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A Scoping Review of Effective Community-Based Primary Healthcare Initiative to Improve Health Outcomes for Persons with Intellectual and Developmental Disabilities

Un examen de la portée des écrits sur l'efficacité des initiatives en soins de santé communautaires de première ligne afin d'améliorer la santé des personnes ayant une déficience intellectuelle et un trouble du développement

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Keywords

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Abstract

Persons with Intellectual and Developmental Disabilities (IDD) experience poorer health and have more difficulty accessing mainstream healthcare services compared to the general population. To narrow the gap between the health status and healthcare utilization of persons with and without IDD, a number of policies, programs, tools and initiatives have been introduced worldwide, including transitioning persons with IDD residing in institutions to a variety of living arrangements in the community such as group homes. The present scoping review syntheses and critically analyzes empirical evidence on effective healthcare initiatives and programs that best address disparities related to healthcare and social support needs of persons with IDD living in the community. Using an iterative approach, a comprehensive search strategy was constructed to locate literature reviews, as well as quantitative and qualitative empirical studies published between 2008 and 2017. A total of 25 published studies met the inclusion criterion and therefore were included in our analysis.

Results are presented emphasising merits and methodological limitations of included studies, as well as discussing current gaps in the literature and providing recommendations for policy and practice.

Résumé

Les personnes ayant une déficience intellectuelle et développementale (DID) sont en moins bonne santé et ont plus de difficulté à accéder aux services de santé usuels, comparativement à la population générale. Afin de réduire l'écart entre l'état de santé et l'utilisation des soins de santé des personnes avec et sans DID, plusieurs politiques, programmes, outils et initiatives ont été introduits à travers le monde, incluant la transition des personnes résidant dans des institutions vers différents milieux résidentiels dans la communauté comme les foyers de groupe. Cet examen de la portée des écrits synthétise et analyse de manière critique les preuves empiriques de l'efficacité des programmes de soins de santé et des initiatives qui répondent le mieux aux disparités liées aux besoins de soins de santé et de soutien social des personnes ayant une DID vivant dans la communauté. À l'aide d'une approche itérative, une stratégie de recherche exhaustive a été élaborée afin d'identifier des revues des écrits scientifiques ainsi que des études empiriques quantitatives et qualitatives publiées entre 2008 et 2017. Un total de 25 études publiées a répondu aux critères d'inclusion et a donc été inclus dans cette analyse. Les résultats sont présentés en soulignant les forces et les limites méthodologiques des études incluses, ainsi qu'en discutant des lacunes actuelles dans les écrits scientifiques et en fournissant des recommandations pour les politiques et les pratiques.

Mots-clés : déficience intellectuelle et développementale, initiatives en soins de santé, initiatives en soins de santé communautaires de première ligne, santé, examen de la portée

Persons with intellectual and developmental disabilities (IDD) experience poorer health and have more difficulty accessing mainstream healthcare services compared to the general population. As a group, persons with IDD experience a higher prevalence of physical and mental health disorders, a shorter life expectancy, fewer opportunities to engage in health-promoting activities (Felce et al., 2008; Krahn et al., 2010), and therefore more unmet healthcare needs (Shooshtari et al., 2012; Ouellette-Kuntz et al., 2005), compared to persons without IDD.
Multiple factors contribute to these observed disadvantages (Robertson et al., 2014; Robertson, et al., 2011; Ouellette-Kuntz et al., 2005). For instance, some persons with IDD have complex healthcare needs because of comorbidities associated with specific conditions such as obesity in people with Prader Willi syndrome or cardiac anomalies in individuals with Down syndrome. Cognitive and adaptive limitations that impact health literacy and health-related problem-solving abilities frequently impede the communication with healthcare professionals and contribute to a limited involvement in personal healthcare decisions. Broader determinants of health also deserve attention in this population as persons with IDD are often exposed to unhealthy and stressful environments (Olsson & Hwang, 2003) and tend to have lower incomes compared to the general population (Krahn et al., 2006).

There are several factors related to the healthcare system itself that contribute greatly to the observed health disadvantages experienced by persons with IDD. For example, primary healthcare providers attribute time constraints during consultations to poor quality of care (Beange & Lennox, 1998), and recognize their lack of knowledge about this population's healthcare needs (Barr et al., 1999; Michael & Richardson, 2008). Additional barriers in the provision of quality care to persons with IDD include managing challenging behaviours, difficulty in making accurate diagnoses due to differential presentation of some diseases (e.g., dementia), comorbid physical and mental health conditions, communication difficulties and inconsistent social support (Brousseau et al., 2004; Christakis, et al., 2001; Inkelas et al., 2004; Wood et al., 2007). Collectively, these barriers often result in treatment plan failure, a loss of continuity of care, more hospitalizations, and increased use of expensive emergency services. In addition, the lack of coordination, communication and collaboration between healthcare services and social services is of great concern, especially for persons with comorbid mental health disorders (Lunsky et al., 2006). There is a growing understanding of the need to empower not only persons with IDD, but also their paid and informal caregivers to advocate for appropriate healthcare on their behalf.

To narrow the gap between the health status and healthcare utilization of persons with and without IDD, a number of policies, programs, tools and initiatives have been introduced worldwide, including transitioning persons with IDD residing in institutions to a variety of living arrangements in the community such as group homes. In accordance with a normalization philosophy, community living for persons with IDD was encouraged and healthcare for persons with IDD shifted from specialized care to mainstream care to reduce health disparities experienced by this population. There is some evidence of improved quality of life for persons with IDD as a result of community living due to a number of factors including more choice-making opportunities, larger social networks and more friends, more access to mainstream activities and more participation in community life, more chances to acquire new skills and develop or maintain existing skills, and higher life satisfaction (Kozma et al., 2009). However, the shift from specialized care to mainstream care has been criticized for not adequately meeting the special care needs of persons with IDD with complex health issues (Meijer et al., 2004).

Because of their unique needs and the systemic barriers they face in accessing and receiving timely and appropriate healthcare, persons with IDD risk falling between silos within the healthcare system. A more coordinated approach responsive to the needs of this vulnerable population is key to improving their health and the quality of the care they receive. Community-based primary healthcare is an approach to health that goes beyond the traditional healthcare system by fostering the coordination and continuity of all services that play a role in the provision of services, including social services and education (Haggerty et al., 2007). This coordination is a key element of a system that prevents and manages chronic diseases and is responsive to the complex needs of persons with IDD. Primary healthcare involves a broad range of preventative and healthcare services provided by a range of healthcare providers in diverse community settings, outside of hospitals and the traditional medical system. Many persons with IDD have complex care needs that are best met through community-based primary healthcare, where a range of health, social and educational services are delivered in a coordinated manner to meet the needs of this vulnerable population.

The present scoping review synthesized and critically analyzed empirical evidence on effective healthcare initiatives and programs that best address disparities related to healthcare and social support needs of persons with IDD living in the community. Recommendations for policy makers and healthcare professionals are provided in accordance with the main findings of this review. We conducted the scoping review with three main objectives: 1) to summarize and analyze research findings on effective healthcare initiatives and programs that best address the healthcare and social support needs of persons with IDD living in the community, 2) to identify gaps in the literature related to the first objective, and 3) to offer recommendations for future research and healthcare practice for persons with IDD. The present study addresses important knowledge needs and fills a literature gap. Despite an exponential increase in the number of persons with IDD living in the community worldwide, to date no one has systematically synthesized the research in order to provide a portrait of the effective healthcare initiatives and programs to address the unique healthcare and social support needs of persons with IDD living in the community. Furthermore, our scoping review extends previous reviews on effective interventions for persons with IDD in several ways: i) our search focused specifically on community-based primary health care services, which are the most relevant in consideration of progress with regards to deinstitutionalization; ii) studies of all research methodologies and designs were included; and iii) services for persons with any type of IDD (e.g., Down syndrome, autism spectrum disorders, fragile X syndrome, cerebral palsy and fetal alcohol spectrum disorders) were included.

Methods

This scoping review examined literature published between 2008 and 2017. Scoping reviews are a form of knowledge synthesis that address exploratory research questions aimed at mapping key concepts, types of evidence, and gaps in research related to a defined field by systematically searching, selecting and synthetizing existing knowledge (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Peters et al., 2015). In developing our scoping review, the methodological framework provided by Arksey and O'Malley (2005) and enhanced by Levac, et al. (2010) was integrated with the most recent methodological guidance for conducting scoping reviews developed by the Joanna Briggs Institute (Peters et al., 2015; Peters, Godfrey, McInerney, et al., 2015).

Search Strategy

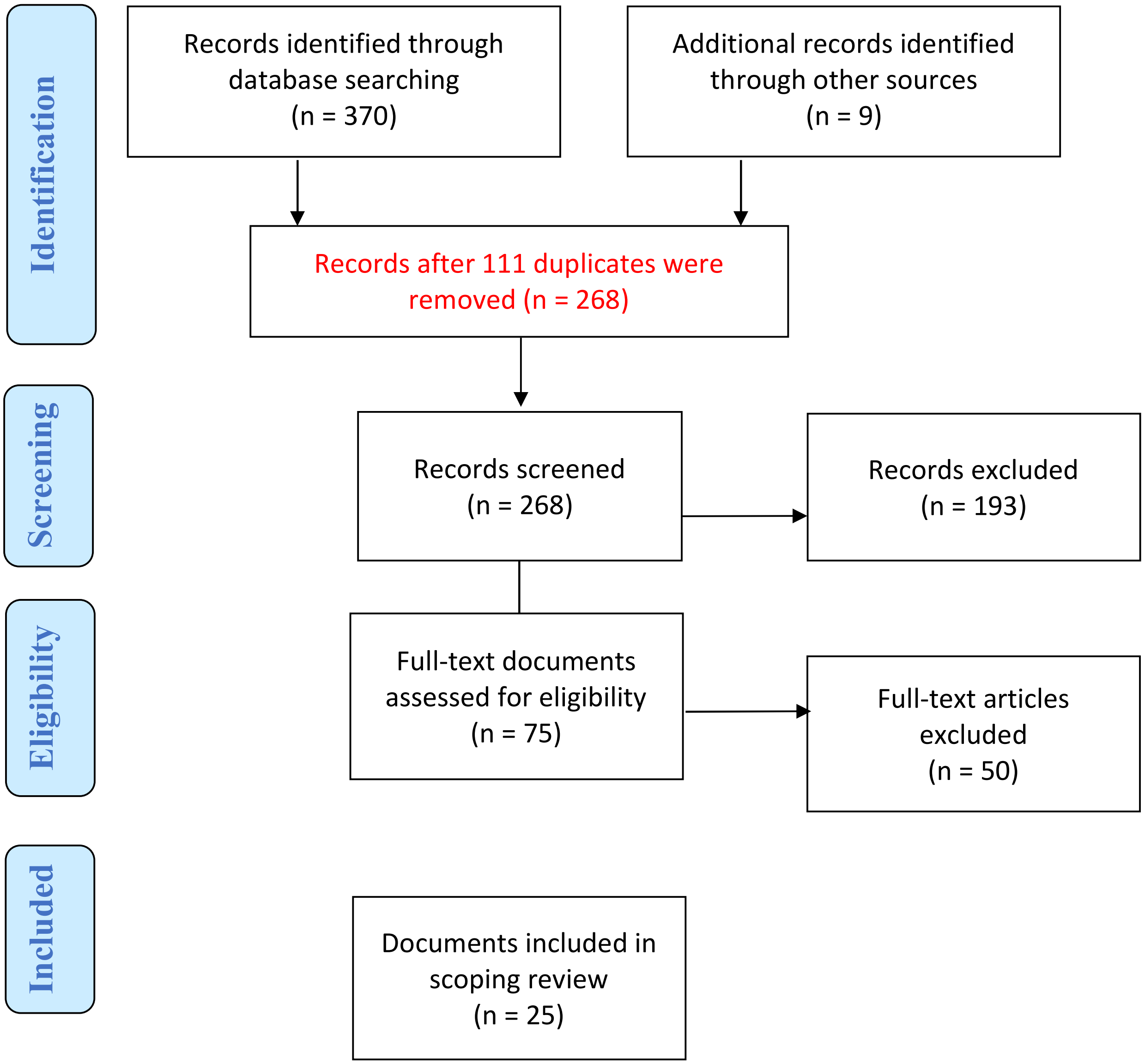
Using an iterative approach, a comprehensive search strategy was constructed to locate literature reviews, as well as quantitative and qualitative empirical studies. Relevant keywords and subject headings were combined using Boolean operators (AND, OR), and database search tools, including proximity operators, truncation and filters were also used. Search terms included those related to intellectual and development disability and community-delivered healthcare services. The search strategy for the Medline database is available in the appendix. The following databases were searched in April 2015 and searches were later updated in February 2017: Medline, Cumulative Index to Nursing and Allied Health Literature, PsycINFO, PubMed , Embase, Cochrane Library, Academic Search Complete, Social Services Abstracts, Social Work Abstracts, Scopus, Social Sciences Citation Index, Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, Epistemonikos, and Campbell Collaboration.

Search results were limited to publications: 1) in English and 2) between 2008 to search date (February 2017). This timeframe was chosen to capture literature published since the Balogh et al. (2008) Cochrane review of randomised controlled trials (RCTs) of organizational healthcare interventions for mental and physical health needs of persons with IDD was published. A limited search of the grey literature was also conducted using an iterative approach with variants of the database search strategy in the Google search engine as well as reputable websites. Additional studies, reports and reviews were identified through screening reference lists of relevant publications.

Results

As depicted in Figure 1, the initial database search led to the identification of 379 references. After the exclusion of 111 duplicates, these references were reduced to 268 records, whose titles and abstracts were reviewed to assess their relevance. After excluding 193 records, 75 manuscripts were reviewed in full-text and 25 documents met the inclusion criteria. Table 1 presents the main characteristics of the 25 studies included in the present scoping review.

Figure 1. PRISMA flow diagram.



Our comprehensive review of the literature revealed that a number of community-based initiatives have been developed to enhance the health and facilitate access to primary healthcare for persons with IDD who live in community settings. All except one of the evaluated initiatives were implemented in developed countries such as the United Kingdom ($n = 4$), the United States of America ($n = 4$), Australia ($n = 3$), the Netherlands ($n = 2$), Scotland ($n = 1$), Northern Ireland ($n = 1$), and Canada ($n = 1$). The only study conducted in a developing country evaluated the effectiveness of a multi-disciplinary clinic for persons with Down syndrome in Taiwan (Lee et al., 2016). In addition to the Canadian study that evaluated the effectiveness of a continuing education course for health professionals (Balogh et al., 2015), the Canadian Consensus guidelines on primary care of adults with IDD (Sullivan et al., 2011) was the only other Canadian resource found.

Table 1. Description of Articles Included in the Scoping Review.

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
Care of Adults with Developmental Disabilities: Effects of a Continuing Education Course for Primary Care Providers (Balogh et al., 2015) Canada (Ontario)	To evaluate the effects of an interdisciplinary, guideline-based continuing education course on measures related to the care of adults with developmental disabilities	Before-and-after study with a control group	47 primary care providers (physicians, registered nurses, and nurse practitioners)	Participants either only received reference material about primary care of people with IDD (control group) or participated in a continuing education course on primary care of people with IDD in addition to receiving the reference material (intervention group)	Compared to the control group, the intervention group showed significant *increases in the frequency of guideline use*, *frequency of assessment of patients' behaviour change, comfort level in caring for people with IDD, and knowledge of primary care related to adults with DD*
‘Planning Live’: Using a Person-Centered Intervention to Reduce Admissions to and Length of Stay in Learning Disability Inpatient Facilities (Bartle et al., 2016) UK	To assess the effect of a person-centered intervention in reducing the number and length of inpatient admissions to a Learning Disability Service, and to investigate if the intervention was experienced as helpful by those who participated	Mixed methods before-and-after study without a control group	102 clients referred for a possible inpatient admission over a two-year period (April 2013-April 2015) and their wider network systems	‘Planning live’ meeting: person-centered intervention consisting in a meeting lasting 1-2 hours that is attended by patients and their supporting systems, and is aimed at enabling positive problem-solving and action planning	No reduction in *number of inpatient admissions* Statistical reduction in *median length of inpatient stay* The process was largely seen as helpful by *participating professionals, families, and patients*

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
The Perspectives of Stakeholders of Intellectual Disability Liaison Nurses: A Model of Compassionate, Person-Centered Care (Brown et al., 2016) UK	To investigate the experiences of patients with IDD, family, and paid carers regarding the role of liaison nurses and the delivery of compassionate, person-centred care To propose a model of person-centred care embedded in these experiences	Qualitative design with Interpretative Phenomenological Analysis of data Semistructured interviews and focus groups	5 adult patients with IDD and their families or paid carers (n = 13)	New model of compassionate, person-centered care developed by synthesizing participants' perspectives	Identified themes: *vulnerability, presence and the human interface, information balance, critical points and broken trust, roles and responsibilities, managing multiple transitions, and 'flagging up' and communication*
Electronic Health Records: Optimizing Communication to Support the Nonverbal Medical Patient with Developmental Disabilities (Calman et al., 2015) USA	To investigate the effectiveness of a creative partnership between two organizations that serve persons with IDD	Descriptive study	Staff of primary care providers	Epic electronic health record and practice management system with a fully integrated electronic health record practice management system (InstituteLink)	The partnership led to a *successful, comprehensive care network* for severely developmentally disabled patients due to the use of InstituteLink to share patients' information
Do Health Checks for Adults with Intellectual Disability Reduce Emergency Hospital Admissions? Evaluation of a Natural Experiment (Carey et al., 2017) UK	To evaluate the effects of annual health checks for adults with IDD in reducing their emergency hospital admissions	Natural experiment incorporating practice and individual-level designs	Large English primary care database: 126 fully participating practices versus 68 non-participating practices, and 7,487 adults with IDD versus 46,408 matched controls	Annual health checks	Annual health checks in primary care for adults with IDD did not alter *overall emergency admissions*, but they appeared influential in *reducing preventable emergency admissions*

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
An Evaluation of a Behavioural Support Team for Adults with a Learning Disability and Behaviours the Challenge from a Multi-Agency Perspective (Christopher & Horsley, 2016) UK	To assess if the Dudley Behavioural Support Team (BST) meets guidelines set out by the government for ensuring the quality of services provided to persons with IDD	Cross-sectional design Structured interview conducted using a questionnaire containing quantitative and qualitative questions	19 staff members from independent service providers and social services	Behavioural Support Team (BST): specialist community-based service for adults with IDD and behaviours that challenge those who are supporting them	The quantitative results indicated that the BSTs are *meeting the guidance to a high standard* and qualitative data suggested this is achieved through a focus on joint working and a fluid, flexible approach
'What Vision?': Experiences of Team Members in a Community Service for Adults with Intellectual Disabilities (Clare at al., 2017) UK	To measure perceptions among the healthcare and care management team members who support persons with IDD of: 1) their personal well-being, 2) the functioning of their team, and 3) the organisation's commitment to quality and culture	Cross-sectional design 3 standardized mail questionnaires	73 staff members of five multidisciplinary and inter-agency community teams (CTs) that form a county-wide community-based service for adults with IDD	Multidisciplinary community teams that support adults with IDD living in community settings	The perceived *absence of a vision for the service*, combined with a dominant culture viewed by its members as strongly focused on bureaucracy and process, potentially compromises the ability of these CTs to respond proactively to the needs of people with IDD
The Role of Aging and Disability Resource Centers in Serving Adults Aging with Intellectual Disabilities and Their Families: Findings from Seven States (Coyle et al., 2016) USA	To develop an understanding of how aging and disability resource centers (ADRCs) administer resources and support to the population of adults aging with IDD and their family caregivers	Qualitative investigation 60-minute in-depth telephone qualitative interview containing semi-structured questions	21 ADRCs staff members in seven US states	Activities of aging and disability resource centers (ADRCs) as they seek to serve older adults with IDD and their family caregivers	ADRCs are not *focusing explicitly on adults aging with IDD and their family caregivers*, but meeting the needs of this population is a future goal of ADRCs Challenges related to services for adults aging with IDD highlight *existing unmet needs* of this population

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
Knowledge Exchange and Integrated Services: Experiences from an Integrated Community Intellectual (Learning) Disability Service for Adults (Farrington et al., 2015) UK	To examine knowledge exchange dynamics in a specialist integrated intellectual (learning) disability service, and to consider their significance in terms of integrated service delivery	Qualitative study focusing on knowledge exchange and integrated services Semi-structured qualitative interviews	25 members of an integrated intellectual disability service comprising specialist healthcare provision with social care commissioning and management	Specialist integrated intellectual (learning) disability service comprising specialist healthcare provision with social care commissioning and management	*Exchange of knowledge between health staff and care management staff* was problematic because of a lack of integrated clinical governance Team meetings and workplace interactions allowed for *informal exchange of knowledge*, but presented challenges in terms of completeness and sustainability
The Health Home: A Service Delivery Model for Autism and Intellectual Disability (Fueyo et al., 2015) USA	To describe the patient-centered service delivery model "Health Home"	Descriptive study	N/A	The patient-centered health- care home (health home) model as a new conceptual framework to build systems of care for persons IDD and their families to improve health outcomes and care integration of persons with IDD	N/A
Use of the My Health Record by People with Communication Disability in Australia: A Review to Inform the Design and Direction of Future Research (Hemsley et al., 2016) Australia	To review the literature on the use of the Australian Personally Controlled Electronic Health Record (PCEHR), by persons with IDD, and to propose a range of methods that can be used in future research to support the use in this population	Literature review Cross-disciplinary perspective	N/A	The Personally Controlled Electronic Health Record (PCEHR), MyHR, which represent an electronic record containing summaries of patients' health information from all their participating healthcare providers	Identification of 2 small studies Outlines a range of research methods suitable for investigating the use of MyHR by people who have communication disability, their family members, and their direct support workers

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
Individual Support Planning (ISP) with People with ID in the Netherlands: Official Requirements and Stakeholders' Expectations (Herps, Buntinx, & Curfs, 2016) Netherlands	To describe, summarize and discuss requirements for ISP as found in Dutch official IDD policy to enhance ISP practices, and to report the results of consultations with stakeholders and experts working in the field of IDD	Desk research of relevant Dutch Acts and official policy documents Consultations with 2 panels of stakeholders and experts over a 1-year period	11 relevant stakeholders at the national policy level 45 professionals working in the field of ID	Individualized Support Planning with persons with IDD	A variety of criteria on *content, procedures, quality and person-centeredness of ISP* is being used by different stakeholders
Individual Support Plans for People with Intellectual Disabilities in Residential Services: Content Analysis of Goals and Resources in Relation to Client Characteristics (Herps, Buntinx, Schalock, et al., 2016) Netherlands	To explore what domains of quality of life are associated with Individual Support Plan (ISP)-referenced goals and objectives, what support resources are referenced for achieving the goals and objectives, and how domains and resources are related to demographic characteristics such as a client's age, gender and IDD level	Cross-sectional study Revision of participants' ISPs	209 adults with IDD	Individual Support Plan (ISP) of adults with IDD	In light of current ISP practices, results suggest that attention should be paid to: 1) *distinguishing between a 'service contract' and an ISP*, 2) *keeping a focus on the whole person in all age groups and levels of functioning*, and 3) *involving the service recipient in ISP development and implementation*
Addressing the Needs of Individuals with Autism: Role of Hospital-Based Social Workers in Implementation of a Patient-Centered Care Plan (Iannuzzi et al., 2015) USA	To describe the role of hospital-based social workers in implementing a patient-centered care plan for persons with IDD	Descriptive study	N/A	Patient-centered care plan for persons with IDD in hospital settings that takes into account all aspects of communication and sensory processing differences present in this population	Provide some of the characteristics of the social worker position as it's described in the paper

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
Primary Care for Adults with Down Syndrome: Adherence to Preventive Healthcare Recommendations (Jensen et al., 2013) USA	To evaluate the adherence of primary care physicians to age- and condition-specific preventive care in a cohort of adults with Down Syndrome	Retrospective observational cohort study Secondary analysis of administrative data (Data Repository) and review of patients' charts	62 adults with Down Syndrome	Preventive healthcare screening domains for adults with Down Syndrome	Inconsistent *preventive care* was observed in adults with Down Syndrome over this 8.5-year study period (2000-2008)
Integrated Care for Down Syndrome (Lee et al., 2016) Taiwan	To describe an integrated care model for persons with Down Syndrome	Descriptive study	200 patients with Down Syndrome	An integrated multi-disciplinary care model with protocol-driven surveillance for persons with Down Syndrome	The clinic supports persons with DS and their caregivers, *focuses on early detection and prevention of medical and developmental issues*, with genetic checks performed regularly by subspecialists
Learning Disability Liaison Nursing Services in South East Scotland: A Mixed Methods Impact and Outcome Research Study (MacArthur et al., 2010) UK	To explore and identify the impact of Learning Disability Liaison Nursing (LDLN) services on the healthcare experiences of people with a learning disability attending for general hospital care	Mixed methods impact and outcome study Focus groups and semi-structured interviews	85 people including persons with IDD (n=5), carers (n=16), primary care (n=39) and general hospital (n=19) staff from all disciplines, and the liaison nurses themselves (n=6)	Learning Disability Liaison Nursing (LDLN) services for persons with IDD attending for general hospital care	The LDLN services were highly valued by all stakeholders through contributing to achieving person-centered outcomes The liaison nurses have an important role in raising the status of people with IDD in general hospitals as their expert knowledge and skills promote the development of effective systems and processes that contribute to improving patient experiences

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
Integrating Care for Individuals with FASD: Results from a Multi-Stakeholder Symposium (Masotti et al., 2015) Canada	To bring together key stakeholders to define existing systems, gaps, and research needs for FASD To reach multi-stakeholder consensus relevant to the issue of integrated care for individuals with FASD	Qualitative investigation that used content analysis Symposium organized in 4 sessions	60 participants and presenters were experts/leaders in their area and had significant experience with FASD	Integrated services for persons with FASD	Health outcomes and integration would improve by implementing: multi-disciplinary primary care group practice models, FASD system advocates, and patient-centred medical homes
Optimizing the Uptake of Health Checks for People with Intellectual Disabilities (McConkey et al., 2015) UK	To document the uptake of annual health checks of adults with IDD across general practitioner (GP) practices in Northern Ireland over a 3-year period	Cross-sectional study Audit of anonymized data held by health and social personnel	GP Practices and adults with IDD	Annual health checks for adults with IDD undertaken by community family doctors such as general practitioners (GPs)	Fewer than 50% of adults with IDD are receiving a health check every year Younger persons with IDD, those living with family members or independently, and persons resident in more socially deprived areas are more likely to miss their annual helath checks
Promoting Healthy Aging of Individuals With Developmental Disabilities (Roll & Bowers, 2017) USA	To examine an innovative Community Outreach Nursing Program (CONP) designed to promote healthy aging in persons with IDD living in the community	Qualitative case study 10 in-depth interviews, 1 focus group, and analysis of documents	3 nurses who were working in the program and 7 people who collaborated in the program	Innovative Community Outreach Nursing Program (CONP) designed to promote healthy aging in persons with IDD living in the community	The CONP entails person-centered health education, advocacy for the safe return home, support for staff, and enabling social participation

Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
Stakeholders' Perspectives towards the Use of the Comprehensive Health Assessment Program (CHAP) for Adults with Intellectual Disabilities in Manitoba (Shooshtari et al., 2016) Canada	To determine the feasibility of implementing the Comprehensive Health Assessment Program (CHAP) for comprehensive health assessments of adults with IDD in Manitoba, Canada	Qualitative study with an Interpretive Description design Semistructured individual interviews and focus groups Content analysis	24 caregivers and primary care providers of adults with IDD	Comprehensive Health Assessment Program (CHAP)	The future implementation of the CHAP was strongly supported For its successful implementation, *training of healthcare professionals and support staff and change in regulations and policies* were recommended
Effectiveness of caregiver training in mindfulness-based positive behavior supports (MBPBS) vs. training-as-usual (TAU): A randomized controlled trial (Singh et al., 2016) USA	To evaluate in a randomized controlled trial (RCT) the comparative effectiveness of Mindfulness-Based Positive Behavior Support (MBPBS) and Training-as-Usual (TAU) for caregivers in a congregate care facility for individuals with severe and profound IDD	Randomized Controlled Trial (RCT)	75 caregivers of persons with IDD: 37 randomly allocated to the experimental group (MBPBS) and 38 randomly allocated to the control group (TAU)	Mindfulness-Based Positive Behavior Support (MBPBS) training for caregivers of persons with IDD	MBPBS was significantly more effective than TAU in *enabling the caregivers to manage their perceived psychological stress*, and *to reduce the use of physical restraints* and *stat medications for aggressive behavior of the individuals in their care*

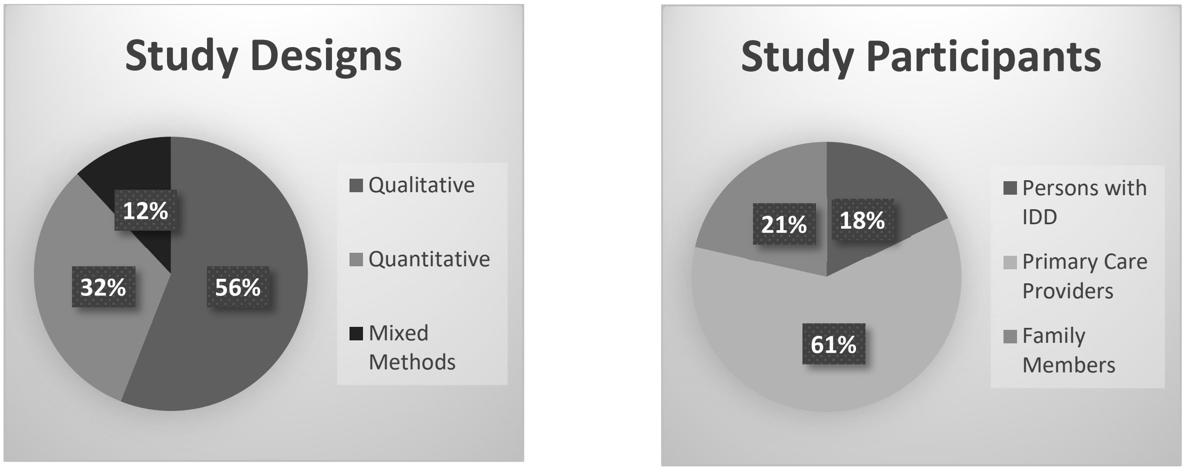
Study and Setting	Objectives	Design and Methods	Participants	Initiative	Results
Primary Care of Adults with Developmental Disabilities: Canadian Census Guidelines (Sullivan et al., 2016) Canada	To update the 2006 Canadian guidelines for primary care of adults with IDD and to make practical recommendations based on current knowledge to address the particular health issues of adults with IDD	Consensus development method involving 2 steps: 1) literature search, and 2) discussion of recommended changes to the 2006 Guidelines	39 knowledgeable and experienced Canadian clinicians and researchers on primary healthcare of adults with IDD	Updated Canadian guidelines for primary care of adults with IDD product of the Colloquium on Guidelines for the Primary Health Care of Adults with Developmental Disabilities held on March 20, 2009, in Toronto, Ontario	*Improving clarity* *Promoting ethical practices* *Developing new guidelines*
Improving Access to Electronic Health Records for People with Intellectual Disability (van Dooren et al., 2013) Australia	To identify the facilitators and barriers to registering for an Australian eHealth record network for persons with IDD and those who support them, including families and paid staff, to determine where improvements to the registration process, if any, might be required	Qualitative investigation Individual interviews including open-ended questions Thematic analysis	9 adults, including persons with IDD, family members, and residential support workers	Australian electronic health record (eHealth record) that can be shared between doctors and other healthcare providers	Decision-makers involved in the roll-out of the eHealth record networks should *incorporate 'reasonable accommodations' to improve accessibility for people with intellectual disability and those who support them to manage their health information*
Building a Person-Centered Medical Home: Lessons from a Program for People with Developmental Disabilities (Weedon et al., 2012) USA	To describe the main characteristics of the University of Utah Healthy Outcomes Medical Excellence (HOME) Program and present some of its outcomes for persons with IDD and their families	Descriptive cross-sectional study	Persons with IDD and their family members	The University of Utah Healthy Outcomes Medical Excellence (HOME) Program, which provides comprehensive outpatient primary medical and mental health services for people with IDD across the lifespan	High family satisfaction with clinicians and over quality of program Significant decreases in length of inpatient hospitalization Clinical outcomes better than or comparable with state and national averages

Within the context of universal healthcare coverage in Canada, a better integration of health and social support services is recommended to better meet this population's needs and expectations. In our review of the literature, there is evidence to support the effectiveness of comprehensive multi-disciplinary health clinics (Coyle et al., 2016; Farrington et al., 2015; Weedon, et al., 2012) and care teams (Christopher & Horsley, 2016; Clare et al., 2017) that include social workers (Iannuzzi et al., 2015), community nurses (MacArthur et al., 2010), electronic health records (Calman et al., 2015; Hemsley, et al., 2016), comprehensive health assessment tools, such as the Comprehensive Health Assessment Program (CHAP; Bakker-van Gijssel et al., 2017) and community outreach nursing programs (Roll & Bowers, 2017) including the provision of compassionate, person-centred care (Brown et al., 2016) via coordinated health planning (Bartle et al., 2016; Herps et al., 2016; Herps et al., 2016) using multidisciplinary primary care group practices (Masotti et al., 2015) to improve access to integrated services. Providing training and educational opportunities to persons with IDD as well as their paid and unpaid caregivers are among other effective initiatives identified in this review (Balogh et al., 2015; Chapman et al., 2013; Singh et al., 2016) Meanwhile, there is no evidence on the effectiveness of some of the suggested initiatives, for example, the introduction of health facilitators (McConkey et al., 2015).

With regard to the research methodology and design of included studies, most of the reviewed investigations were conducted using qualitative, descriptive, or mixed methods research approaches. The qualitative studies provide descriptive results from small samples of community-service staff and family members of persons with IDD (Coyle et al., 2016; Farrington et al., 2015; Herps et al., 2016; Masotti et al., 2015; Roll & Bowers, 2017; Shooshtari et al., 2016). Only two studies provided qualitative data on the effectiveness of community-based initiatives that considered the perspectives of persons with IDD (Brown et al., 2016; van Dooren et al., 2013). Other investigations provided a mere description of community-based initiatives from the perspective of the service staff, without using any specific measures or indicators to evaluate their effectiveness (Calman et al., 2015; Fueyo et al., 2015; Iannuzzi et al., 2015; Lee et al., 2016). Three studies performed secondary analysis of anonymized administrative health and social data, individualized support plans, and patients' charts to describe utilization of community-based healthcare services (Herps et al., 2016; Jensen et al., 2013; McConkey et al., 2015). Three mixed methods studies integrated quantitative and qualitative data collected from persons with IDD as well as their support systems to assess the effectiveness of various community-based services in promoting health and well-being of individuals with IDD and supports for family caregivers (Bartle et al., 2016; Christopher & Horsley, 2016; MacArthur et al., 2010).

Only a small proportion of investigations that met the inclusion criteria implemented quantitative research methodologies and designs to evaluate the effectiveness of community-based initiatives, including two cross-sectional studies (Clare et al., 2017; Weedon et al., 2012), one before-and-after study (Balogh et al., 2015), one natural experiment (Carey et al., 2017), and one randomized control trial (RCT) (Singh et al., 2016). None of these studies assessed intervention effectiveness (i.e., changes between pre- and post-) using objective, valid and reliable standardized measures. Of these five investigations, only Weedon et al. (2012) included the perspective of the persons with IDD to whom the service was delivered in their evaluation of person-centered community services. The remaining four studies were limited to family member and paid care provider perspectives only. Figure 2 presents a graphical representation of the specific proportions of included studies categorized by study design and study participants.

Figure 2. Proportion of included studies by study design and study participant group type.



Most studies assessed effectiveness of community-based initiatives with subjective indicators via interviews with service staff or family members of persons with IDD (Bartle et al., 2016; Brown et al., 2016; Christopher & Horsley, 2016; Coyle et al., 2016; Farrington et al., 2015; Herps et al., 2016; MacArthur et al., 2010; Masotti et al., 2015; Roll & Bowers, 2017; Shooshtari et al., 2016; van Dooren et al., 2013), while other studies used health and social records, or data collected by healthcare providers (Carey et al., 2017; Jensen et al., 2013; McConkey et al., 2015; Singh et al., 2016). The perspectives of persons with IDD have been largely overlooked in this literature, as well as the use of standardized measures to assess the health and quality of life of this population. The conclusions of some of the reviewed studies may be biased due to the fact that effectiveness of the community-based initiatives were based solely on the perceptions and opinions of the same care providers who were involved in service planning or delivery, or evaluated by the clinicians who developed and implemented the interventions (e.g., Brown et al., 2016).

Discussion

From this scoping review, we have identified major gaps in the literature on community-based health initiatives for persons with IDD. Specifically, there is a lack of both qualitative and quantitative studies assessing the effectiveness of healthcare initiatives offered in the community. In particular, the voices and perspectives of persons with IDD using the services are essentially non-existent. Equally scarce in the literature are objective measures of effectiveness and outcomes assessed with standardized measures and indicators. Thus, we advocate for the development of research to address these gaps as a critical priority. For example, the CHAP (Lennox et al., 2007; Lennox et al., 2010), and the San Martin Scale (Verdugo et al., 2014) or the INICO-FEAPS Scale (Gomez et al., 2015) are valid and reliable standardized assessment tools to evaluate health status and quality of life of persons with IDD, respectively. Future research should track changes between pre- and post-community-based interventions with objective measures such as these standardized tools to minimize biases in reporting effectiveness of interventions.

Another important gap in the literature on effective community-based healthcare initiatives for persons with IDD is the long-term impact of the interventions such as, comprehensive health assessments or health checks. Research indicates that comprehensive health assessments (or health checks) offer several benefits. Comprehensive assessments promote good health allowing for early detection of new diseases and thus aids in preventative healthcare (Lennox et al., 2007). Health checks have also been shown to reduce unnecessary emergency hospital admissions for epilepsy and seizures (Carey et al., 2017). What still remains unknown is the longer-term effects of these healthcare interventions.

Well-designed studies of a longitudinal nature are needed to determine the long-term effects of community-based healthcare interventions. Such evaluation will not only provide valuable information on the impact of improved health, access to healthcare services and quality of life of persons with IDD, but also give insight into the effects on the healthcare system. Preventative healthcare, as opposed to reactive, should reduce the need for expensive medical interventions and/or hospital admissions and result in cost-savings for the healthcare system. Only comprehensive longitudinal evaluations will help support these hypotheses.

Future research is needed to address several knowledge gaps. Specifically, updated reviews of the scientific literature related to effective policies, programs and initiatives aimed at improving the health, access to healthcare and coordination of health and social services for persons with IDD are extremely important in the provision of evidence-based care. The resulting knowledge must then be translated and disseminated to a wide variety of stakeholders including, persons with IDD, their families and care providers, clinicians, care managers, and policy makers. In order to facilitate uptake and ensure evidence-based care is available to improve the health, well-being and quality of life of persons with IDD, information about effective policies, programs and initiatives has to be accessible to stakeholders in user-friendly language.

Key Messages from This Article

People with disabilities: You deserve access to the best possible health and social services in your community. Your voice and perspective on these services must be heard and respected.

Professionals: The care you provide should be preventative, comprehensive and person-centered as it needs to be tailored to each individual person’s needs and based on what is important and meaningful to that person.

Policymakers: Professionals need to be educated about providing high quality care to persons with disabilities and given enough time to properly assess the health and quality of life of persons with disabilities.

Messages clés de l’article

Personne ayant une incapacité : Vous méritez d’avoir accès aux meilleurs services sociaux et de santé possible dans votre communauté. Votre voix et votre point de vue sur ces services doivent être écoutés et respectés.

Professionnels : Les soins que vous prodiguez doivent être préventifs, complets et centrés sur la personne, car ils doivent être adaptés aux besoins uniques de chaque personne et être basés sur ce qui est important et significatif pour cette personne.

Décideurs : Les professionnels doivent être formés à fournir des soins de haute qualité aux personnes ayant une incapacité et avoir suffisamment de temps pour évaluer adéquatement la santé et la qualité de vie de ces personnes.

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