Adults with intellectual and developmental disabilities and interprofessional, team-based primary health care: a scoping review

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ABSTRACT

Objective: This scoping review aimed to examine the state of the evidence for interprofessional, team-based primary health care for adults with intellectual and developmental disabilities.

Introduction: Adults with intellectual and developmental disabilities are a complex, vulnerable population known to experience health inequities. Interprofessional primary health care teams are recommended to improve access to comprehensive and coordinated health care for these individuals. Limited information is available regarding what services interprofessional primary health care teams provide and how services are evaluated specific to the care of this population.

Inclusion criteria: This scoping review considered all studies that referenced individuals with intellectual and/or developmental disabilities who were 18 years and older. It considered all studies that referred to health care provision within a primary health care context. All studies that discussed the provision of interprofessional primary health care services were included. "Interprofessional primary health care team" was the term used to describe services provided by health providers (e.g. physicians, nurse practitioners, nurses, dietitians, social workers, mental health workers, occupational therapists, physical therapists) working in a team-based model of care.

Methods: This scoping review was conducted in accordance with the JBI methodology for scoping reviews. Quantitative, qualitative, and mixed-methods study designs were considered for inclusion. In addition, systematic reviews, program descriptions, clinical reviews, and opinion papers were considered. Studies published in English and French were included. The period considered was from 2000 to the date of the searches (July and August 2018 for bibliographic databases and January 2019 for the final searches of unpublished studies and selected papers from key authors).

Results: The search identified 2761 records. Despite the global search strategy, only 20 records were included in the final review, mainly consisting of work based in the United States and Canada. Results were heterogeneous and descriptive in nature, consisting of cross-sectional designs, program descriptions, and clinical reviews. The findings represent only a few distinct interprofessional primary health care team models of care and multiple contributions from a small pool of researchers. Roles for physicians, nurse practitioners, nurses, social workers, and mental health providers were identified. Ten studies identified either patient-reported outcomes or health-utilization outcomes. Overall, there was no consistent reporting of outcomes across studies, and outcomes specifically related to many interprofessional services were not captured. Although interprofessional, team-based approaches are supported at a policy and practice level, the concept of interprofessional primary health care for this population remains understudied and is challenged by differences in primary health care provision across the world, complexity in how the field is defined, as well as a lack of consistent reporting of the organizational attributes and processes that support interprofessional primary health care provision.

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The authors declare no conflict of interest.

DOI: 10.11124/JBISRIR-D-19-00200

Conclusions: To fully realize the potential of interprofessional primary health care teams, health services research is needed to describe organizational attributes and processes and evaluate interventions for this population. Engaging in this work will ultimately provide a more fulsome evidence base to support high-quality, interprofessional primary health care provision for adults with intellectual and developmental disabilities.

Keywords Developmental disability; intellectual disability; interprofessional care; multidisciplinary team; primary health care

JBI Evid Synth 2020; 18(0):1–46.

Introduction

Intellectual and developmental disabilities (IDDs) impact 1% to 2% of the global population[1,2] and refer to a broad range of developmental conditions associated with lifelong challenges in cognitive and/or adaptive functioning.[3] Many terms have been used synonymously to describe this range of conditions, including intellectual disability, developmental disability, learning disability (in the United Kingdom), and mental retardation.[4] Intellectual and developmental disability is the term now recommended by key international groups[5,6] and will be used throughout this review.

Adults with IDD are recognized as a vulnerable population with complex needs.[7] One factor associated with increased complexity among adults with IDD is a higher prevalence of mental health conditions, physical health conditions, and multi-morbidity as compared with the general population.[8,9] It is well recognized that adults with IDD are more likely to develop chronic conditions including, but not limited to, congestive heart failure, chronic obstructive pulmonary disease, asthma, diabetes, and mental illness than people without IDD.[9-12]

In addition to having complex health needs, it has long been recognized that adults with IDD are vulnerable to experiencing health service inequities.[7,11,13] In 1995, Beange *et al.*[14] found that adults with IDD in Australia live with, on average, five health conditions, of which half are not identified or are poorly managed. The care of adults with IDD continues to be a concern as physicians in the United Kingdom note high levels of unmet physical and mental health needs when completing annual health checks (an example of a periodic health examination).[11] Barriers to health service access result in ineffective monitoring of preventable conditions and missed opportunities to promote health and well-being.[15] Consequently, adults with IDD are more likely to visit the emergency department and to be hospitalized for conditions (e.g. asthma, diabetes) that should be managed through outpatient services.[16,17] It is expected that health care utilization will continue to rise as individuals with IDD live longer and the risk of multi-morbidity increases.[18]

Improving primary health care (PHC) can have many potential benefits for this population.[19] As the World Health Organization notes, PHC can meet 80% to 90% of individuals' health needs over their lifespan.[20] Health providers in PHC are the main point of contact with the health system and offer screening, ongoing management support, and/or assistance with referrals to specialists.[20,21] Primary health care services continue to evolve to meet the needs of communities; and interprofessional PHC team approaches are gaining traction in order to address population trends in aging, chronic disease, multi-morbidity, and increasing health complexities.[22-25]

The aim of interprofessional PHC teams is to improve coordinated, comprehensive care for all patients, including populations with complex needs.[26] Increased access to a range of health providers (e.g. nurse practitioners, dietitians, social workers) in PHC can assist in screening, care coordination, health promotion, and chronic disease management interventions.[27,28] Evidence from Canada and the United States indicates these interprofessional PHC teams have the potential to improve quality of care, increase patient and family satisfaction, decrease hospitalization, reduce emergency room use, and lead to better health outcomes in general.[29-32] There is not one approach to interprofessional PHC and teams differ in composition, size, programming, funding structures, and what they are called. Examples of interprofessional PHC teams currently in use globally can include primary care teams, community health centers, patient medical homes (e.g. Family Health Teams

is one example of this approach in Canada), and a specific subset of health homes in the United States (PHC Medicaid-based practices only).[33-36]

Adults with IDD have complex health needs and interprofessional PHC teams could be well aligned to meet their unique health and health service needs. Although an interprofessional PHC team approach is supported in guidelines,[22,37] there remains a concerning lack of evidence to support and inform this approach to PHC for adults with IDD. A preliminary search of the literature was conducted through MEDLINE, CINAHL, *JBI Database of Systematic Reviews and Implementation Reports*, Cochrane Database of Systematic Reviews, and Epistemonikos. No current scoping reviews or systematic reviews specifically related to the work of interprofessional PHC teams for this group were identified. There were, however, a limited number of systematic reviews completed that explore the provision of PHC for adults with IDD,[38-40] and one that explored the impact of organizational-level health service interventions.[41]

A systematic review by Byrne *et al.*[38] looked at PHC interventions targeting health promotion and disease prevention of adults with IDD. This review of five studies found that health checks were the only intervention to improve health promotion and secondary prevention outcomes for this population. These findings are consistent with the systematic reviews completed by Robertson *et al.*,[39,40] specifically on health check interventions. Robertson's team found that health check interventions consistently led to a) the identification of unmet health needs, and b) appropriate, targeted follow-up.[40] Health check interventions function to address known health service challenges by increasing the knowledge of health needs of people with IDD among health care providers and caregivers, as well as to identify gaps in health services.[39]

A systematic review by Balogh *et al.*[41] examined the effects of health care organization interventions for persons with IDD. As noted, although the review did not specifically focus on interprofessional PHC, this group studied organizational interventions such as "multidisciplinary teams," "formal integration of services," and "revision of professional roles," which are relevant to our focus on interprofessional PHC teams. Seven studies met the inclusion criteria in the review by Balogh *et al.*;[41] the majority of the studies investigated the impact of organizational interventions on the mental health of adults with IDD and no studies reported on interventions to address non-psychiatric care. Balogh *et al.*[41] could not make conclusive recommendations for the organization of health care services based on the available evidence.

Interprofessional teams are not a new phenomenon in health care; however, their use within a PHC context is evolving and, at present, we do not know how interprofessional PHC teams' function to care for more complex and vulnerable populations. Lennox and colleagues make a call to action for system-level research that focuses on quality PHC for adults with IDD.[42] Given the recommendation for interprofessional PHC for this population, research is required to better understand the state of the evidence. A greater understanding of the organization and provision of interprofessional PHC for adults with IDD, including the types of health providers engaged and the extent of interprofessional interventions and outcomes, is warranted. This scoping review is the first to systematically report on this approach to PHC provision for adults with IDD and provides an important foundation for future work on the topic.

Review questions

What is the current evidence for interprofessional, team-based PHC for adults with IDD?

Secondary questions that informed and focused the scoping review were:

- What are the aims and characteristics (type, health provider, delivery mode, processes) of interprofessional PHC team services for adults with IDD?
- What types of health or health service outcomes have been reported in the literature in the implementation of interprofessional PHC team interventions for adults with IDD?
- What evidence gaps in interprofessional PHC for adults with IDD can be identified?

Inclusion criteria

Participants

This scoping review considered all studies that specifically referenced adults 18 years and older with IDD. Intellectual disability is characterized by impairment in cognitive functioning and challenges in adaptive behaviors and skill development prior to the age of 18 years.[5] There is known heterogeneity

within this population in regards to cognitive functioning, with 85% of individuals functioning in the mild range of intellectual disability, 10% in moderate, 4% in severe, and 2% in profound levels.[1] Developmental disability is typically diagnosed before the age of 22 years. It is a larger umbrella term that is inclusive of intellectual disabilities and is characterized by the presence of a chronic disability due to a mental and/or physical impairment that substantially impacts adaptive skills and functional performance in everyday activities.[5] Individuals may also have concurrent physical, behavioral, or mental health conditions. Given the nature of this review, evidence of a formal diagnosis was not required and studies referencing individuals along the spectrum of cognitive and adaptive functioning were included. Studies referring only to children and adolescents with IDD were excluded as health care services typically differ for this group.[41]

Concept

This scoping review considered all studies that discussed the provision of interprofessional services within PHC teams. Interprofessional care was the term used to describe services provided by health providers in these teams. Health providers included, but were not limited to, physicians, nurse practitioners, nurses, physician assistants, registered dietitians, social workers, mental health workers, pharmacists, occupational therapists, physiotherapists, psychologists, chiropodists, respiratory therapists, health education workers, and case managers. Studies that referenced outcomes resulting from receiving care from an interprofessional PHC team were included (e.g. physical, mental health, health service outcomes). Studies that referred solely to the work of a physician and a nurse in a traditional PHC practice were excluded.

Context

This scoping review considered all studies conducted in or focused on a PHC context. ''Interprofessional PHC model of care'' was the term used to describe the organization of PHC services (e.g. primary care team, community health center, patient medical home, health homes). For this study, PHC was defined as: ''the first level of contact of individuals, the family and community with [a] national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.''[43(para.6)]

Types of sources

This scoping review considered a wide range of quantitative and qualitative designs. Both experimental and quasi-experimental study designs were included (e.g. randomized controlled trials, non-randomized controlled trials, before and after studies, interrupted time series studies), as well as analytical observational studies, including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies. The scoping review also considered descriptive observational study designs including case series, individual case reports, and descriptive cross-sectional studies. Studies that focused on qualitative data including, but not limited to, traditions such as phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research, were considered. Systematic reviews that met the inclusion criteria were also considered. Program descriptions, clinical reviews, text and opinion papers were also included.

Studies published in English and French were included. The period considered was from 2000 to the date of the searches (July and August 2018 for bibliographic database searches and January 2019 for the final searches of unpublished studies and additional selected papers from key authors). The most current period of primary health care policy reform began in the early 2000 s and justified this timeframe.[44-46]

Methods

This scoping review was conducted in accordance with the JBI methodology for scoping reviews.[47] This review was conducted in accordance with an *a priori* protocol.[48]

Search strategy

The search strategy was designed to locate both published and unpublished studies. A multi-step search strategy was conducted in collaboration with a librarian. An initial limited search of MEDLINE and CINAHL was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy. The search strategy, including all

identified keywords and index terms, was adapted for each included information source and further searches were completed (an example search strategy is provided in Appendix I). Furthermore, during full text reviews, all reference lists were scanned to identify any additional sources. Authors (HOK, NB) sent emails to key authors in the field requesting any completed or in-progress research on the topic. The first author was in further contact with two study authors regarding their work.

Information sources

Databases were searched using both OVID and EBSCO platforms, and included: AMED, CINAHL, Embase, Ovid EMCARE, MEDLINE, *JBI Database of Systematic Reviews and Implementation Reports*, the Cochrane Library, and Global Health. Sources of unpublished studies and gray literature searched included a custom Google Scholar Search, Grey Literature Report, Open Grey, and a review of select professional organization websites (e.g. Association of University Centers on Disabilities, Centre for Developmental Disability Health, Improving Health and Lives (IHaL), International Association for the Scientific Study of Intellectual and Developmental Disabilities, Surrey Place, Sonoran University Center for Excellence in Developmental Disabilities, Education, Research and Service – Medical Home for Youth and Adults with Developmental Disabilities).

Study selection

Following the search, all identified citations were imported into Mendeley V.1.19.4 (Mendeley Ltd., Elsevier, Netherlands), and then uploaded into Covidence (Veritas Health Innovation, Melbourne, Australia). Titles and abstracts were screened by two independent reviewers (JD, EW) for assessment against the inclusion criteria for the review. Any conflicts between the two reviewers were resolved with a third independent reviewer (NB). Three reviewers (JD, EW, NB) completed the full-text reviews with each paper requiring the agreement of two reviewers. In the situation where there was disagreement between two reviewers, the third independent reviewer completed the additional review. The first author (NB) completed a final review of all full text papers included in the study and the list was confirmed by a fourth and fifth reviewer (CD, HOK).

Data extraction

Data were extracted from papers included in the scoping review by three independent reviewers (NB, JD, EW) using a modified JBI data extraction tool as specified in the review protocol.[48] The data extracted were consistent with a scoping review extraction framework outlined by JBI[47,49,50] and included formal citation (author(s), title, year and source of publication), country of origin (where the study was conducted or published), study design, purpose, population, description of concept, intervention strategies, outcomes, and key findings related to the scoping review questions. Context was removed as all studies were situated within PHC. Duration of intervention was removed from the original data extraction tool as no findings pertained to that category. Authors of papers were contacted to request additional data where required. Any disagreements between the reviewers was resolved through discussion and use of a fourth reviewer (CD).

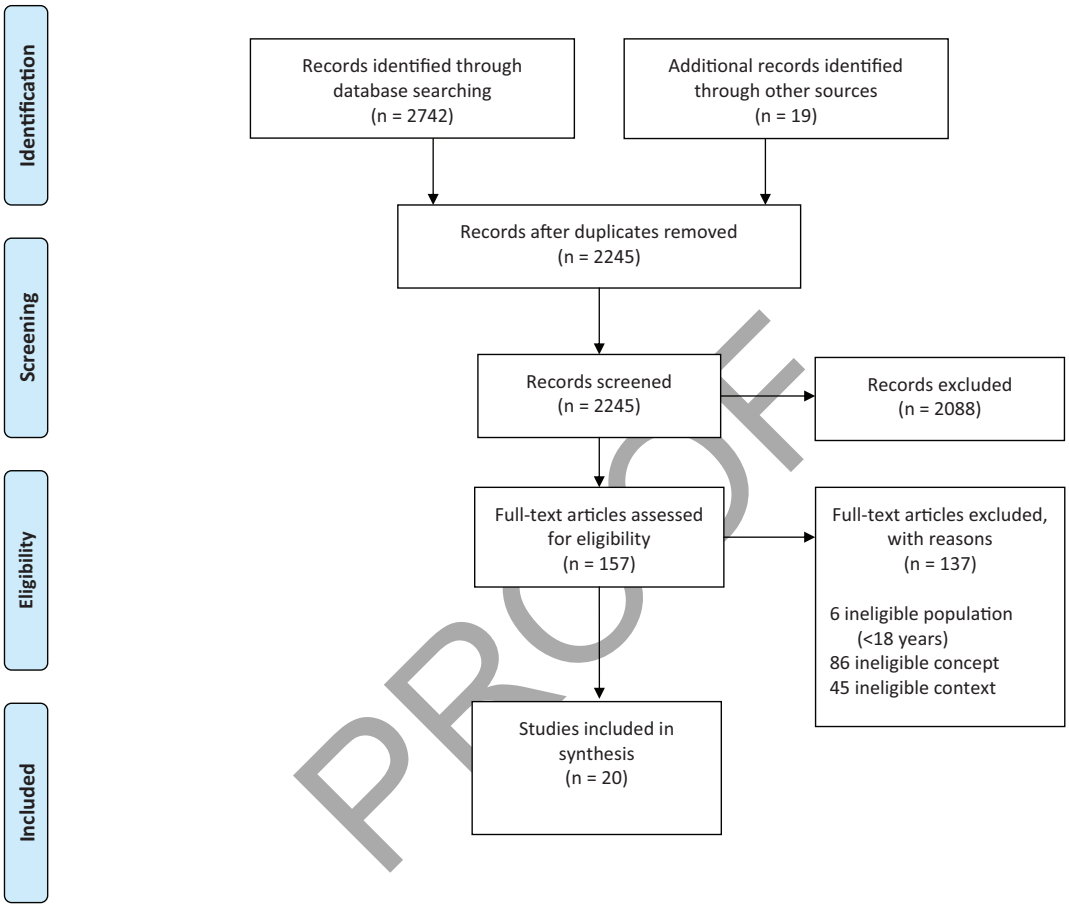
Data presentation

Results are described in detail narratively in the following section. Characteristics of the included studies (Appendices III and IV) are presented in tabular form in a manner that aligns with the objectives of the scoping review and scoping review guidelines as per JBI.[47,49,50]

Results

Study inclusion

The search strategy identified 2761 references. Duplicates were removed and 2245 records were included for title and abstract screening. Abstract and title screening further excluded 2088 records. The full text review included 157 references and 137 were eventually excluded. Forty-five references were excluded as they didn't report on work completed within a PHC context. Eighty-six references were excluded due to an ineligible concept; many papers did not directly mention interprofessional care or focused on the relationship between interprofessional specialist IDD services and PHC teams. A final six references were excluded as they did not directly state the population of interest (adults with IDD) or discussed children or adolescents with IDD. The study selection process and decisions for inclusion are reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Figure 1: Search results and study selection and inclusion process[53]

Analyses and a PRISMA flow diagram (Figure 1) is provided.[51]

Characteristics of included studies

This scoping review identified 20 references: nine references were from the United States,[28,29,56,57,58,60,61,63,66] 10 from Canada,[22,30,52,53-55,62,65,67,68] and one from South Africa.[64] A range of study designs were identified and included cross sectional (3),[52,54,55] case-control (2),[53,61] process evaluation (1),[68] and chart audit/reviews (2).[63,64] A series of reviews were included, such as clinical reviews (4),[22,62,65,67] book chapters (3),[28,30,66] a review article (1),[57] and program descriptions (3).[29,58,60] Lastly, one website was included that described an interprofessional PHC team that was discussed in case examples in the previously mentioned reviews.[56] The references described three main models of interprofessional PHC: community health centers,[58,64] patient medical homes (which includes family health teams)[52,53-55,56,68] and health homes.[28,60,61] All references identified adults with IDD as their population of interest; however, detailed population characteristics were available for nine studies only as a result of the type of study designs (e.g. many of the program descriptions and

clinical reviews did not provide detailed information regarding their patients).[29,52-55,58,61,63,64] Four of the nine studies were from an Ontario cohort of 66,484 adults with IDD (38,090 men and 28,394 women), 18 to 64 years old (2009/2010).[52-55]

This scoping review includes multiple references from the same authors or pool of authors. As mentioned, although four distinct studies were included from Ontario, Canada, they describe findings from one cohort of adults identified in the province and represent the work of a dedicated research network. Furthermore, given the high number of reviews (e.g. book chapters, clinical reviews, program descriptions) included in this study, many of the case examples are cited across references. For example, multiple references discuss the Developmental Disabilities Health Alliance (DDHA) health home, an interprofessional PHC team located in New Jersey, United States, and the Developmental Disabilities Health Centre (DDHC) in Colorado, United States.

Review findings

Review question 1 (part A): What are the aims and characteristics (type, health provider) of interprofessional PHC team services for adults with IDD?

Provider and type of service

Although a range of health providers and interprofessional services were mentioned, the majority of the evidence pertained to the work of physicians, nurse practitioners, nurses, social workers, and mental health providers. The characteristics of the providers, services, and team processes involved in interprofessional PHC for adults with IDD are presented in Appendix III. Provider roles and scope of work is described further below.

Physicians

Physicians across all studies assumed traditional PHC responsibilities including episodic and preventative care, chronic condition management, and care coordination across the health sector. Additionally, in interprofessional PHC teams, physicians were found to conduct joint initial visits with mental health providers,[56,57] conduct joint home visits with nursing,[58] and work as consultants in nurse-practitioner focused models.[28] In the family health team model in Ontario, Canada, patients are typically registered (or enrolled) with a physician, or in some teams a nurse practitioner, and this enables patients' access to available interprofessional PHC team services.[59]

Nurse practitioners

Nurse practitioners with advanced training in mental health and basic neurological services are the core interprofessional team members in the DDHA – health home model for adults with IDD in the state of New Jersey.[28,60,61] In this specialized, community-based model for adults with IDD, patient care is managed through a set of practice guidelines developed for persons with IDD. Nurse practitioners have full diagnostic and treatment capacity, and work to full scope as the main PHC providers, completing additional care coordination activities, including scheduling, lab testing, follow-up, and medication management.[28,60] When additional care is needed, patients can be referred to a consulting physician or mental health providers on the team.[28]

Nurses

Nurses are core members of an interprofessional PHC team and provide a number of PHC services for adults with IDD. Nurses were specifically identified as providing support for annual health reviews (e.g. health check interventions),[58,62] referral tracking, and specialist appointment bookings,[63] as well as working in care manager capacities.[58] Wroth's[58] paper discusses the role of nurse care managers in a community health center program aimed to support frail and elderly people and adults with IDD in group homes in the state of North Carolina, United States. The nurse care managers took on a number of tasks, including identifying these complex patients, working as the lead contact for the homes, liaising with a main PHC provider, and assisting with care plans, health assessments, scheduling, and medication management. The nurses would also complete home and joint visits with the physician and work collaboratively with the team pharmacist to ensure care plans were followed.[58]

Social workers

Social workers were also described as core members of the interprofessional PHC team and often worked with adults with IDD in system navigation roles and case management of complex health and social issues.[29,55,63] Berens and Peacock[63] specifically

outline a description of the role of the social worker in an academic patient medical home and transition clinic for adolescents and adults with IDD in Houston, Texas. This clinic was meant to serve as a transition clinic; however, due to lack of available PHC providers in the community, it evolved into an ongoing patient medical home for adults with IDD. The social worker on this team addressed a wide range of social concerns for this population in regards to overall lack of transition readiness, case management needs, unresolved issues regarding guardianship, vocational possibilities, and insurance/Medicaid system navigation.[63]

Mental health providers

A range of mental health providers were identified (e.g. psychologists, counselors, behavior therapists) as being involved in interprofessional PHC care for adults with IDD. Services provided in this context included psychological and adaptive functioning assessments for school and disability supports,[64] as well as mental health care provision in PHC (e.g. counselling services/supportive psychotherapy, and psycho-education).[64-66] A retrospective chart audit of a South African community health center's counseling psychology service provided a compelling case for the need to embed mental health services in interprofessional PHC teams for adults with IDD.[64] Petersen identified that over a five-year period (1997 to 2001), 42.4% of patients were diagnosed with IDD.[64] The high percentage of patients referred to PHC for assessment for IDD or scholastic challenges was attributed to a lack of available services in the education system. Petersen argued that the community need was beyond the scope of the current PHC mental health nurse and that counseling psychological services were warranted in the care of this population in this context.[64]

Other health providers

Recommendations for the engagement of other health providers in the care of adults with IDD in the PHC context was noted. Health providers such as pharmacists, speech language pathologists, registered dietitians, occupational therapists, and physiotherapists were identified as valuable team members; however, the evidence for their engagement in an interprofessional PHC team context was limited largely to recommendations for their use.[22,62,65,67] Acknowledging that many physicians and patients do not have access to interprofessional health providers in PHC, Green *et al.*[65] called on physicians to advocate for equitable access to expertise in medicine, occupational therapy, speech language therapy, and nursing for adults with IDD, specifically for assistance in the management of behaviors that challenge in this group.

Review question 1 (part B): What are the aims and characteristics (delivery mode, processes) of interprofessional PHC team services for adults with IDD?

Organizational processes

There were a variety of service delivery processes identified by the interprofessional PHC teams in this scoping review. It is important to specifically highlight these processes to further our understanding of the organizational-level interventions employed to engage and integrate interprofessional PHC services in the care of adults with IDD. The identified processes include co-location of providers,[29,57,66] joint visits,[57,58,66] shared electronic medical records,[28] the standardization of service processes across multiple sites,[28] care coordination,[28,29,58] home visits,[28,60] collaborative care processes (e.g. daily rounds),[29,63] and access to a range of interprofessional health services. The Neurobehavioral HOME model provides a detailed example of interprofessional PHC team processes.[29] The team included general practitioners, pediatricians, social workers, advanced practice nurses, and behavioral health providers. Within this team, there was a focus on interprofessional collaboration (via interprofessional case management, daily rounds) to address chronic care management issues, develop care plans, link to community resources, provide system navigation, and offer daily crisis appointments for urgent access. The Neurobehavioral HOME program also described environmental considerations for increasing access, including physical accessibility and co-location of interprofessional PHC services.[29]

Delivery mode: specialty versus generalist interprofessional PHC teams

The interprofessional PHC teams identified in this review represent a range of approaches to PHC provision for adults with IDD. In the United States there are examples of patient medical homes and health homes specifically focused on the PHC of

adults with IDD.[28,29,63] There are also examples of focused programs of care for adults with IDD within general PHC teams, for example, health check in family health teams.[62,68] Finally, there are examples of services within general PHC teams that happen to see a significant percentage of this population within their programs and are recognizing the unique PHC needs of adults with IDD.[64] Beyond patient medical homes, Grier[30] also acknowledged alternative models of PHC delivery and jurisdictions that employ specialist IDD physicians (e.g. Netherlands) and IDD or learning disability nurses (e.g. United Kingdom, Ireland) who work collaboratively with PHC practices to provide health care for adults with IDD.

Review question 2: What types of health or health service outcomes reported in the literature in the implementation of interprofessional PHC team interventions for adults with IDD?

In this scoping review, 10 papers identified outcomes and these are summarized in Appendix IV. Outcomes of interprofessional PHC team services fell into two categories: 1) patient-reported measures (e.g. experience and satisfaction) and 2) health service utilization (e.g. access to services, utilization of emergency departments, and screening). The majority of the studies measured the impact of belonging to an interprofessional PHC team versus usual care or non-team-based PHC. Wroth's work[58] reported on outcomes anecdotally (as identified by administrators) and no formal evaluation mechanisms had been established as of the date of the paper. There was limited information describing the evaluation of services that directly related to a service or intervention explicitly provided by a health provider. Petersen's[64] review of a community health center's counseling service was the only paper to specifically measure use of an interprofessional service within a larger PHC team context. Results from the audit identified that a high percentage of patients using this service over a five-year period (1997 to 2001) had an IDD (42.4%) and, as a result, he advocated there was an increased need for psychological assessment at the PHC level.[64]

The DDHA health home model had the longest and most robust evaluation history spanning 30 years.[28] The benefit of longevity in this interprofessional PHC team model allows for increased opportunities for longitudinal analysis of health service utilization data. In a three-year comparison of the DDHA health home versus usual care (2007 to 2009), Walsh *et al.*[61] found that patients seen in the DDHA model had on average fewer emergency room visits (62% to 79% fewer depending on the year; for example, in 2009, there were 1.92 visits per person for the DDHA group compared to 9.35 visits per person for the usual care group). There was also, on average, fewer inpatient admissions for the DDHA group (68% to 69% fewer depending on the year; for example, in 2009, there were 0.52 admissions per person for the DDHA group compared to 1.67 visits per person for the usual care group).[61] The Neurobehavioral HOME model identified that they reported on similar outcomes including family satisfaction, number of in-patient hospital admissions, average length of stay in hospital, and hospital re-admission rates.[29] Many of the health service outcomes decreased with the implementation of case management in the program (e.g. re-admission rates dropped from 13.8% to 8.6%).[29] Authors also noted that 77% of their patients with IDD met the target of 6.5 or below for their hemoglobin A_{1c}, which is above general state and country proportions of 27.6% and 33%, respectively.[29]

Four studies referenced analyses of secondary data for a population-based cohort of adults with IDD in Ontario, Canada, accessing general interprofessional PHC teams. Health service utilization was described for individuals enrolled with a physician in a family health team versus individuals receiving PHC in other PHC models.[52-55] This work demonstrates that adults with IDD are being supported by interprofessional PHC teams in the province. In addition, it contributes to a population-level understanding of the impact of an interprofessional PHC team approach for adults with IDD on certain health indicators and health services (i.e. periodic health examinations, cancer screening, and chronic disease management). Importantly, researchers found no difference in health service utilization for adults with IDD in family health teams versus other PHC models for periodic health examinations,[53] psychiatric emergency follow-up within 30 days, or hospitalizations for ambulatory-care-sensitive conditions.[52,55] Data for adults with IDD who received preventative cancer screening was also very similar in family health teams versus other PHC models.[55] The proportion of adults with IDD in family health teams as compared to those receiving their PHC in

other models was found to be 36.2% versus 32% for colorectal cancer, 59.7% versus 52.2% for breast cancer, and 36.8% versus 33.7% for cervical cancer, respectively.[55]

Review question 3: What evidence gaps in interprofessional PHC for adults with IDD can be identified?

There were three main evidence gaps identified in this scoping review: i) access to interprofessional PHC teams; ii) processes to engage interprofessional health providers in the care of adults with IDD in PHC teams; and iii) measurement and outcome evaluation.

Access

The scoping review results identified an evidence gap in our understanding of access to, and subsequent use of, interprofessional PHC services by adults with IDD. What is known is that there continues to be a significant challenge in access to interprofessional PHC teams, particularly in the Canadian context.[54,65] Although similar to the general population, only 20% of adults with IDD were accessing family health teams in Ontario, the most prominent model of interprofessional PHC in the province.[54] There was also a recognition that many physicians and patients do not readily have access to publicly funded, interprofessional PHC services, which creates a challenge in providing equitable care and enacting a team approach.[22,65] Williams and Ervin[66] identify concerns with access to appropriate mental health services in PHC and challenges with the integration of mental health and physical health services in interprofessional PHC teams. They cite that challenges are a result of both remuneration systems, as well as culture.[66] A greater understanding of this population's access to interprofessional PHC teams and services would be of value to target interventions and engagement of a wide range of health providers in these teams.

Organizational processes

There is limited understanding of organizational and health-provider-level processes in interprofessional PHC team settings, as it relates to the provision of interprofessional PHC for adults with IDD. A study by Durbin *et al.*,[68] although not specifically describing health provider roles or services, makes an important contribution to this scoping review. Durbin's research group worked with two family health teams in Ontario to complete a process evaluation of the implementation of health checks for adults with IDD.[68] The authors explicitly identified attempts to engage in an interprofessional team approach to complete health checks as per national guidelines.[22] However, the authors noted additional logistical challenges associated with having the most appropriate health providers available, as well as subsequent scheduling challenges and anticipated patient burden (e.g. increased length of appointments, multiple appointments).[68] Durbin and colleagues are among the first to explicitly identify a gap in health-provider engagement and recognize that collaborative processes are still developing within this model of interprofessional, team-based PHC.[68]

Measurement and outcome evaluation

A final gap identified in this scoping review was organizational performance measurement and evaluation of an interprofessional PHC approach for adults with IDD. In some cases, interprofessional PHC teams recognized a need for evaluation (e.g. patient satisfaction, quality of care, cost-savings of model); however, they had not set up formal evaluation mechanisms.[58,63] The evidence available focuses largely on the impact of belonging to an interprofessional PHC team versus non-team PHC. There was limited description, and consequently evaluation, of a range of health provider services in interprofessional PHC teams. To assess the value of access to interprofessional PHC, there is a need to move beyond patient enrollment in a team alone to measuring the impact and value of interprofessional PHC services. There is also a recognition of the need to evaluate care in other available models of interprofessional PHC such as community health centers and nurse practitioner-led clinics.[54]

Discussion

This scoping review was intended to specifically map the available evidence for interprofessional PHC for adults with IDD, a recommended approach to PHC delivery for this population.[22] It is the first review to focus on describing the aims and characteristics, outcomes and evidence gaps in interprofessional PHC for adults with IDD. To date, results have been limited and heterogeneous. Despite the global search strategy, very few results were obtained overall with 20 references identified, mainly consisting of work

based in the United States and Canada. The findings represent only a few distinct organizational models (e.g. patient medical home, health homes and community health centers) and multiple contributions from a smaller pool of established researchers within the field. The evidence currently available is largely observational and descriptive in nature including cross-sectional designs, program descriptions, and clinical reviews.

As noted, characteristics of interprofessional services were described primarily for physicians, nursing, mental health, and social work. The nursing profession is well established in interprofessional PHC teams.[69] Given the long-standing history of nursing in PHC and the development of advanced nursing roles, it is not surprising to find that nurses are actively contributing to the care of adults with IDD in interprofessional PHC teams. Services provided by nurse practitioners and nurses appear to reflect a broad scope of PHC provision, which includes episodic care, preventative care, chronic disease management, as well as ongoing care management/co-ordination.[69] Access to a nurse practitioner (as illustrated in the DDHA health home model in the United States) has demonstrated a decrease in emergency room visits and shorter inpatient admissions for this population.[61] This is one of the few studies that identifies the impact of the interprofessional PHC team health providers on health service utilization for adults with IDD.

The engagement of mental health providers and social work within interprofessional PHC teams is appropriate given a high prevalence of mental health conditions in this population[11] and known challenges with access to appropriate services across health and social sectors.[7] These health professions provide services that address medical and social complexity through a comprehensive, integrated care approach that encompasses the broad social determinants of health.[70] Although the results of this scoping review indicated clear roles for both social work and mental health providers on the interprofessional PHC team, social workers on generalist interprofessional PHC teams continue to face challenges with role clarity, inappropriate referrals, and a lack of prioritization of psychosocial and mental health concerns.[70] This has implications for adults with IDD that access generalist interprofessional PHC teams, as social workers may or may not be readily engaged in the care of this group. As teams expand to include other health providers, further examination of how additional health professions could contribute to the care of adults with IDD is warranted.

Few studies identified outcomes and overall there was no consistent reporting of outcomes across studies. Patient satisfaction via practice surveys appears to be the main patient-reported outcome measure used and its use was limited. Further development of accessible patient-reported outcome measures to capture the experiences of this group and embed them into standard care processes is warranted. Greater use of these measures could function to address issues of equity as well as appropriately tailor PHC services. There were no studies included that directly measured changes in physical or mental health outcomes; however, these may be being routinely captured through condition-specific programs of care (e.g. diabetes mellitus management, lung health) versus directly identified as outcomes of interest for this population. This would be particularly relevant in generalist PHC teams that do not specialize in care for this population. Health care utilization outcomes were the most prevalent, with key measures identified as access to care including preventive care, emergency department use, and inpatient admissions (e.g. average length of stay).

An identified gap is that outcomes related to health providers in interprofessional PHC teams, beyond physicians, are not regularly being captured. There were limited outcomes reported that could be directly attributed to a particular health provider intervention or service. As noted from the study in Ontario using secondary data, information on interprofessional PHC services could not be obtained with the available practice level data[52-55] and, consequently, it is not known whether an interprofessional team was involved in care. It is possible that individuals enrolled in an interprofessional PHC team could not be accessing any interprofessional services despite recommendations and perceived potential benefits of this approach for this population. The research from Ontario also demonstrated that there were no differences in health services utilization based on family health team involvement and calls into question the value of the approach in improving the health of adults with IDD. The current ability to describe and measure the impact and involvement of interprofessional PHC services becomes more important in light of this work and

future research should attempt to address the contributions of a range of health providers within these teams.

Although there is support for the approach at a policy and practice level, the concept of interprofessional PHC for this population remains understudied. It is challenged by differences in PHC access across the world, complexity in how the field is defined and funded, as well as a lack of consistent reporting of organizational attributes (e.g. structures, composition, and processes of interprofessional PHC provision). In this review interprofessional PHC included services provided within established team models of care within the United States and Canadian contexts. It is important to note that interprofessional PHC teams are not unique to North America. Within the United Kingdom specifically, the existence and value of various team compositions within PHC is acknowledged;[71] however, information on the organizational attributes of these PHC teams is not well documented in the available literature (e.g. team compositions and processes of care) and as such has been identified as a challenge in this review.

During the process of this review the existence of specialist teams and health services for this population were identified. In the United States, specific patient medical homes or health homes are being established to support adults with IDD and address health needs not being met through generalist PHC practice. In Australia, a specialist interprofessional team provides consultative services for physicians in the care of this group (e.g. Center for Developmental Disability Health).[72] In addition, the United Kingdom, Australia, New Zealand, and Ireland have recognized nursing designations in the field of IDD that include learning disability nurses (United Kingdom),[73,74] registered nurses – developmental disability (Australia, New Zealand),[75] and intellectual disability clinical nurse specialists (Ireland).[76] These professionals provide health services to individuals with IDD and their families, and often perform various primary, secondary, and tertiary prevention tasks (e.g. episodic and preventative care, assessment, health facilitation, education).[73,74]

In the United Kingdom and Ireland, IDD/learning disability health providers work in many capacities within uni- or multi-professional learning disability teams or in health facilitator roles to support the health of adults with IDD alongside the physician and PHC team.[77] A large part of the role of these specialized interprofessional services appears to be to improve care for this group by bridging health and social sectors, supporting general practices, fostering collaboration, and informally or formally facilitating access to health care for adults with IDD.[74,77-79] Although in the United Kingdom and Ireland PHC teams may collaborate and/or have an IDD/learning disability health provider on the team, it does not appear to be standard practice, and the services of these IDD/learning disability health providers were largely seen as specialist services distinct from the PHC team.[77] Although different approaches exist in these countries, a shared overall aim to support the unique health care needs of this group is recognized. An outstanding question is whether the care needs of adults with IDD are best met through specialized IDD interprofessional PHC teams, collaboration between (or access to) specialist IDD/learning disability teams and general PHC teams, or with generalist interprofessional PHC teams. There is no doubt there is much to learn from all these approaches as we continue to work to support the health and quality of life of all adults with IDD.

Limitations

This scoping review aimed to map available evidence for interprofessional PHC for adults with IDD. As acknowledged, variability in PHC delivery and PHC team composition across contexts and countries, a lack of accepted terminology, and the relatively unexplored role of many health providers within interprofessional PHC settings was a challenge in identifying relevant work. The lack of consistent reporting of organizational attributes of interprofessional PHC models (e.g. team composition and contribution of health providers) may have also led to exclusion of important interprofessional contributions within these PHC teams. Given the heterogeneous results, data could only be descriptive in nature and present the range of evidence on the topic. Studies included in the review ranged from 2000 to 2019 only and were limited to English- and French-language studies. As per the scoping review methodology, this review did not assess the quality of the included studies.

Conclusion

This scoping review is the first to map the current state of the evidence regarding interprofessional PHC for adults with IDD. Although descriptive in

nature, the results do serve to demonstrate that progress is being made to describe and evaluate care for this vulnerable group within interprofessional PHC teams. Nevertheless, it is clear that further work is required to demonstrate that quality, comprehensive, and coordinated interprofessional PHC for adults with IDD is occurring.

Recommendations for research

Further research is needed to understand the impact of an interprofessional approach to PHC, and the specific contribution of a range of health providers to health outcomes for complex and under-served populations, such as adults with IDD, who are thought to benefit from interprofessional PHC. To fully realize the value of this approach, research at the health services level is needed that includes greater description of interprofessional PHC processes, services, and programs of care beyond health service utilization outcomes. Once interprofessional services that are valued by health providers and patients can be identified, they can start to be measured through organizational processes such as quality improvement plans. There is a robust evidence base regarding the health needs of adults with IDD and research is needed in the PHC context to pilot and evaluate targeted interprofessional services for this group, including interventions for mobility, falls prevention, chronic disease self-management, and healthy aging. Engaging in this work will ultimately help to inform the field, provide a more fulsome evidence base for an interprofessional approach to PHC delivery for adults with IDD, and improve the health of adults with IDD.

Acknowledgments

Emily Weatherbed, MSc.OT candidate, and Jane Duggan, MSc.OT candidate, contributed to the development of the protocol and with the identification and extraction of the papers.

This scoping review is part of the primary author's (NB) doctoral work and will contribute towards a PhD in Rehabilitation Science at Queen's University, Kingston, Canada.

Funding

Funding was provided by Queen's University to support the doctoral work of the primary author (NB).

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Appendix I: Search strategy

AMED (Allied and Complementary Medicine) <1985 to August 2018>

Date searched: 8 August 2018

1 disabled/ (1803)
2 mental retardation/ (2414)
3 ((intellectual$ or development$ or mental$) adj3 disab$).ab,ti. (4021)
4 (learn$ adj3 (disab$ or disorder$)).ab,ti. (2209)
5 "neurodevelopmental disorder".ab,ti. (18)
6 IDD.ab,ti. (20)
7 1 or 2 or 3 or 4 or 5 or 6 (8938)
8 exp patient care team/ or primary health care/ or "continuity of patient care"/ (2561)
9 ((interprofessional$ or inter-professional$) adj2 (care or team$)).ab,ti. (97)
10 ((multidisciplinary or multi-disciplinary) adj2 (care or team$)).ab,ti. (698)
11 ((Team-based or team) adj2 (care or practice)).ab,ti. (615)
12 (primary adj3 care).ab,ti. (2392)
13 (person adj3 care).ab,ti. (207)
14 "continuity of patient care"/ or transition to adult care/ (205)
15 Community Health Services/ (1906)
16 (health care adj3 utiliz$).ab,ti. (175)
17 or/8-16 (7354)
18 7 and 17 (313)
19 limit 18 to yr="2000 -Current" (217)
20 limit 19 to (English or French) (217)

Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R) <1946 to July 5, 2018>

Date searched: 5 July 2018

1 disabled persons/ or mentally disabled persons/ (41,737)
2 exp Intellectual Disability/ (9,0628)
3 ((intellectual$ or development$ or mental$) adj3 disab$).ab,ti. (22,324)
4 (learn$ adj3 (disab$ or disorder$)).ab,ti. (10,327)
5 "neurodevelopmental disorder".ab,ti. (2899)

6 IDD.ab,ti. (1646)
7 1 or 2 or 3 or 4 or 5 or 6 (152,457)
8 Patient Care Team/ (60,683)
9 ((interprofessional$ or inter-professional$) adj2 (care or team$)).ab,ti. (2033)
10 ((multidisciplinary or multi-disciplinary) adj2 (care or team$)).ab,ti. (20,551)
11 ((Team-based or team) adj2 (care or practice)).ab,ti. (9739)
12 8 or 9 or 10 or 11 (84,419)
13 Primary Health Care/ (68,301)
14 (primary adj3 care).ab,ti. (119,659)
15 (person adj3 care).ab,ti. (2507)
16 13 or 14 or 15 (144,042)
17 7 and 12 and 16 (94)

EBM Reviews - Cochrane Database of Systematic Reviews <2005 to August 8, 2018>

Date searched: 8 August 2018

1 "disabled persons".ab,ti. (1)
2 (Intellectual$ adj3 disab$).mp. [mp=title, abstract, full text, keywords, caption text] (130)
3 ((intellectual$ or development$ or mental$) adj3 disab$).ab,ti. (39)
4 (learn$ adj3 (disab$ or disorder$)).ab,ti. (9)
5 "neurodevelopmental disorder".ab,ti. (4)
6 IDD.ab,ti. (1)
7 1 or 2 or 3 or 4 or 5 or 6 (158)
8 "Patient Care Team".ab,ti. (0)
9 ((interprofessional$ or inter-professional$) adj2 (care or team$)).ab,ti. (1)
10 ((multidisciplinary or multi-disciplinary) adj2 (care or team$)).ab,ti. (21)
11 ((Team-based or team) adj2 (care or practice)).ab,ti. (2)
12 "Primary Health Care".ab,ti. (8)
13 (primary adj3 care).ab,ti. (184)
14 (person adj3 care).ab,ti. (6)
15 "continuity of patient care".ab,ti. (0)
16 "Community Health Services".ab,ti. (0)

17 (health care adj3 utiliz$).ab,ti. (7)
18 or/8-17 (215)
19 7 and 18 (7)
20 limit 19 to yr="2000 -Current" (6)

Global Health <1973 to 2018 Week 32>

Date searched: 8 August 2018

1 people with disabilities/ or people with mental disabilities/ or people with physical disabilities/ (3773)
2 mental retardation/ (1047)
3 ((intellectual$ or development$ or mental$) adj3 disab$).ab,ti. (1636)
4 (learn$ adj3 (disab$ or disorder$)).ab,ti. (464)
5 "neurodevelopmental disorder".ab,ti. (152)
6 IDD.ab,ti. (575)
7 1 or 2 or 3 or 4 or 5 or 6 (6819)
8 "Patient Care Team".ab,ti. (13)
9 ((interprofessional$ or inter-professional$) adj2 (care or team$)).ab,ti. (88)
10 ((multidisciplinary or multi-disciplinary) adj2 (care or team$)).ab,ti. (1801)
11 ((Team-based or team) adj2 (care or practice)).ab,ti. (640)
12 primary health care/ (10,735)
13 (primary adj3 care).ab,ti. (22,324)
14 (person adj3 care).ab,ti. (202)
15 ("continuity of patient care" or "transition to adult care").mp. [mp=abstract, title, original title, broad terms, heading words, identifiers, cabicodes] (78)
16 "Community Health Services".mp. [mp=abstract, title, original title, broad terms, heading words, identifiers, cabicodes] (3450)
17 (health care adj3 utiliz$).ab,ti. (1886)
18 or/8-17 (30,466)
19 7 and 18 (189)
20 limit 19 to yr="2000 -Current" (175)
21 limit 20 to (english or french) (161)

Ovid Emcare <1995 to 2018 week 31>

Date searched: 3 August 2018

1 "disabled persons".ab,ti. (673)
2 (Intellectual$ adj3 disab$).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] (9793)
3 ((intellectual$ or development$ or mental$) adj3 disab$).ab,ti. (14,389)
4 (learn$ adj3 (disab$ or disorder$)).ab,ti. (6599)
5 "neurodevelopmental disorder".ab,ti. (719)
6 IDD.ab,ti. (573)
7 1 or 2 or 3 or 4 or 5 or 6 (22,174)
8 "Patient Care Team".ab,ti. (102)
9 ((interprofessional$ or inter-professional$) adj2 (care or team$)).ab,ti. (1542)
10 ((multidisciplinary or multi-disciplinary) adj2 (care or team$)).ab,ti. (11,457)
11 ((Team-based or team) adj2 (care or practice)).ab,ti. (6292)
12 "Primary Health Care".ab,ti. (9538)
13 (primary adj3 care).ab,ti. (69,585)
14 (person adj3 care).ab,ti. (1836)
15 "continuity of patient care".ab,ti. (132)
16 "Community Health Services".ab,ti. (343)
17 (health care adj3 utiliz$).ab,ti. (5125)
18 or/8-17 (92,266)
19 7 and 18 (598)
20 limit 19 to yr="2000 -Current" (526)
21 limit 20 to (adult <18 to 64 years> or aged <65+ years>) (210)
22 limit 21 to (English or French) (205)

********** Only used keywords, NO indexed terms.

Embase <1974 to August 15, 2018 >

Date searched: 15 August 2018

1 disabled person/ or physically disabled person/ (27,758)
2 mentally disabled person/ (441)
3 ((intellectual$ or development$ or mental$) adj3 disab$).ab,ti. (28,000)
4 (learn$ adj3 (disab$ or disorder$)).ab,ti. (13,136)
5 "neurodevelopmental disorder".ab,ti. (3479)
6 IDD.ab,ti. (2108)
7 1 or 2 or 3 or 4 or 5 or 6 (71,625)
8 patient care/ or case management/ or patient care planning/ (280,399)
9 ((interprofessional$ or inter-professional$) adj2 (care or team$)).ab,ti. (2918)
10 ((multidisciplinary or multi-disciplinary) adj2 (care or team$)).ab,ti. (35,240)
11 ((Team-based or team) adj2 (care or practice)).ab,ti. (14,632)
12 primary health care/ or primary medical care/ (142,412)
13 (primary adj3 care).ab,ti. (152,541)
14 (person adj3 care).ab,ti. (2892)
15 transition to adult care/ (1163)
16 community care/ or community based rehabilitation/ or community health nursing/ or community integration/ or community program/ (74,066)
17 (health care adj3 utiliz$).ab,ti. (11,919)
18 or/8-17 (571,049)
19 7 and 18 (4337)
20 limit 19 to yr="2000 -Current" (3156)
21 limit 20 to (adult <18 to 64 years> or aged <65+ years>) (1321)
22 limit 21 to (english or french) (1274)
23 from 22 keep 1-1274 (1274)
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JBI EBP Database - <Current to August 8, 2018>

Date searched: 8 August 2018

1 "disabled persons".af. (5)
2 (Intellectual$ adj3 disab$).af. (47)
3 ((intellectual$ or development$ or mental$) adj3 disab$).af. (107)
4 (learn$ adj3 (disab$ or disorder$)).af. (41)
5 "neurodevelopmental disorder".af. (4)
6 IDD.af. (1)
7 1 or 2 or 3 or 4 or 5 or 6 (138)
8 "Patient Care Team".af. (22)
9 ((interprofessional$ or inter-professional$) adj2 (care or team$)).af. (33)
10 ((multidisciplinary or multi-disciplinary) adj2 (care or team$)).af. (378)
11 ((Team-based or team) adj2 (care or practice)).af. (201)
12 "Primary Health Care".af. (189)
13 (primary adj3 care).af. (853)
14 (person adj3 care).af. (116)
15 "continuity of patient care".af. (19)
16 "Community Health Services".af. (17)
17 (health care adj3 utiliz$).af. (65)
18 or/8-17 (1260)
19 7 and 18 (43)
20 limit 19 to yr="2000 -Current" (43)
21 from 20 keep 1-43 (43)

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CINAHL (EBSCOhost)

Date searched: 20 August 2018

#	Query	Limiters/expanders	Last run via	Results
S1	(MH "Mentally Disabled Persons") OR (MH "Disabled")	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	24,860

(*Continued*)

#	Query	Limiters/expanders	Last run via	Results
S2	(MH "Intellectual Disability")	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	11,507
S3	(intellectual* OR development* OR mental*) N3 disab*	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	21,585
S4	learn* N3 (disab* OR disorder*)	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	9102
S5	"neurodevelopmental disorder"	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	233
S6	IDD	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	224
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	47,644
S8	(MH "Multidisciplinary Care Team")	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	28,504
S9	(interprofessional* OR inter-professional*) N2 (care OR team*)	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	1725
S10	(multidisciplinary OR multi-disciplinary) N2 (care OR team*)	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	33,263
S11	(team-based OR team) N2 (care OR practice)	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	34,845
S12	(MH "Primary Health Care")	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	38,555

(*Continued*)

#	Query	Limiters/expanders	Last run via	Results
S13	primary N3 care	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	64,216
S14	(MH "Continuity of Patient Care")	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	9250
S15	(MH "Community Health Services") OR (MH "Community Mental Health Services")	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	20,744
S16	health care N3 utiliz*	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	6751
S17	person N3 care	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen – Advanced Search	4959
S18	S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	134,384
S19	S7 AND S18	Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	2578
S20	S7 AND S18	Limiters - Published Date: 20000101-20181231 Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	2112
S21	S7 AND S18	Limiters - Published Date: 20000101-20181231; Age Groups: All Adult Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	783
S22	S7 AND S18	Limiters - Published Date: 20000101-20181231; Age Groups: All Adult; Language: English, French Expanders - Apply related words Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database – CINAHL	764

Appendix II: Studies ineligible following full-text review

1.	Smallman S, Engel B, Nelson J. Obesity services for adults with learning disabilities. J Hum Nutr Diet. 2011;24(3):304-5. *Reason for exclusion:* ineligible concept
2.	Brown M, MacArthur J, McKechanie A, Mack S, Hayes M, Fletcher J. Learning disability liaison nursing services in south-east Scotland: a mixed-methods impact and outcome study. J= Intellect Disabil Res. 2012;56(12):1161-74. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services.
3.	Powrie E. Caring for adults with a learning disability in the community. Br J Nurs. 2001;10(14):928-34. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services
4.	Davies N, Duff M. Breast cancer screening for older women with intellectual disability living in community group homes. J Intellect Disabil Res. 2001;45(3):253-7. *Reason for exclusion:* ineligible concept
5.	Mitchell D. Learning disability nursing. Br J Learn Disabil. 2004;32(3):115-18. *Reason for exclusion:* ineligible context
6.	Harrison S. Improving primary care services for people with learning disability. Practice. 2005;101(1):38-40. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services.
7.	Marriott A, Turner S, Ashby S, Rees D. Cancer screening for people with learning disabilities and the role of the screening liaison nurse. Tizard Learn Disabil Rev. 2015;20(4):239-46. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services.
8.	Loughran S, O'Brien D. Epilepsy liaison nursing. Nurs Times. 2002;98(10):32-4. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services.
9.	Nicholson L, Cooper SA. Access to healthcare services by people with intellectual disabilities: a rural-urban comparison. J Intellect Disabil. 2011;15(2):115-30. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services.
10.	Taggart L, Truesdale-Kennedy M, Scott J, Working with people with people with intellectual and developmental disabilities who have diabetes. J Diabetes Nurs. 2015;19(5):190-4. *Reason for exclusion:* ineligible concept
11.	Taggart L, Coates V, Truesdale-Kennedy M. Management and quality indicators of diabetes mellitus in people with intellectual disabilities. J Intellect Disabil Research. 2013;57(12):1152-63. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHCT services.

12.	Lewer A, Harding C. Communication is the key: improving outcomes for people with learning disabilities. Tizard Learn Disabil Rev. 2013;18(3):132-40. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services.
13.	Lewis SA. A nurse-led clinic for adults with epilepsy and learning disability experiencing prolonged and/or repeated tonic-clonic seizures in the community to reduce risk of status epilepticus and the risk of sudden unexpected death in epilepsy (SUDEP). Epilepsia. 2010;51(Suppl.4):13. *Reason for exclusion:* ineligible context
14.	Hames A, Carlson T. Are primary health care staff aware of the role of community learning disability teams in relation to health promotion and health facilitation? Br J Learn Disabil. 2006;34(1):6-10. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services.
15.	Doody O, Slevin E, Taggart L. Focus group interviews examining the contribution of intellectual disability clinical nurse specialists in Ireland. J Clin Nurs. 2017;26(19-20):2964-75. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services.
16.	Doody O, Slevin E, Taggart L. Activities of intellectual disability clinical nurse specialists in Ireland. Clin Nurs Spec. 2017;31(2):89-96. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services.
17.	Dosen A. Integrative treatment in persons with intellectual disability and mental health problems. J Intellect Disabil Res. 2007;51(1):66-74. *Reason for exclusion:* ineligible context
18.	Slevin E, McConkey R, Truesdale-Kennedy M, Barr O, Taggart L. Community learning disability teams: perceived effectiveness, multidisciplinary working and service user satisfaction. J Intellect Disabil. 2007;11(4):329-42. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services.
19.	Northway R, Edwards J. Helping a person with autism to overcome her fear of needles. Prim Health Care. 2011;21(10). *Reason for exclusion:* ineligible concept. Focus on specialist teams/services in collaboration with PHC services.
20.	Biswas AB, Vahabzadeh A, Hobbs T, Healy JM. Obesity in people with learning disabilities: possible causes and reduction interventions. Nurs Times. 2010;106(31):16-18 *Reason for exclusion:* ineligible concept. Focus on specialist teams/services.
21.	Escribano Hernández A, Hernández Corral T, Ruiz Martín E, Porteros Sánchez JA. Results of a dental care protocol for mentally handicapped patients set in a primary health care area in Spain. Med Oral, Patol Oral Cir Bucal. 2007;12(7):492-5. *Reason for exclusion:* ineligible concept
22.	Young AF, Chesson RA, Wilson AJ. People with learning disabilities, carers and care workers awareness of health risks and implications for primary care. Fam Practice. 2007;24(6):576-84. *Reason for exclusion:* ineligible concept

23.	Rajpura A, Sethi S. Evidence-based standards of care for adults with epilepsy—a literature review. Seizure. 2004;13(1):45-54. *Reason for exclusion:* ineligible concept. Focus on specialist teams/services.
24.	Reichard A, Turnbull HR. Perspectives of physicians, families, and case managers concerning access to health care by individuals with developmental disabilities. Ment Retard. 2004;42(3):181-94. *Reason for exclusion:* ineligible concept
25.	Balogh RS, Lake JK, Lin E, Wilton A, Lunsky Y. Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. Diabet Med. 2015;32(2):235-42. *Reason for exclusion:* ineligible concept
26.	Bergström H, Hagströmer M, Hagberg J, Elinder LS. A multi-component universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: a cluster randomised controlled trial. Res Dev Disabil. 2013;34(11):3847-57. *Reason for exclusion:* ineligible context
27.	Bershadsky J, Taub S, Engler J, Moseley CR, Lakin KC, Stancliffe RJ,*et al.* Place of residence and preventive health care for intellectual and developmental disabilities services recipients in 20 states. Public Health Rep. 2012;127(5):475-85. *Reason for exclusion:* ineligible concept
28.	Bradley VJ. Changes in services and supports for people with developmental disabilities: new challenges to established practice. Health Soc Work. 2000;25(3):191. *Reason for exclusion:* ineligible context
29.	Brolan CE, Ware RS, Lennox NG, Gomez MT, Kay M, Hill PS. Invisible populations: parallels between the health of people with intellectual disability and people of a refugee background. Aust J Prim Health. 2011;17(3):210-3 *Reason for exclusion:* ineligible concept
30.	Brown M, Chouliara Z, MacArthur J, McKechanie A, Mack S, Hayes M, *et al.* The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person-centred care. J Clin Nurs. 2016;25(7-8):972-82. *Reason for exclusion:* ineligible context
31.	Burton H, Walters L. Access to medicare-funded annual comprehensive health assessments for rural people with intellectual disability. Rural Remote Health. 2013;13(3):2278. *Reason for exclusion:* ineligible concept
32.	Doody CM, Markey K, Doody O. The experiences of registered intellectual disability nurses caring for the older person with intellectual disability. J Clin Nurs. 2013;22(7-8):1112-23. *Reason for exclusion:* ineligible context
33.	Moriconi C, Schlamb C, Harrison B. Down syndrome and dementia: guide to identification, screening, and management. J Nurse Pract. 2015;11(8):812-18. *Reason for exclusion:* ineligible concept

34.	Tyler CV, Zyzanski SJ, Panaite V, Council L. Nursing perspectives on cancer screening in adults with intellectual and other developmental disabilities. Intellect Dev Disabil. 2010;48(4):271-7. *Reason for exclusion:* ineligible context
35.	Camfield PR, Bahi-Buisson N, Trinka E. Transition issues for children with diffuse cortical malformations, multifocal postnatal lesions, (infectious and traumatic) and Lennox–Gastaut and similar syndromes. Epilepsia. 2014; 55:24-8. *Reason for exclusion:* ineligible population
36.	Carey IM, Hosking FJ, Harris T, DeWilde S, Beighton C, Shah SM, *et al.* Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment. J Epidemiol Community Health. 2017;71(1):52-8. *Reason for exclusion:* ineligible concept
37.	Carlson T, Hyde S, Hames A. Lifespan or separate: which service is best? How should service providers respond to people needing support as they enter adulthood? Learn Disabil Pract. 2003;6(10):16-22. *Reason for exclusion:* ineligible concept
38.	Carnaby S, Roberts B, Lang J, Nielsen P. A flexible response: person-centred support and social inclusion for people with learning disabilities and challenging behaviour. Br J Learn Disabil. 2011;39(1):39-45. *Reason for exclusion:* ineligible context
39.	Christopher R, Horsley S. An evaluation of a behavioural support team for adults with a learning disability and behaviours that challenge from a multi-agency perspective. Br J Learn Disabil. 2016;44(3):194-203. *Reason for exclusion:* ineligible context
40.	Clark A, Browne S, Boardman L, Hewitt L, Light S. Implementing UK autism policy & national institute for health and care excellence guidance-assessing the impact of autism training for frontline staff in community learning disabilities teams. Br J Learn Disabil. 2016;44(2):103-10. *Reason for exclusion:* ineligible concept
41.	Cook A, Lennox N. General practice registrars' care of people with intellectual disabilities. J Intellect Dev Disabil. 2000;25(1):69-77 *Reason for exclusion:* ineligible concept
42.	Courtney-Long EA, Stevens AC, Carroll DD, Griffin-Blake S, Omura JD, Carlson SA. Primary care providers' level of preparedness for recommending physical activity to adults with disabilities. Prev Chronic Dis. 2017;14(E114). *Reason for exclusion:* ineligible concept
43.	Felce D, Baxter H, Lowe K, Dunstan F, Houston H, Jones G, *et al.* The impact of checking the health of adults with intellectual disabilities on primary care consultation rates, health promotion and contact with specialists. J Appl Res Intellect Disabil. 2008;21(6):597-602. *Reason for exclusion:* ineligible concept

44.	McLaughlin D, Barr O, McIlfatrick S, McConkey R. Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: a mixed methods study. Palliat Med. 2014;28(10):1213-21. *Reason for exclusion:* ineligible concept. Focus on collaboration with teams outside of primary care.
45.	Osborn DP, Horsfall L, Hassiotis A, Petersen I, Walters K, Nazareth I. Access to cancer screening in people with learning disabilities in the UK: cohort study in the health improvement network, a primary care research database. PLoS One. 2012;7(8):e43841. *Reason for exclusion:* ineligible concept
46.	Danquah A, Limb K, Chapman M, Burke C, Flood A, Gore S, *et al*. An investigation of factors predictive of continued self-injurious behaviour in an intellectual disability service. J Appl Re Intellect Disabil. 2009;22(4):395-9. *Reason for exclusion:* ineligible context
47.	Bakker-van Gijssel EJ, Lucassen PL, Hartman TO, Van Son L, Assendelft WJ, van Schrojenstein Lantman-de Valk HM. Health assessment instruments for people with intellectual disabilities – a systematic review. Res Dev Disabil. 2017;64:12-24. *Reason for exclusion:* ineligible concept
48.	Evans F. Non-aversive care of people on the autism spectrum. Learn Disabil Pract. 2014;17(5). *Reason for exclusion:* ineligible context
49.	Smith G, Ouellette-Kuntz H, Green M. Comprehensive preventive care assessments for adults with intellectual and developmental disabilities: Part 2: 2003 to 2014. Can Fam Physician. 2019;65(Suppl 1):S53-8. *Reason for exclusion:* ineligible concept
50.	Smith G, Ouellette-Kuntz H, Green M. Comprehensive preventive care assessments for adults with intellectual and developmental disabilities: Part 1: How do we know if it is happening? Can Fam Physician. 2018;64(Suppl 2):S57-62. *Reason for exclusion:* ineligible concept
51.	Krahn GL, Drum CE. Translating policy principles into practice to improve health care access for adults with intellectual disabilities: a research review of the past decade. Ment Retard Dev Disabil Res Rev. 2007;13(2):160-8. *Reason for exclusion:* ineligible concept
52.	Grimby G. Focused multidisciplinary services for young people with disabilities. Lancet. 2002;360(9342):1264-5. *Reason for exclusion:* ineligible population
53.	Baxter H, Lowe K, Houston H, Jones G, Felce D, Kerr M. Previously unidentified morbidity in patients with intellectual disability. Br J Gen Pract. 2006;56(523):93-8. *Reason for exclusion:* ineligible concept
54.	Hackerman F, Schmidt CW, Dyson CD, Hovermale L, Gallucci G. Developing a model psychiatric treatment program for patients with intellectual disability in a community mental health center. Community Ment Health J. 2006;42(1):13-24. *Reason for exclusion:* ineligible context

55.	Hall T, Kriz D, Duvall S, Nguyen-Driver M, Duffield T. Healthcare transition challenges faced by young adults with autism spectrum disorder. Clin Pharmacol Ther. 2015;98(6):573-5. *Reason for exclusion:* ineligible concept
56.	Hallawell B. Issues emerging from the London learning disability plan. Br J Nurs. 2001;10(3):173-8. *Reason for exclusion:* ineligible concept
57.	Heutmekers M, Naaldenberg J, Frankena TK, Smits M, Leusink GL, Assendelft WJ, *et al.* After-hours primary care for people with intellectual disabilities in the Netherlands—current arrangements and challenges. Res Dev Disabil. 2016;59:1-7. *Reason for exclusion:* ineligible concept
58.	Heyman B, Swain J, Gillman M. Organisational simplification and secondary complexity in health services for adults with learning disabilities. Soc Sci Med. 2004;58(2):357-67. *Reason for exclusion:* ineligible concept
59.	Iacono T, Humphreys J, Davis R, Chandler N. Health care service provision for country people with developmental disability: an Australian perspective. Res Dev Disabil. 2004;25(3):265-84. *Reason for exclusion:* ineligible concept
60.	Lin JD, Yen CF, Loh CH, Hsu SW, Huang HC, Tang CC, *et al.* A cross-sectional study of the characteristics and determinants of emergency care utilization among people with intellectual disabilities in Taiwan. Res Dev Disabil. 2006;27(6):657-67. *Reason for exclusion:* ineligible context
61.	Lin JD, Yen CF, Li CW, Wu JL. Health, healthcare utilization and psychiatric disorder in people with intellectual disability in Taiwan. J Intellect Disabil Res. 2005;49(1):86-94. *Reason for exclusion:* ineligible concept
62.	Hall J, Starrett B. Assessing the health care needs of Kansas' young adults with disabilities. Kans Nurse.2007;82(7):5-7 *Reason for exclusion:* ineligible context
63.	Watson JM, McDonnell V, Bhaumik S. Valuing people: evaluating referral systems. A study of a multidisciplinary single point of referral system to dedicated adult learning disability health services in Leicester, UK. Br J Dev Disabil. 2005;51(101):155-70. *Reason for exclusion:* ineligible context
64.	MacArthur J, Brown M, McKechanie A, Mack S, Hayes M, Fletcher J. Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'getting it right' for people with learning disabilities receiving general hospitals care. J Adv Nurs. 2015;71(7):1552-63. *Reason for exclusion:* ineligible context
65.	Owens J, Dyer TA, Mistry K. People with learning disabilities and specialist services. Br Dent J. 2010;208(5):203. *Reason for exclusion:* ineligible concept

66.	Jackett JM. Transition and beyond for individuals with autism spectrum disorders (ASDS): A New Jersey case study of the adult service sector, its inherent shortcomings, and hope for the future. Seton Hall Law Rev. 2010;40(4):1733-74. *Reason for exclusion:* ineligible context
67.	Janlöv AC, Ainalem I, Andersson AC, Berg A. An improvement program as a way to intensify inter-professional collaboration in the community for people with mental disabilities: a follow-up. Issues Ment Health Nurs. 2016;37(12):885-93. *Reason for exclusion:* ineligible population
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Appendix III: Characteristics of included studies

Author /year	Country	Study design	Purpose	Population	Description of concept	Interprofessional PHC interventions	Impressions/significant findings
Balogh *et al.*[54]	CAN	Observational cross-sectional	Examine chronic disease management in Ontario via four indicators of chronic disease management.	H-CARDD Cohort Ages: 18-64 years Total: 66,484 M: 38,090 W: 28,394	Access to tertiary prevention, specifically chronic disease management for individuals enrolled with physician in family health teams	Tertiary prevention: chronic disease management, specifically diabetic care, osteoporosis care, psychiatric follow-up	• Gap in results between individuals with and without IDD in family health teams is similar to overall provincial gap. • Across all age groups adults with IDD had considerably higher rates of hospitalization for ambulatory care sensitive conditions (increasing with age) • Eye examinations and fracture care was higher for patients enrolled in family health team vs. overall provincial rate (fracture care still less than individuals without IDD) • Data does not indicate if interprofessional health providers were involved in tertiary prevention roles.
Berens *et al.*[65]	USA	Chart audit/ review	Program description of the development and implementation of the clinic, patient population, resource needs and lessons learned.	Total N: 332 M: 155 (46.7%) W: 177(53.3%) Ages at first visit range 15-45 years Top 5 identified diagnoses (N) Cerebral palsy (80) Down syndrome (54) Spina bifida (52) Genetic (50) Autism (17) Yrs. reviewed: 2005-2011 Genetic diagnoses included: Williams Synd., neurofibromatosis, Angelman Synd., Turner Synd., bladder exstrophy, Proteus Synd., Rett Synd., Canavan disease, Smith-Magenis Synd., achondroplasia, CHARGE Synd.	Academic, patient medical home and transition clinic for adolescents and adults with IDD. Interprofessional team: med-pediatrician, internal medicine, registered nurses and one social worker Processes: weekly team case management meetings, extended clinic visits and half-day clinics provided (see 5-7 patients/ clinic), social work accessible over phone or in-person Patient eligibility criteria: technology dependence, a diagnosis unfamiliar to most adult providers, intellectual disability, lack of access to appropriate adult health care, need for high level of care coordination, lack of transition readiness.	Social worker roles: case manager, system navigation, accessing community resources to locate employment, education and independent living, address transitions to adult services. Additional registered nurse roles: referral tracking, arrangement of specialist appointments.	• Clinic evolved into adult patient medical home as a result of inability to transition patients to adult PHC services. • As of this publication, not evaluating outcomes; however, recognize a need in future, e.g. satisfaction, quality, cost-savings of approach.
Casson *et al.*[64]	CAN	Clinical review	Recommendations for the provision of health checks in PHC teams	Adults with IDD (population characteristics not identified)	Authors recommend ways in which to engage interprofessional health providers in health check process based on experience in interprofessional, team-based PHC practice.	Recommends: Pre-Health Check: meet and greet with nurse practitioner or registered nurse. Providers can gather background, medical and social history, supports, update patient profile, take vitals, perform part of physical examination. Post-Health Check (as needed): occupational therapist for functional assessment, speech/language for communication, physiotherapist or physiatrist to address mobility issues, nursing to organize further assessments, pharmacist for medication review/reconciliation, social work to assess and support emotional needs, system navigation	• Provides specific recommendations for interprofessional health provider interventions and involvement in health check program.

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Author /year	Country	Study design	Purpose	Population	Description of concept	Interprofessional PHC interventions	Impressions/significant findings
Develop-mental Dis-abilities Health Centre (DDHC)[58]	USA	Website	Service/program description	Adults over 18+ with IDD (population characteristics not identified)	Team composition: physician, nurse practitioner, social work, mental health services (psychiatry), health promotion (dietitian) Processes: co-located services, shared medical record. Need to be enrolled with physician to access psychiatry	Episodic care, behavioral/mental health, chronic disease care, diagnosis, treatment of sudden, minor illness and injury Enrollment services, health education, immunizations, pharmacy services, psychological exams, physical exams, specialty referrals, respiratory management	• Details of interprofessional PHC team provided in Ervin *et al.* (2014).
Dixon[55]	CAN	Observational case-control	Assess the impact of FHT on four access indicators: periodic health exam; screening for breast, cervical and colorectal cancers; avoidable emergency department visits.	H-CARDD Cohort Ages: 18-64 years Intervention group (FHT): Total: 8,647 M: 4,535 W: 4,112 Control group (non-FHT): Total: 37,153 M: 21,068 W: 16,085	Access to secondary prevention when enrolled with physician in family health team vs. non-family health team Exposure window: 2005-2011	Secondary prevention: PHE; colorectal, breast, cervical cancer screening	• FHT model does not appear to impact avoidable ED visits or support greater update of the PHE. • FHT data does not reflect PHE conducted by IHPs working alongside GPs. • Positive trends for uptake of cancer screening for cervical and colorectal; however, breast cancer and cervical cancer uptake not statistically significant.
Durbin *et al.*[70]	CAN	Process evaluation	Describe practice changes made to implement health check [Physical health exam] in FHT. Evaluate how practice context affected the implementation decisions.	Adults with IDD (population characteristics not identified)	Enrollment with physician in Academic Family Health Teams in Ontario. Academic Family Health Teams are interprofessional PHC teams that deliver care "in an environment in which family medicine residents, medical students, and other health professional learners are trained" [80 p. e25]	Implementation of health check program [physical health exam] at two sites. Site 1: physician completed Site 2: physician residents completed Health checks are annual, comprehensive preventative care assessments. Core components of health checks: i. Identification of patients with IDD ii. Proactive invitation for health check visit iii. Staff education and training iV. Delivery of health check (screening for prevalent conditions, adapting communication, using interprofessional approach over a series of visits.)	• Intention was to have a registered nurse or nurse practitioner complete the initial stage of health checks; however, both declined secondary due to logistical challenges with scheduling. • Investigators note it was challenging to systematically implement an interprofessional approach at both sites. • Scheduling was complicated by not knowing which health providers were needed until after the appointment and concern that longer appointments or a second appointment would be challenging for the patient. • Authors note engagement of interprofessional health providers is an area where FHTs are still developing work processes.

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Author /year	Country	Study design	Purpose	Population	Description of concept	Interprofessional PHC interventions	Impressions/significant findings
Ervin *et al.* [59]	USA	Review article	Review the benefits of integrating mental and behavioral health supports in interprofessional PHC teams Provide case examples of current integrated (physical and mental health) PHC teams Developmental Disabilities Health Centre (DDHC)	Individuals with IDD (population characteristics not identified)	Authors note a need for PHC providers to accept mental and behavioral health is part of holistic health care and that psychiatrists, psychologists are needed and valuable PHC to change mental health outcomes. Case Example – DDHC: Processes: Patients see medical and behavioral providers at their initial appointment to assess the physical and psychosocial needs. At subsequent visits, behavioral providers are called into medical appointments as needed and their treatment plan reflects general and behavioral health needs. Patients have opportunity for follow-up visits with behavioral providers or psychiatrist who are on-site and can also support the patient outside DDHC	Case Example - DDHC: Behavioral providers offer a range of experiential therapies, dance/movement therapy, and behavioral therapy. Patients are referred to the above when a model of brief episodic therapy is not likely to address more long-standing mental health concerns.	• Notes the importance of cultural shift and reimbursement models to support the provision of comprehensive, holistic care. • Provides descriptive case examples that outline team processes for engagement of an interprofessional PHC approach.
Green *et al.*[67]	CAN	Clinical review	To provide physicians with an understanding of behaviors that challenge in adults with IDD and strategies for systematic approach to assessment and treatment.	Adults with IDD that present with behaviors that challenge (population characteristics not identified)	Authors recommend that behaviors that challenge are best assessed within an interprofessional PHC team (or patient medical home) model. Note: ideal patient medical home for adults with IDD is an interprofessional clinic that includes expertise in: medicine, occupational therapy, behavior analysis, speech language pathology and nursing.	Recommend potential interprofessional interventions: occupational therapist or behavior analyst to review context of behaviors that challenge and advise on creation of enabling environment, conduct functional assessments, speech language to assess and improve functional communication	Recommend access to interprofessional health providers as part of equitable care. Interprofessional team approach is essential to successful, comprehensive intervention. Many physicians practice outside interprofessional PHC teams and consideration should be given to how nursing, physician assistants, or social workers can support assessment/care.
Grier[30]	CAN (author) INT'L review	Book chapter	Review of patient medical home models for IDD	Adults with IDD (population characteristics not identified)	References interprofessional, PHC as key principle of patient medical home. Reviews current patient medical home research in regards to this population.	Provides overview of interventions. Covered in primary references included in this scoping review (e.g. DDHA)	• Provides review of breadth of current practice approaches for PHC of adults with IDD. • Specific patient medical home models discussed as well as other global PHC initiatives in United Kingdom, Australia, and the Netherlands. • Outcomes primarily related to being enrolled in a PHC team model. Research does not address which provider completes (e.g. physician, nurse practitioner, nurse).

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Author /year	Country	Study design	Purpose	Population	Description of concept	Interprofessional PHC interventions	Impressions/significant findings
Isaacs *et al.*[56]	CAN	Observational cross-sectional	Examination of health service use by adults with IDD in Ontario, Canada	H-CARDD Cohort Ages: 18-64 years Total: 66, 484 M: 38, 090 W: 28, 394	Measured % of individuals accessing one model of interprofessional PHC (Family Health Team); measured % of individuals in Family Health Team that were not enrolled with physician	Not captured in data. Potential for access to interprofessional services through interprofessional PHC team.	• 19.5% of adults with IDD have access to interprofessional PHC team through FHTs. • Other interprofessional PHC models not assessed. • Results do not allow for more detailed analysis of use of interprofessional PHC services in this model of care (other than belonging to team vs non-team care).
Kastner *et al.*[28]	USA	Book chapter	Present health service model for adults with IDD in United States	Adults with IDD enrolled in DDHA health home in New Jersey, United States (population characteristics not identified)	Focus: team approach that relies on interprofessional relationship between physicians and nurse practitioners Services: comprehensive PHC services, care coordination, specialty care Processes: nurse practitioners are primary health providers (team on call all the time), physicians are available when needed, health providers share electronic medical record, mental health care seen in DDHA health home.	Nurse practitioners are cross trained in primary mental health care, as well as in basic neurological services. Nurse practitioners take on PHC and additional care coordination activities including: scheduling appointments, lab testing, assisting in managing insurance issues, clear for surgery, follow up on emergency department visits, renew prescriptions and manage medical documentation.	• Nurse practitioners working to full scope. • Model addresses triple aim (i.e. improving experience of care, improving health, reducing cost) • Model in place 25+ years and able to study population, health utilization and patient satisfaction • Patient quality and satisfaction survey seven times (1995, 98, 99, 04, 05, 06, 07). Results consistent: most surveys completed by proxies with patient assent (1997 – 3.4% by adults with IDD completed survey)
Kastner *et al.*[62]	USA	Program description	To describe the DDHA program.	Individuals with IDD enrolled in DDHA, New Jersey, United States (population characteristics not identified)	Focus: team approach that relies on interprofessional relationship between physicians and nurse practitioners Services: comprehensive PHC services, care coordination, specialty care Processes: nurse practitioners are primary health providers (team on call all the time), physicians are available when needed, health providers share electronic medical record, if patient needs mental health care, seen in DDHA health home.	Nurse practitioners are cross trained in primary mental health care, as well as in basic neurological services. Nurse practitioners take on PHC and additional care coordination activities including: scheduling appointments, lab testing, assisting in managing insurance issues, clear for surgery, follow up on emergency department visits, renew prescriptions and manage medical documentation.	• Authors note processes to increase tailored, accessible care: accessible waiting and examination rooms, home visits if needed, chair scales.

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Author /year	Country	Study design	Purpose	Population	Description of concept	Interprofessional PHC interventions	Impressions/significant findings
Ouellette-Kuntz *et al.*[57]	CAN	Observational cross-sectional	Examine the extent to which primary care received by adults with IDD in Ontario, Canada, corresponds to four secondary prevention guidelines in 2009/10–2011/12.	H-CARDD Cohort Ages: 18-64 years Total: 66,484 M: 38,090 W: 28,394	Access to secondary prevention when enrolled with physician in FHT. Family Health Teams are comprehensive, interprofessional PHC teams with physician leadership. The most prevalent model in Ontario, they can differ in size, team composition, governance and range of programs offered. They are most aligned with the values of the patient medical home.	Secondary Prevention Interventions: PHE, colorectal, breast, cervical cancer screening	• Disparities in secondary prevention identified for adults with IDD eligible for screening when compared with adults without IDD enrolled in FHTs. Screening for patients with IDD (%) vs patients without IDD (%) Cervical cancer (36.8 vs 73.0) Breast cancer (59.7 vs 77.5) Colorectal cancer (36.2 vs 51.5) PHE (22.2 vs 23.7) • Rates for patients with IDD in FHT similar to provincial rates for patients not enrolled in interprofessional PHC Screening for FHT Patients with IDD (%) vs. Non-FHT Patients with IDD (%) Cervical cancer (36.8 vs 33.7) Colorectal cancer (36.2 vs 32.0) Breast cancer (59.7 vs 52.2) PHE (22.2 vs. 22.0)
Petersen [66]	South Africa	Chart audit/ review Years reviewed: 1997-2001	Describe and provide rationale for Integrated PHC mental health services, roles, providers	Total N: 236 M: 88 F: 145 Missing (3) Individuals with IDD (% total M/F) M: 45 (51.1%) F: 53 (36.6%) Ages, N (% of total N/age range) 0-18: 64 (56.6%); 19-29: 17 (27.9%); 30+: 10 (27%)	Community Health Centre- Psychological Referral Service. Semi-rural area in Eastern South Africa; center has mobile/satellite clinics in five tribal areas	Counselling psychologists and trainees provide counseling services/supportive psychotherapy, psychometric testing for school placement, assessment for disability, psycho-education and trauma therapy.	Results revealed high percentage of patients with IDD accessing service for assessment. 42.4% of patients using this service 1997-2001 were diagnosed with IDD, with neurotic mood disorders and PTSD next most common diagnoses Chart review identified a need for increased psychological assessment at PHC level due to lack of availability of these resources within education sector, evidence for new role of counselor in PHC as testing goes beyond PHC mental health nurse scope.
Sullivan *et al.*[22]	CAN	Clinical review (guidelines)	Provide guidance on PHC for adults with IDD; update 2011 version	Adults with IDD (population characteristics not identified)	Interprofessional team approach can assess and address holistically a range of health and developmental needs and, with sufficient supports, can improve outcomes of care. Recommend to engage in or develop an integrated team of professionals (e.g. medical specialists, pharmacists, audiologists, physiotherapy psychology, occupational therapy) to lead, coordinate, and integrate team input.	Recommend potential interprofessional health provider interventions: psychology or occupational therapy for adaptive functioning and cognitive ability; pharmacist to review medications; speech language for communication, respiratory disorders, occupational therapist or behavior therapist for sleep and environmental factors, health promotion; dietitian for dietary needs	• Recommendations for interprofessional health provider interventions and team approach as part of comprehensive guidelines for care of this population.

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Author /year	Country	Study design	Purpose	Population	Description of concept	Interprofessional PHC interventions	Impressions/significant findings
Sullivan *et al.*[69]	CAN	Clinical review (guidelines)	Provide guidance on PHC for adults with IDD; update 2006 version	Adults with IDD (population characteristics not identified)	References interdisciplinary health care as an effective approach to address the complex needs of adults with DD. Identify physician, nurse, and others as required, along with a coordinator (may be physician).	Recommend potential interprofessional involvement /consultation: psychology for adaptive functioning; psychology or behavior therapy for functional analysis; physiotherapy/occupational therapy for adaptations for musculo-skeletal disorders; psychiatry, psychology, speech language to clarify diagnosis in patients with limited unusual language use; psychotherapy	2011 guidelines provide recommendation for interprofessional interventions/consultations as needed vs emphasis on interprofessional PHC teams. Authors recognize that resources may be lacking or unavailable in regional health service systems. Note: 2006 version excluded as does not specifically reference interdisciplinary or integrated approach to primary care. Evolution of language and recommendations reflect larger policy and practice changes to include increased access to interprofessional PHC teams in Canada
Walsh *et al.*[63]	USA	Observational case-control	Examine health service indicators for adults with IDD enrolled in DDHA health home as compared to Medicaid-managed care alone in New Jersey (2007–2009)	Intervention group (DDHA-health home): Total: 185 2007 – 85 2008 – 52 2009 – 48 Control group (Medicaid): Total: 185 2007 – 85 2008 – 52 2009 – 48 Control group matched to DDHA patients for age and gender (details not provided in paper)	DDHA-health home Focus: team approach that relies on interprofessional relationship between physicians and nurse practitioners Services: comprehensive PHC services, care coordination, specialty care Processes: nurse practitioners are primary health providers (team on call all the time), physicians are available when needed, health providers share electronic medical record, if a patient needs mental health care, it is arranged and seen in DDHA health home offices.	Nurse practitioners are cross trained in primary mental health care, as well as in basic neurological services. Nurse practitioners take on PHC and additional care coordination activities including: scheduling appointments, lab testing, assisting in managing insurance issues, clearance for surgery, follow up on emergency department visits, renewal of prescriptions and management medical documentation.	• There is a difference in health service utilization between DDHA health home group and usual care as seen in fewer emergency room visits and hospitalizations
Weedon *et al.*[29]	USA	Program description	To describe the HOME program, a specialized IDD interprofessional PHC team	Patients enrolled in HOME program (2009): Age: Years of Age, N (% of total N) >18: 582 (71%) <18: 238 (29%) Gender: Gender, N (% of total N) M: 550 (67%) F: 270 (33%) Level of IDD: Level of IDD, N (% of Total N) Mild: 337 (41.1%) Moderate: 117 (1.3%) Severe: 41 (5%) Profound: 33 (4%) Unspecified: 107 (13%)	HOME provides primary medical and mental health services to patients 3-82 years old. Features of approach: accessible environment at clinic, medical and mental health services all co-located, coordinated to eliminate transition between pediatric and adult care Team composition: four psychiatrists, general physicians, pediatricians, five social workers, two advanced practice nurses, two behavior providers, five case managers, administrative staff Processes: patient referred to program by physician or community agency, case management, daily rounds, parent provider council	Multi-disciplinary team manages all aspects of care and work collaboratively to: address chronic care management issues, develop of care plans, link to community resources, offer system navigation, offer daily crisis appointments for urgent care	Specialized IDD interprofessional PHC team. Demonstrates collaborative team processes. Does not specifically discuss interprofessional roles/services. Re outcomes: hemoglobin A1C for patients with diabetes (77% met goal of 6.5 or below vs state and country proportions of 27.6% and 33% respectively)

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Author /year	Country	Study design	Purpose	Population	Description of concept	Interprofessional PHC interventions	Impressions/significant findings
Williams *et al.*[68]	USA	Book chapter	Review benefits of integrating mental and behavioral supports in interprofessional PHC teams	IDD (population characteristics not identified)	Integration of mental/behavioral and physical health providers to support comprehensive needs of this population	Provides case examples of models: DDHC and DDHC (see original sources)	• Approximately 35%-40% of people with IDD live with mental health conditions. • Challenges to interprofessional care-remuneration systems, culture and coordination with community/developmental services • Call to continue to seek collaboration across disciplines to all members of interprofessional team.
Wroth[60]	USA	Program description	To describe a novel organizational intervention to provide interprofessional PHC to frail elderly people and adults with IDD in North Carolina.	Frail elderly people and adults with IDD Total: 107 Additional patient demographics not provided.	Community Health Center Team Composition: physicians, nurse care managers, pharmacist Processes: Eligible patients were identified from a sample of 28 care homes in North Carolina, homes and patients were assigned a nurse care manager for care coordination, joint visits with physician and nurse for more rural homes.	Nurse care managers: identify population of IDD within practice, are the lead contact for adult care homes; are available during day hours; liaise with primary care providers in the event of questions from home; perform home visits; complete comprehensive health assessments; care plans; medication reconciliation; book follow-up visits; complete joint home visits with physician to rural care homes; meet with pharmacist to ensure care plans were followed	• Describes a specific program within an interprofessional PHC team for adults with complex health needs supported in care homes (frail elderly people and adults with IDD). • Outcomes reported by anecdote from administrators. • Formal evaluation was not completed at date of paper.

DDHA, Developmental Disabilities Health Alliance; DDHC, Developmental Disabilities Health Centre; ED, emergency department; FHT, family health team; GP, general practitioner; IDD, intellectual and developmental disabilities; IHP, interprofessional health providers; PHC, primary health care; PHE,; PTSD, post-traumatic stress disorder.

Appendix IV: Characteristics of included studies: outcomes

Reference	Patient-reported outcomes	Types of health service outcomes
Balogh *et al.* [54]	—	• Psychiatric follow up (with psychiatrist or family physician within 30 days) • Hospitalization for ambulatory care sensitive condition • Diabetic care (eye examination) • Osteoporosis monitoring (fracture care)
Dixon[55]	—	• Avoidable emergency department utilization rates • Completion of periodic health examination • Cancer Screening
Isaacs *et al.* [56]	—	• Enrollment with physician in PHC team model
Kastner *et al.* [28]	Satisfaction with: quality of care, patient experience, overall health	• Emergency department visits • In-patient admissions • Hospital average length of stay • PHC access indicators include: ease of scheduled appointments, average time spent in waiting rooms, ease of getting help after hours, ease of prescription refills
Kastner *et al.*[62]	Satisfaction with: quality of care, consistency/continuity of care, ability to have questions answered	• PHC access indicators include: ease of scheduled appointments, average time spent in waiting rooms, ease of getting help after hours, ease of prescription refills
Ouellette-Kuntz *et al.*[57]	—	• Completion of periodic health examination • Cancer screening
Petersen[66]	—	• Access to psychological testing
Walsh *et al.*[63]	—	• Emergency department visits • In-patient admissions • Hospital average length of stay • Hospital re-admission rates
Weedon *et al.*[29]	Satisfaction with: quality of care, access, staff knowledgeability and care	• In-patient hospital admissions • Hospital average length of stay • Hospital re-admission rates • Glycemic control

(*Continued*)		
Reference	**Patient-reported outcomes**	**Types of health service outcomes**
Wroth[60]	—	• Continuity of care • PHC access indicators (e.g. wait times, home visits) • Emergency department visits

PHC, primary health care.