In many communities, there is a culture of "doing for" individuals with IDD in regard to managing their health needs in order to keep them safe, while also minimizing risk and liability on the part of the organization [37•]. Within this culture of safety, paid caregivers often express concerns regarding their responsibilities, and struggle with achieving a balance between supporting autonomy and reducing risk associated with managing medical roles [31••, 32••, 33••]. People with IDD are often positioned as having independent choice and responsibility within safe limits (as defined by caregivers); however, it can be challenging for paid caregivers to foster choice when they ultimately feel accountable for the person's health and safety [34••]. However, as Friedman and colleagues highlight, it is also difficult for people with IDD to learn how to make decisions, build skills, and handle risk if the opportunity to participate in these activities is restricted at the outset [37•]. Acknowledging the many personal and contextual factors and tensions that exist for people with IDD and caregivers in relation to self-management of chronic conditions can assist in developing relationships and in clinical decisions regarding the provision of appropriate and accessible SMS [31••, 33••].

Identifying health provider and caregiver roles in creating the conditions for people with IDD to safely exercise autonomy, build confidence, and practice new self-management skills is an important step in optimizing SMS interventions for this group [33••]. Greater awareness of how to offer supported-decision making is needed to facilitate opportunities for negotiated autonomy, whereby people with IDD, their caregivers and health providers establish roles, responsibilities, and plans for self-management goals and tasks [31••]. In addition, gaining an accurate assessment of both individual capabilities and available supports to be able to tailor SMS interventions appropriately for people with IDD is also important. Caregivers and health providers are well positioned to provide opportunities for building self-efficacy and skill development (e.g., decision making, problem solving) [31••]. Prerequisites for the delivery of SMS for people with IDD by health providers should include attention to facilitating: (1) the availability of accessible information; (2) opportunities for supported-decision making; (3) ownership of self-management strategies; and (4) ongoing encouragement to take on responsibility and offering "back up" support [8••]. For health providers, regularly scheduled meetings [32••] and telephone consultations [29••] are two additional ways found to be effective when providing SMS for adults with IDD.

Building the Capacity of Caregivers

The main difference in self-management for people with IDD compared with people without IDD is that other people are typically involved in supporting daily medical and life needs. [30••] Heath providers should recognize caregivers as having the potential to be positive and supportive partners, and that people with IDD have trust in their abilities [32••]. Caregivers can support self-management goals and skill development in a number of ways including: assisting in information gathering, implementation (e.g., opportunities for exposure and incidental learning) and goal monitoring, and providing ongoing encouragement [8••, 31••, 32••].

Educating caregivers on self-management and SMS interventions can build their capacity to support self-management goals and related tasks. The success of self-management strategies often relies on paid caregivers' and family members' perceptions and knowledge of health conditions [32••]. In a study on diabetes self-management, Cardol and colleagues found that many paid caregivers had limited knowledge of diabetes and no training in self-management although they provided support to individuals with IDD and diabetes [30••]. In a study exploring the perceptions of caregivers supporting women with IDD and mental health problems, Taggart and colleagues identified that caregiver knowledge and attitudes could impact health service access [38]. These authors noted that in some cases, women with IDD were not referred to mainstream mental health services because staff believed that mainstream health providers and services could not engage successfully with this population [38]. As a result, caregivers may fail to recognize, or underestimate health needs of people with IDD, and consequently, people with IDD may not access the services they could benefit from [31••, 33••, 38].

Additional challenges noted by paid caregivers are that they frequently rotate through care homes and do not have always have access to education, or the most up-to-date information (e.g., on communication and SMS approaches) which impedes their ability to provide optimal care [29••, 30••]. Recognizing this health providers can provide flexible and on-going refreshers to all available caregivers to ensure they acquire the knowledge, skills, and abilities to provide consistent, quality care [29••, 32••]. Pre-meetings for caregivers have been incorporated into diabetes CDSMP interventions for people with IDD and can help to address these concerns [7•, 25, 27]. Furthermore, while the continuity of paid caregivers may not be feasible, the aim should be to provide continuity of information and clinical management across contexts and all those involved in supporting a person with

IDD's self-management goals. Informational continuity means that information on a person's history and prior events are available and can be used to support appropriate care [39]. Management continuity ensures that supports received from different stakeholders (i.e., health providers, caregivers) are connected in a coordinated and consistent manner [39].

Attending to Emotional Needs and Psychosocial Factors

Self management of health conditions CAN BE hard with or without an IDD. Adults with IDD have raised concerns that they need resources, time, and space to discuss how to manage the emotions that accompany living with their chronic health conditions [8••]. In a study by Cardol and colleagues in the Netherlands, 17 people with mild to moderate IDD and diabetes spoke about how their mood can make it more difficult to self-manage [30••]. For example, it can be frustrating and harder to stick to recommended condition-specific diets when people feel down or lonely, and it is often frightening getting injections and tests [30••]. Four people with mild IDD living with diabetes in the United Kingdom also discussed feeling different from others in their group homes because of their additional health needs; these feelings could be socially stigmatizing which further impacted their motivation to participate in health promotion and self-management tasks [40•]. Living in a communal home environment can increase challenges with managing emotions, some of which include: daily schedules, the need to accommodate others' needs in the home and managing temptations, particularly around food (e.g., when other people eat non-diabetes-friendly foods) [29••].

In an exploratory study examining self-management support for people with IDD living with cardiovascular disease, paid caregivers of people with IDD ($N = 11$) identified that attending to emotional well-being was one of the fundamental pieces of building a collaborative, trusting relationship, the aspect that needs to be attended to first before you can start working on other aspects of care [8••]. Also, participants across stakeholder groups (e.g., a person with IDD, a caregiver, and 3 health providers) identified that having available, accessible information was really valuable in managing the emotional impact of living with this chronic condition [8••]. Similarly, in a study on diabetes, family members with diabetes were identified as important supports to teach about management of psychosocial elements of their health conditions from a "lived experience" perspective [30••]. The CDSMP for people with IDD in the UK was one SMS intervention that explicitly included topics such as "dealing with difficult feelings," "taking your mind off things," and "feeling low and sad" [26•]. This could be an area that is explored further within existing SMS interventions to ensure there is adequate time and support to address emotional needs. Greater efforts should be made to facilitate health promotion in communal living contexts to minimize the challenges identified by people with IDD and offer group health promotion activities and peer led programming to allow for peer sharing and collaborative problem solving [26•].

Discussion

This rapid review synthesized findings from a small body of literature related to the provision of SMS for people with IDD. Importantly, the findings draw on perspectives from a range of stakeholders including people with IDD, caregivers, and health providers. Key considerations raised in this review included the following: addressing complex issues of autonomy and responsibility for self-management, the need to build capacity among caregivers to support self-management in people with IDD and lastly, the need to remain attentive to the emotional needs of people with IDD who may experience additional challenges in understanding and expressing their feelings.

Health system transformations have increasingly focused on chronic condition management, whereby prevention, self-management, and patient activation are considered critical [5, 9•]. Increasing capacity for self-management is proposed as one intervention to bridge "the gap between patients' needs and the capacity of…health care services to meet those needs" [4, p366]. People with IDD have high and often complex health needs and are a population that can easily be missed in the provision of SMS because of unique personal (e.g., communication and comprehension) and contextual (e.g., support of caregivers, group living) challenges. Cardol and colleagues suggest that ideas of "self-management may be too closely associated with the idea of independence, which does not fit the reality of people with IDD" [33, p387]. It can be argued that the idea of autonomy and "doing things independently" is not realistic or feasible either for many individuals without IDD, and that there is a need to critically reflect on assumptions of autonomy, capability, responsibility, and risk in relation to the provision of SMS in general [41, 42]. How we conceptualize autonomy helps to us to ask different questions and offer guidance on how to respect and engage in shared decision making (one of the core principles of SMS). Framing shared decision making within an alternative model of autonomy, such as relational autonomy (vs. individualistic), highlights the social context and central role of others in engaging the patient [41] and tailoring SMS interventions which may be more aligned with the needs of this group.

To optimize SMS for adults with IDD, health providers need to be equipped with the knowledge and skills to successfully build on principles of SMS and engage strategies to support participation in medical, life, and emotional self-management roles. This is also important for caregivers who may not have experience, education, or skills related to supporting self-management in people with IDD. The establishment of a collaborative, therapeutic relationship, and effective health care communication is critical and includes getting to know the person with IDD, assessing strengths and capabilities and involving them in developing care plans [43]. Anderson and Funnell suggest that empowerment is not about whether people are equally able; it is about supporting people in a non-judgmental way and enabling them to build their knowledge and skills [44]. If seen through an empowerment paradigm, SMS is less about facilitating autonomy and more about offering multiple ways to increase self-efficacy and self-management skills in each person [44]. For example, supported decision making could include opportunities to practice making decisions with key support people available to provide encouragement, problem solve, and discuss.

Many of the core SMS principles and processes rely on effective communication. Recently, research has focused on health information exchange to better understand how to support knowledge exchange in health visits for people with IDD [45, 46]. Health passports are one initiative to facilitate informational continuity across health contexts (e.g., hospital) [47, 48]. In addition, communication tools such as “Know Your Normal”, developed by the autism community, provide a template for people to self-manage their emotional lives [49]. Additional tools such as “About Me” and “My Healthcare Visit” have been developed in Canada to aid in preparing and establishing the conditions for effective and appropriate health care in collaboration with the person with IDD, their caregivers, and health providers [50].

A large focus of SMS interventions has been on medical management of health conditions and attention to mental health, and mental health promotion for adults with IDD remains limited. This is concerning given that between 40 and 50% of people with IDD experience poor mental health or addiction in adulthood [16, 51]. Acknowledging the mental health needs of this group is a critical component of any SMS intervention and increased training, and resources are needed for health providers to help people with IDD understand and express their emotions and provide opportunities to learn how to manage and promote their mental health.

Conclusion

The ultimate goals of SMS for people with IDD should be to develop and support the skills needed to live healthy and well, and to work in collaboration with health providers and care givers, rather than managing health conditions independently. It is critical that health providers are well-equipped with the knowledge, tools, and resources required to provide and adapt SMS for the people with IDD who they support in their practices and communities, and a lack of attention to this group may propagate ongoing health service inequities. Many adults with IDD want to be involved in managing their health, and many can, with a commitment to person-centered care grounded in strength-based approaches, on-going support from knowledgeable caregivers and attention to their emotional needs, as well as physical and life roles.

This paper adds to the discussion of SMS for adults with IDD by synthesizing the current literature and identifying unique considerations and tensions that exist for people with IDD related to engaging in self-management. The review was informed by an emerging body of literature related specifically to self-management for people with IDD. Attention to the specific needs of this group was considered important as people with IDD are not being regularly recognized in the broader literature on self-management research and the extent that these SMS interventions are inclusive of people with IDD cannot be discerned. In addition, the lack of uptake of available modified CDSMP and best practices for implementing SMS for adults with IDD is especially disconcerting given the philosophical and legislative rights of adults with IDD to the same range, quality, and standards of health care and health promotion [24].

Future health services should look to expand access and evaluation of SMS interventions that are inclusive of people with IDD and their caregivers. In addition, there is a need to co-develop SMS approaches that promote skills (e.g., decision making, problem solving) and self-efficacy among people with IDD and consider the unique health and contextual factors associated with having an IDD. Lastly, ongoing work is needed to build capacity among caregivers and health providers to facilitate conditions for people with IDD to live well with chronic conditions. This work will support the transition of people with IDD from passive recipients of health care to active participants in their health and wellness [37•].

Compliance with Ethical Standards

Conflict of Interest Nicole Bobbette, Yani Hamdani, and Yona Lunsky declare no conflicts of interest relevant to this manuscript.

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