

Care Coordination for Adults with Down syndrome or Intellectual and Developmental Disabilities: A Scoping Review

Samrawit Amare Misiker, BS
Coordinator, The Down Syndrome Program
Kirk Kerkorian School of Medicine, University of Nevada, Las Vegas
3014 W. Charleston Blvd. Ste 150, Las Vegas, NV, 89102
702-755-9436
samrawitmisiker@gmail.com

Diana Anguiano, BS
Program Assistant, The Down Syndrome Program
Kirk Kerkorian School of Medicine, University of Nevada, Las Vegas

Miah Strellnauer, BS
Program Assistant, The Down Syndrome Program
Kirk Kerkorian School of Medicine, University of Nevada, Las Vegas

John Hatch, BS
Program Assistant, The Down Syndrome Program
Kirk Kerkorian School of Medicine, University of Nevada, Las Vegas

Kate Martin, MD, MPH, MBA, MS
Director, The Down Syndrome Program
Associate Dean for Graduate Medical Education and Designated Institutional Official (DIO)
Professor of Family and Community Medicine
Kirk Kerkorian School of Medicine, University of Nevada, Las Vegas

AUTHOR NOTE

This manuscript has not been published and is not under review at another journal. The authors do not state any known conflict of interest.

ABSTRACT

Individuals with Down syndrome (Ds) have an elevated risk for a variety of health conditions. As a result, the need for care coordination is greater for those with Ds as it can help navigate the challenges often associated with the healthcare system. The aim of this scoping review was to map the existing research on care coordination for adults with Ds. However, a preliminary search of the literature showed sparse results for care coordination for adults with Ds. Subsequently, the scope of the study was expanded to include adults 21 years of age and older with intellectual and developmental disabilities (IDD). The Joanna Briggs Institute methodology for scoping reviews was utilized. A total of five

databases were systematically searched and identified a total of 4,572 records. Following a robust screening process, two articles were eligible for inclusion. The articles discussed care coordination efforts that stemmed from previously existing programs and were tailored for adults with IDD. These articles did not assess the impact of their efforts; however, their challenges can be used to guide new care coordination programs. This scoping review's findings identify a gap in the literature for care coordination for adults with IDD and Ds.

KEYWORDS:

Down syndrome; care coordination; intellectual and developmental disabilities

INTRODUCTION

Down syndrome (Ds) is a chromosomal disorder caused by the presence of a full or partial extra copy of the 21st chromosome. The prevalence of Ds in the United States is estimated to be 1 in 707 births (Mai et al., 2019). Individuals with Ds have an elevated risk for a variety of health conditions. More than 60% of Ds births are affected by at least one birth defect (Heinke et al., 2021; Stoll et al., 2015). Congenital heart disease is present in about 44% of Ds births (Freeman et al., 1998; Stoll et al., 2015). Compared to the overall population, individuals with Ds have atrioventricular canal defects and duodenal stenosis at a higher frequency (Cleves et al., 2007; Torfs & Christianson, 1998). Ds is also associated with an increased risk and prevalence of Hirschsprung disease, a condition in which the absence of nerve cells in the large intestine hinder its functioning (Heuckeroth, 2015; Torfs & Christianson, 1998).

Due to the range of co-occurring medical conditions associated with Ds, treatment from different specialists is required. Consequently, the need for care coordination is greater for this population. McDonald et al. (2007) formulated the following definition of care coordination:

Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care. (p. 5)

Care coordination can help individuals and their families navigate the healthcare system. It can

also involve connecting patients to appropriate resources within their communities (Council on Children with Disabilities, 2005; Rizzo et al., 2016). Positive experiences of care coordination have been correlated with increased satisfaction with chronic illness care, primary care providers, and the overall organization of care (Wang et al., 2015). Care coordination has also been found to decrease the financial burden on families, the amount of illness-related school absences, and emergency department visits (Turchi et al., 2009).

The aim of this scoping review was to map the current research on care coordination for adults with Ds. A preliminary search of the literature showed that there were sparse results for care coordination efforts for people with Down syndrome and none were focused on the adult population. In a scoping review on quality indicators for Down syndrome care, van den Driessen Mareeuw et al. (2017) expanded their research to include intellectual disabilities due to the limited information available on Ds alone. Based on these observations, our research team expanded the scope of this review to include individuals with intellectual and developmental disabilities (IDD). According to the American Psychiatric Association (2013), intellectual disabilities are losses in mental abilities that are acquired during the developmental period (p. 33). Developmental disability is an umbrella term for conditions that are characterized by physical, cognitive, or self-care limitations that begin in childhood (Yeargin-Allsopp et al., 1992). Since Down syndrome is classified as an IDD, the care coordination efforts for individuals with IDD are relevant to our study.

Furthermore, the most similar reviews found during the preliminary literature search were those of Skelton et al. (2021) and Bobbette et al. (2020). The Bobbette et al. systematic review on interprofessional team-based primary health care for adults with IDD did not focus on the Ds population. The results of the scoping review conducted by Skelton et al. on care coordination for children with Down syndrome were limited to individuals under 21 years of age. As such, there is a need for a scoping review that surveys care coordination efforts for individuals with Ds and/or IDD above 21 years of age.

Our review was conducted to identify the existing care coordination efforts for adults with IDD and potential gaps in research while highlighting the findings specific to Down syndrome. The primary research questions addressed were as follows:

1. What care coordination efforts have been implemented for adults with Down syndrome or Intellectual and Developmental Disabilities?
2. What is the impact of care coordination efforts for adult patients with Down syndrome or Intellectual and Developmental Disabilities?

METHODS

The methodology for this scoping review was based on the framework from the Joanna Briggs Institute (JBI) Manual for Evidence Synthesis (Peters et al., 2020). A protocol was developed and registered on the Open Science Framework on March 10, 2022. Table 1 summarizes the population, concept, context (PCC) framework recommended by the JBI for scoping reviews (Peters et al., 2020).

Table 1. PCC Framework.

PCC	Definition
Population	Studies that are focused on adults with Down syndrome or intellectual and developmental disabilities. Studies that include data about all age groups will only be used if the results are not combined and are separated for different age groups.
Concept	Studies that discuss care coordination of some sort.
Context	The context in which care coordination is discussed does not determine eligibility for this study. Studies can be conducted in any country and any setting.

Eligibility Criteria

Inclusion Criteria

Below are the inclusion criteria that this study used:

- articles published in peer reviewed journals
- research using any study designs
- published any time before the start of the literature search (April 4, 2022)
- languages that the research team is fluent in (English, Spanish, French, and Amharic)
- study includes adult participants 21 years of age and above
- study includes participants diagnosed with Down syndrome and/or IDD
- involves care coordination
- location of the study is open to all countries
- article from any perspective (provider, patients, family members, etc.)

Exclusion Criteria

Below are the exclusion criteria that this study used:

- articles that are not peer reviewed or are in gray literature
- non-research or opinion-based articles
- all other languages that are not mastered by the research team
- study does not specify the age of participants
- participants are not diagnosed with Down syndrome or intellectual and developmental disabilities
- study focuses on participants with IDD and a co-occurring condition (e.g., Alzheimer's disease)

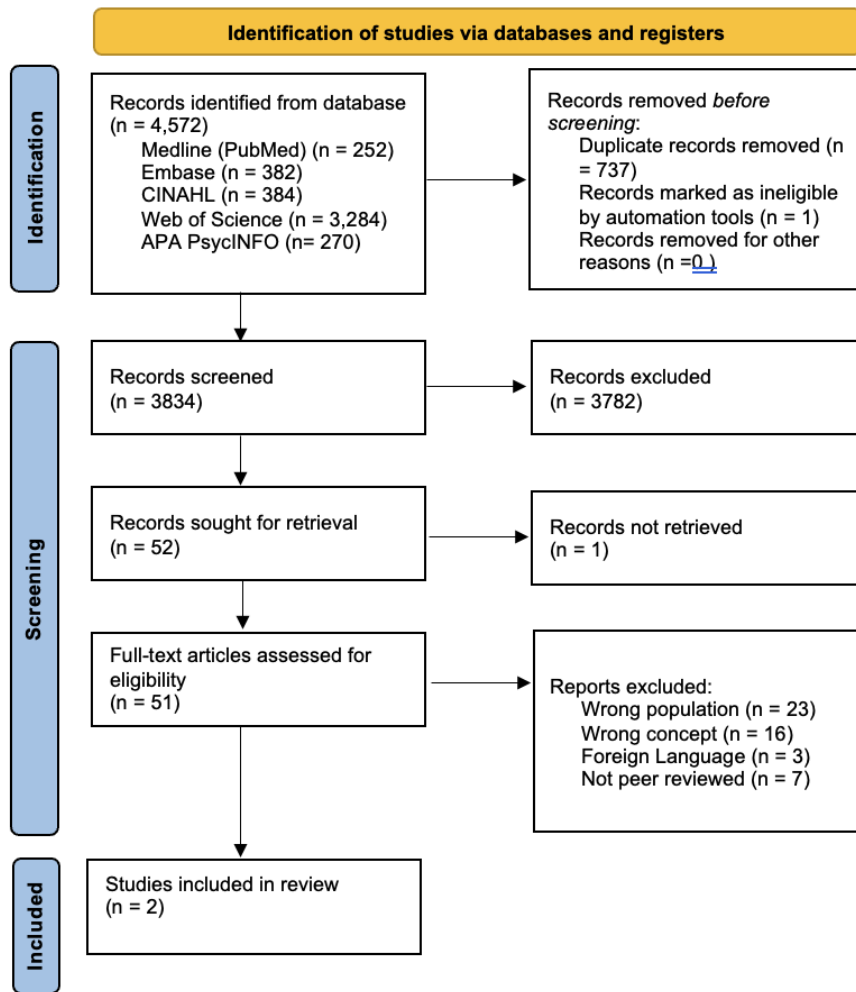
- study focuses specifically on an intellectual or developmental disability that is not Down syndrome

Search Strategy

We systematically searched the databases of Medline (PubMed), Embase, CINAHL, Web of Science, and APA PsycINFO for articles published by the start of the literature search on April 4, 2022. These databases were selected with the help of a research librarian in an effort to find relevant articles within different disciplines. The first group of search terms were terms that were related to Down syndrome. The second group of search terms were related to care coordination. The third group of search terms were related to the adult population and was developed using the search hedge from Mortazavi et al. (2016). The fourth group of search terms were peer reviewed publication types eligible for inclusion. An initial search of Medline (PubMed) was conducted to determine relevant search terms. Search strategies were translated from PubMed and altered based on the format of the different interfaces. The search strategy was peer reviewed by a research librarian and can be found in Appendix A.

The results from the literature search were exported to Rayyan for deduplication, title and abstract screening, and full-text screening. Both the title and abstract screening and the full-text review were conducted independently by two reviewers (SM, DA). In cases of disagreement between the reviewers, a third reviewer (JH) made the final decision. Once all studies were screened, the reference lists from the studies selected for inclusion were searched, and any relevant articles were screened. No statistical software was utilized. This process is displayed in Figure 1 using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) diagram (Page et al., 2021).

Figure 1. PRISMA Flow Diagram.



Data Extraction

Once the relevant studies were identified, the results were extracted by two reviewers (AN, JH), independently. Any disagreements between the two reviewers were resolved by a third reviewer (MS). The team later edited the data extraction table for length and clarity. Per our protocol, the charting table was amended throughout the data extraction process. “Intervention Type/Duration” was removed as there were no findings and was replaced by the category “Care Coordination Efforts” to clearly address research question one. “Outcomes” was renamed “Impact” for clarity. “Definition of Care Coordination” was removed because neither study defined care coordination. When needed, authors were contacted for additional information to clarify

their articles’ eligibility. The results are displayed in Appendix B.

Deviations

The original tool selected for deduplication presented an array of technical difficulties. As such, the research team decided to utilize Rayyan instead. Additionally, the protocol contained two errors. The first error was the inclusion of Scopus as one of the databases to be searched. The second error was the omission of the fifth search hedge for Web of Science. These errors were rectified prior to the search and were noted in this manuscript. Furthermore, the research team found that the eligibility criteria was not specific enough and decided that articles had to specifically use the terms IDD or Down syndrome to be considered for

eligibility. No syndromes, disorders, or other medical issues that fall into the umbrella term of IDD were considered unless the term IDD was utilized by the researchers and the study investigated those with IDD, not the illness specifically. The research team also excluded studies that investigated those with IDD and any other co-occurring illness, disorder, etc., as the results would not apply to all individuals with IDD. Only studies investigating individuals with Down syndrome or IDD were considered.

RESULTS

Included Studies

The search strategy identified 4,572 records from the databases. After duplicates were removed, 3,834 records were included in the title and abstract screening. This screening resulted in 52 records that were included for the full-text screening. The full text of one study was not able to be retrieved. From the remaining 51 records, a total of 47 records were excluded. The reviewers excluded 21 records that were focused on an ineligible population, 16 that were ineligible concepts, seven that were not peer-reviewed, and three that were in a foreign language not mastered by the research team. This resulted in four records proceeding to data collection. However, during this process, two studies were removed due to population ineligibility that was not previously noted. The study selection process is reported in the PRISMA flow diagram.

This study included two records. One was a cross-sectional study in the United States (Williamson et al., 2018) and one was a program description in Canada (Martin et al., 2019). Williamson et al. (2018) collected their data from interviews with stakeholders, care coordinators, and caregivers. Martin et al. (2019) surveyed individuals with IDD and sourced data from clients' coordinated care plan. Age ranges of participants were 21-62 years old (Martin et al., 2019) and 22-38 years old (Williamson et al., 2018). Both studies focused on adults with IDD, however Williamson et al. specified that 27.27% of participants were diagnosed with Down syndrome.

Care Coordination Efforts

The resulting articles discussed two different care coordination efforts for adults with IDD. These efforts are embedded within Canadian (Martin et al., 2019) and U.S. (Williamson et al., 2018) government programs operated at the provincial level and state level respectively. Martin et al. (2019) detailed a care coordination model within the Health Links program

that was established by the Ontario Ministry of Health and Long-Term Care in Kingston, Ontario. Williamson et al. (2018) referred to care coordination within KanCare, a Medicaid managed care program in Kansas.

Both articles described new care coordination efforts. Williamson et al. (2018) studied a full-fledged program and Martin et al. (2019) described a pilot program that built on a prior existing Health Links program for individuals with IDD. However, Williamson et al. conducted a case study on KanCare as a possible guide for other state Medicaid programs considering implementing managed care.

Care Coordination Team

The articles described different individuals responsible for the coordination of care. In Williamson et al. (2018), both a targeted case manager and care coordinator worked with the individual with IDD and their family caregivers. Martin et al. (2019) described a sole care coordinator working with the individual with IDD and their caregivers. Additionally, the care coordinator role involved the development of a care coordination plan that listed healthcare professionals who constituted the patient's care team, which ranged from 5-23 professionals (Martin et al., 2019).

Impact

Martin et al (2019) and Williamson et al. (2018) did not assess or measure the impact of their respective care coordination efforts.

Barriers

Communication, organizational, and collaboration barriers made care coordination delivery difficult. Communication and organizational problems were exemplified in Williamson et al. (2018). Care coordinators had large caseloads that resulted in employee turnover and weaker relationships with families (Williamson et al., 2018). Families were concerned that care coordinators were not fully understanding family situations and were not asking about caregivers' wellness and support needs (Williamson et al., 2018). The pilot program Martin et al. (2019) described primarily experienced collaboration issues amongst the different sectors of patient care.

DISCUSSION

The purpose of this scoping review was to map existing care coordination efforts for adults with

IDD with a focus on adults with Ds. To date, this is the first scoping review focused on care coordination for adults with IDD and/or Ds. Despite expanding our research from Ds to IDD, our research yielded limited results with only two articles meeting our eligibility criteria. Although one of the articles specified the number of participants with Ds (Williamson et al., 2018), neither were focused on this population. However, our findings may be beneficial when implementing new care coordination programs.

Regarding research question one, both articles demonstrated care coordination efforts that were developed from currently existing programs and tailored to adults with IDD. Williamson et al. (2018) illustrated how existing government programs can be expanded to better meet the needs of people with IDD. KanCare collaborated with private organizations as part of the managed care approach, which allowed access to services that were not previously available such as respite care (Williamson et al., 2018). Tailoring prior existing programs to IDD might be more feasible than implementing a novel program, however conclusive statements cannot be made without further research.

As previously mentioned, the care coordination efforts in this review were also part of government programs. This review did not feature articles with community-based or private care coordination initiatives. Without a comparison to non-government efforts, we cannot assess whether public efforts adequately address the need of care coordination for adults with IDD. Further research is required to investigate whether it is beneficial to implement care coordination at the government level.

It is of note that although care coordinators were the only professionals involved in coordination meetings with the families in both studies reviewed, it has been observed that other professionals such as physicians and nurses, may act as care coordinators in addition to their clinical duties (Anderson et al., 2012; Tschudy et al., 2016). However, a designated care coordinator is ideal as their sole responsibility is to coordinate care; whereas other professionals may not have the time or training to provide quality care coordination due to their many responsibilities (Reeves et al., 2020).

The findings of this scoping review did not address research question two, as impact was not assessed.

Although the impacts of care coordination efforts were not assessed, each study did find negative outcomes and barriers to their program designs. These barriers stemmed from issues both within (Williamson et al., 2018) and outside (Martin et al., 2019) of the programs. Williamson et al.

(2018) faced internal issues regarding communication and organization, which affected the relationships between care coordinators and families. In contrast, Martin et al. (2019) experienced external collaboration issues.

These barriers need to be addressed to ensure quality care coordination. According to Bowers et al. (2017), better experiences with care coordination led to improved patient outcomes. Therefore, it is important to consider organizational and management practices, as well as communication strategies when implementing new programs. Hiring adequate numbers of care coordinators can help ensure manageable caseloads and ample time to develop better relationships with individuals with IDD and their families. Doing so may allow for in-person visits, which will build stronger relationships between care coordinators and families (Stewart et al., 2018). Another approach to reduce caseload is to delegate non-care coordination tasks to less experienced staff (Friedman et al., 2016). In addition to workload, stronger communication with family caregivers needs to be implemented. Emphasis should be placed on training care coordinators to communicate effectively in order to address patient and family needs. Finally, to address the collaborative issues between different sectors, care teams should be composed of professionals that understand the needs of adults with IDD (Martin et al., 2019). An integrated model of care coordination was suggested in order to circumvent these issues (Martin et al., 2019). This can be applied by having multiple specialists and professionals working together in-house to reduce collaborative issues (Homaira et al., 2022).

Limitations

The scoping review is subject to some limitations. As with any review, relevant articles may have been omitted. In the case of our study, there are at least three reasons this may have occurred. Firstly, the lack of consistent terminology when referencing care coordination created a challenge to identify relevant publications. Secondly, our review only included results for adults aged 21 and over. The restricted age range and lack of reporting on the age of the participants across publications may have led to the exclusion of relevant articles. Finally, the aim of the review was to highlight findings on Down syndrome; as such, other conditions that may fall under the classification of IDD were not considered for inclusion. Additionally, if this article is to be used for implementation purposes, it is important to consider that our scoping review did not evaluate the quality of the included articles.

Conclusion

This review is an important contribution to the literature on care coordination for adults with IDD, as it maps out the different efforts that exist for this population. With only two articles eligible for inclusion, it suggests that this topic remains largely under-explored. Nevertheless, our findings pinpoint key points to consider when implementing care coordination programs for adults with IDD.

Our findings also identify a gap in research on care coordination for adults with Ds. Neither article included in this review focused on Down syndrome specifically. This highlights the need for further research to explore this area. As noted earlier, adults with Ds are a population that can benefit from the coordination of care. With the increase in life expectancy of people with Ds over the past few decades, the care coordination needs also increase (Presson et al., 2013). It is evident that more work is needed to be done to identify best practices in care coordination to serve aging people with Ds and IDD.

Acknowledgements

The authors would like to thank Ahmed-Nadeem Tariq for his contributions to the protocol and data extraction process. Additional thanks to Aidy Weeks (Director, School of Medicine Library, University of Nevada, Las Vegas) for her contributions to the search strategy and guidance throughout the research process.

REFERENCES

- Anderson, D. R., St Hilaire, D., & Flinter, M. (2012). Primary care nursing role and care coordination: An observational study of nursing work in a community health center. *Online Journal of Issues in Nursing*, 17(2), Article 3. <https://doi.org/10.3912/OJIN.Vol17No02Man03>
- American Psychiatric Association. (2022). Neurodevelopmental disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787.x01_Neurodevelopmental_Disorders
- Bobbette, N., Ouellette-Kuntz, H., Tranmer, J., Lysaght, R., Ufholz, L.-A., & Donnelly, C. (2020). Adults with intellectual and developmental disabilities and interprofessional, team-based primary health care: a scoping review. *JBI Evidence Synthesis*, 18(7), 1470–1514. <https://doi.org/10.11124/JBISRIR-D-19-00200>
- Bowers, A., Owen, R., & Heller, T. (2017). Care coordination experiences of people with disabilities enrolled in medicaid managed care. *Disability and Rehabilitation*, 39(21), 2207–2214. <https://doi.org/10.1080/09638288.2016.1219773>
- Cleves, M. A., Hobbs, C. A., Cleves, P. A., Tilford, J. M., Bird, T. M., & Robbins, J. M. (2007). Congenital defects among liveborn infants with Down syndrome. *Birth Defects Research Part A: Clinical and Molecular Teratology*, 79(9), 657–663. <https://doi.org/10.1002/bdra.20393>
- Council on Children With Disabilities. (2005). Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs. *Pediatrics*, 116(5), 1238–1244. <https://doi.org/10.1542/peds.2005-2070>
- Freeman, S. B., Taft, L. F., Dooley, K. J., Allran, K., Sherman, S. L., Hassold, T. J., Khoury, M. J., & Saker, D. M. (1998). Population-based study of congenital heart defects in Down syndrome. *American Journal of Medical Genetics*, 80(3), 213–217. [https://doi.org/10.1002/\(SICI\)1096-8628\(19981116\)80:3%3C213::AID-AJMG6%3E3.0.CO;2-8](https://doi.org/10.1002/(SICI)1096-8628(19981116)80:3%3C213::AID-AJMG6%3E3.0.CO;2-8)
- Friedman, A., Howard, J., Shaw, E. K., Cohen, D. J., Shahidi, L., & Ferrante, J. M. (2016). Facilitators and barriers to care coordination in patient-centered medical homes (PCMHs) from coordinators' perspectives. *Journal of the American Board of Family Medicine*, 29(1), 90–101. <https://doi.org/10.3122/jabfm.2016.01.150175>
- Heinke, D., Isenburg, J. L., Stallings, E. B., Short, T. D., Le, M., Fisher, S., Shan, X., Kirby, R. S., Nguyen, H. H., Nestoridi, E., Nembhard, W. N., Romitti, P. A., Salemi, J. L., & Lupo, P. J. (2021). Prevalence of structural birth defects among infants with Down syndrome, 2013–2017: A US population-based study. *Birth Defects Research*, 113(2), 189–202. <https://doi.org/10.1002/bdr2.1854>
- Heuckeroth. (2015). Hirschsprung's disease, Down syndrome, and missing heritability: too much collagen slows migration. *The Journal of Clinical Investigation*, 125(12), 4323–4326. <https://doi.org/10.1172/JCI85003>

- Homaira, N., Dickins, E., Hodgson, S., Chan, M., Wales, S., Gray, M., Donnelly, S., Burns, C., Owens, L., Plaister, M., Flynn, A., Andresen, J., Keane, K., Wheeler, K., Gould, B., Shaw, N., Jaffe, A., Breen, C., Altman, L., & Woolfenden, S. (2022). Impact of integrated care coordination on pediatric asthma hospital presentations. *Frontiers in Pediatrics*, *10*. <https://doi.org/10.3389/fped.2022.929819>
- Mai, C. T., Isenburg, J. L., Canfield, M. A., Meyer, R. E., Correa, A., Alverson, C. J., Lupo, P. J., Riehle-Colarusso, T., Cho, S. J., Aggarwal, D., & Kirby, R. S. (2019). National population-based estimates for major birth defects, 2010–2014. *Birth Defects Research*, *111*(18), 1420–1435. <https://doi.org/10.1002/bdr2.1589>
- Martin, M. I., Grier, E., Bobbette, N., Casson, I., Durbin, J., Gemmill, M., Lunsy, Y., & Ouellette-Kuntz, H. (2019). Implementation of Health Links coordinated care plans for adults with intellectual and developmental disabilities: Cross-sectoral pilot program. *Canadian Family Physician*, *65*(Supplement 1), S41–S46.
- McDonald, K. M., Sundaram, V., Bravata, D. M., Lewis, R., Lin, N., Kraft, S. A., McKinnon, M., Paguntalan, H., & Owens, D. K. (2007). *Closing the quality gap: A critical analysis of quality improvement strategies: Vol. 7: Care coordination*. Agency for Healthcare Research and Quality (US).
- Mortazavi S.S., Shati M., Keshtkar A., Malakouti S.K., Bazargan M., & Assari S. (2016). Defining polypharmacy in the elderly: A systematic review protocol. *BMJ Open*, *6*(3). <https://doi.org/10.1136/bmjopen-2015-010989>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *372*, Article n71. <https://doi.org/10.1136/bmj.n71>
- Peters, M.D.J., Godfrey C., McInerney P., Munn Z., Tricco A.C., & Khalil, H. (2020). Chapter 11: Scoping reviews (2020 version). In E. Aromataris & Z. Munn (Eds.), *JBI Manual for Evidence Synthesis*. JBI. <https://doi.org/10.46658/JBIMES-20-12>
- Presson, A. P., Partyka, G., Jensen, K. M., Devine, O. J., Rasmussen, S. A., McCabe, L. L., & McCabe, E. R. (2013). Current estimate of Down Syndrome population prevalence in the United States. *The Journal of Pediatrics*, *163*(4), 1163–1168. <https://doi.org/10.1016/j.jpeds.2013.06.013>
- Reeves, E., Liebig, B., & Schweighoffer, R. (2020). Care coordination in palliative home care: Who plays the key role? *International Journal of Integrated Care*, *20*(3), Article 15. <https://doi.org/10.5334/ijic.5466>
- Rizzo, V. M., Rowe, J. M., Shier Kricke, G., Krajci, K., & Golden, R. (2016). AIMS: A care coordination model to improve patient health outcomes. *Health & Social Work*, *41*(3), 191–195. <https://doi.org/10.1093/hsw/hlw029>
- Skelton, B., Knafl, K., Van Riper, M., Fleming, L., & Swallow, V. (2021). Care coordination needs of families of children with Down syndrome: A scoping review to inform development of mHealth applications for families. *Children*, *8*(7), 558. <https://doi.org/10.3390/children8070558>
- Stewart, K.A., Bradley, K. W. V., Zickafoose, J. S., Hildrich, R., Ireys, H. T., & Brown, R. S. (2018). Care coordination for children with special needs in Medicaid: lessons from Medicare. *The American Journal of Managed Care*, *24*(4), 197–202.
- Stoll, C., Dott, B., Alembik, Y., & Roth, M.-P. (2015). Associated congenital anomalies among cases with Down syndrome. *European Journal of Medical Genetics*, *58*(12), 674–680. <https://doi.org/10.1016/j.ejmg.2015.11.003>
- Torfs, C. P., & Christianson, R. E. (1998). Anomalies in Down syndrome individuals in a large population-based registry. *American Journal of Medical Genetics*, *77*(5), 431–438. [https://doi.org/10.1002/\(SICI\)1096-8628\(19980605\)77:5%3C431::AID-AJMG15%3E3.0.CO;2-J](https://doi.org/10.1002/(SICI)1096-8628(19980605)77:5%3C431::AID-AJMG15%3E3.0.CO;2-J)
- Tschudy, M. M., Raphael, J. L., Nehal, U. S., O'Connor, K. G., Kowalkowski, M., & Stille, C. J. (2016). Barriers to care coordination and medical home implementation. *Pediatrics*, *138*(3). <https://doi.org/10.1542/peds.2015-3458>
- Turchi, R. M., Berhane, Z., Bethell, C., Pomponio, A., Antonelli, R., & Minkovitz, C. S. (2009). Care coordination for CSHCN: Associations with family-provider relations and family/child outcomes. *Pediatrics*,

- 124(Supplement 4), S428–S434.
<https://doi.org/10.1542/peds.2009-1255O>
- van den Driessen Mareeuw, F. A., Hollegien, M. I., Coppus, A. M. W., Delnoij, D. M., & de Vries, E. (2017). In search of quality indicators for Down syndrome healthcare: A scoping review. *BMC Health Services Research*, 17(1), 284.
<https://doi.org/10.1186/s12913-017-2228-x>
- Wang, M. C., Mosen, D., Shuster, E., & Bellows, J. (2015). Association of patient-reported care coordination with patient satisfaction. *Journal of Ambulatory Care Management*, 38(1), 69–76.
<https://doi.org/10.1097/JAC.000000000000021>
- Williamson, H. J., Perkins, E. A., Massey, O. T., Baldwin, J. A., Lulinski, A., Armstrong, M. I., & Levins, B. L. (2018). Family caregivers as needed partners: Recognizing their role in medicaid managed long-term services and supports. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 214–225.
<https://doi.org/10.1111/jppi.12258>
- Yeargin-Allsopp, M., Murphy, C. C., Oakley, G. P., & Sikes, R. K. (1992). A multiple-source method for studying the prevalence of developmental disabilities in children: The Metropolitan Atlanta Developmental Disabilities Study. *Pediatrics*, 89(4), 624–630.
<https://publications.aap.org/pediatrics/article/89/4/624/58156/A-Multiple-Source-Method-for-Studying-the?searchresult=1>

Appendix A. Search Strategy

Date searched: April 4, 2022

Medline (PubMed)

Total Results: 252

1. "Down Syndrome"[MeSH Terms] OR "Intellectual Disability"[MeSH Terms:noexp] OR "Developmental Disabilities"[MeSH Terms] OR "Persons with Mental Disabilities"[MeSH Terms] OR "Down Syndrome"[Title/Abstract] OR "trisomy 21"[Title/Abstract] OR "intellectual disabilit*"[Title/Abstract] OR "intellectual delay*"[Title/Abstract] OR "intellectual disorder*"[Title/Abstract] OR "developmental disabilit*"[Title/Abstract] OR "developmental delay*"[Title/Abstract] OR "developmental disorder*"[Title/Abstract] OR "cognitive disabilit*"[Title/Abstract] OR "cognitive delay*"[Title/Abstract] OR "cognitive disorder*"[Title/Abstract] OR "learning disabilit*"[Title/Abstract] OR "learning delay*"[Title/Abstract] OR "learning disorder*"[Title/Abstract] OR "neurodevelopmental disabilit*"[Title/Abstract] OR "neurodevelopmental delay*"[Title/Abstract] OR "neurodevelopmental disorder*"[Title/Abstract] OR "persons with mental disabilit*"[Title/Abstract]
2. "Case Management"[MeSH Terms] OR "Continuity of Patient Care"[MeSH Terms:noexp] OR "care coordination"[Title/Abstract] OR "coordinated care"[Title/Abstract] OR "coordinating care"[Title/Abstract] OR "integrated care"[Title/Abstract] OR "transitional care"[Title/Abstract] OR "coordination of care"[Title/Abstract] OR "integration of care"[Title/Abstract] OR "care coordination model*"[Title/Abstract] OR "care coordination program*"[Title/Abstract] OR "care coordination service*"[Title/Abstract] OR "care coordination mechanism*"[Title/Abstract] OR "care coordinator*"[Title/Abstract] OR "care team*"[Title/Abstract] OR "care team coordination"[Title/Abstract] OR "care team coordinator*"[Title/Abstract] OR "continuum of care"[Title/Abstract] OR "care continuum"[Title/Abstract] OR "patient care continuity"[Title/Abstract] OR "continuity of care"[Title/Abstract] OR "care continuity"[Title/Abstract] OR "Case Management"[Title/Abstract] OR "care management"[Title/Abstract] OR "health management"[Title/Abstract] OR "healthcare management"[Title/Abstract]
3. "Adult"[MeSH Terms] OR "adult*"[Title/Abstract] OR "young adult*"[Title/Abstract] OR "middle aged"[Title/Abstract] OR "aged"[Title/Abstract] OR "elderly"[Title/Abstract] OR "geriatric"[Title/Abstract] OR "old age"[Title/Abstract] OR "aging"[Title/Abstract] OR "ageing"[Title/Abstract] OR "adult person*"[Title/Abstract] OR "adult people"[Title/Abstract] OR "adult individual*"[Title/Abstract] OR "adult population"[Title/Abstract] OR "adult patient*"[Title/Abstract] OR "aged person*"[Title/Abstract] OR "aged people"[Title/Abstract] OR "aged adult*"[Title/Abstract] OR "aged individual*"[Title/Abstract] OR "aged population"[Title/Abstract] OR "aged patient*"[Title/Abstract] OR "aging person*"[Title/Abstract] OR "aging people"[Title/Abstract] OR "aging adult*"[Title/Abstract] OR "aging individual*"[Title/Abstract] OR "aging population"[Title/Abstract] OR "aging patient*"[Title/Abstract] OR "ageing person*"[Title/Abstract] OR "ageing people"[Title/Abstract] OR "ageing adult*"[Title/Abstract] OR "ageing individual*"[Title/Abstract] OR "ageing population"[Title/Abstract] OR "ageing patient*"[Title/Abstract] OR "old person*"[Title/Abstract] OR "old people"[Title/Abstract] OR "old adult*"[Title/Abstract] OR "old individual*"[Title/Abstract] OR "old population"[Title/Abstract] OR "old patient*"[Title/Abstract] OR "older person*"[Title/Abstract] OR "older people"[Title/Abstract] OR "older adult*"[Title/Abstract] OR "older individual*"[Title/Abstract] OR "older population"[Title/Abstract] OR "older patient*"[Title/Abstract]
4. "randomized controlled trial"[Publication Type] OR "controlled clinical trial"[Publication Type] OR "Observational Study"[Publication Type] OR "Cohort Studies"[MeSH Terms] OR "Controlled Before-After Studies"[MeSH Terms] OR "Historically Controlled Study"[MeSH Terms] OR "Comparative Study"[Publication Type] OR "Epidemiology"[MeSH Terms] OR "Treatment Outcome"[MeSH Terms] OR "Follow-Up Studies"[MeSH Terms] OR "Time Factors"[MeSH Terms] OR "randomized"[Title/Abstract] OR "randomised"[Title/Abstract] OR "placebo"[Title/Abstract] OR "randomly"[Title/Abstract] OR "trial"[Title/Abstract] OR "groups"[Title/Abstract] OR "epidemiolog*"[Title/Abstract] OR "prevalence"[Title/Abstract] OR "chang*"[Title/Abstract] OR "evaluat*"[Title/Abstract] OR "reviewed"[Title/Abstract] OR "prospective"[Title/Abstract] OR "retrospective"[Title/Abstract] OR "baseline"[Title/Abstract] OR "cohort"[Title/Abstract] OR "consecutive"[Title/Abstract] OR "compare*"[Title/Abstract] OR "compara*"[Title/Abstract] OR "case series"[Title/Abstract]
5. #1 AND #2 AND #3 AND #4

Embase

Total Results: 382

1. 'Down syndrome'/exp OR 'mental deficiency'/exp OR 'developmental delay'/exp OR 'mentally disabled person'/exp OR 'down syndrome':ab,ti,kw OR 'trisomy 21':ab,ti,kw OR 'intellectual disabilit*':ab,ti,kw OR 'intellectual delay*':ab,ti,kw OR 'intellectual disorder*':ab,ti,kw OR 'developmental disabilit*':ab,ti,kw OR 'developmental delay*':ab,ti,kw OR 'developmental disorder*':ab,ti,kw OR 'cognitive disabilit*':ab,ti,kw OR 'cognitive delay*':ab,ti,kw OR 'cognitive disorder*':ab,ti,kw OR 'learning disabilit*':ab,ti,kw OR 'learning delay*':ab,ti,kw OR 'learning disorder*':ab,ti,kw OR 'neurodevelopmental disabilit*':ab,ti,kw OR 'neurodevelopmental delay*':ab,ti,kw OR 'neurodevelopmental disorder*':ab,ti,kw OR 'persons with mental disabilit*':ab,ti,kw
2. 'case management'/exp OR 'continuum of care'/mj OR 'care coordination':ab,ti,kw OR 'coordinated care':ab,ti,kw OR 'coordinating care':ab,ti,kw OR 'integrated care':ab,ti,kw OR 'transitional care':ab,ti,kw OR 'coordination of care':ab,ti,kw OR 'integration of care':ab,ti,kw OR 'care coordination model*':ab,ti,kw OR 'care coordination program*':ab,ti,kw OR 'care coordination service*':ab,ti,kw OR 'care coordination mechanism*':ab,ti,kw OR 'care coordinator*':ab,ti,kw OR 'care team*':ab,ti,kw OR 'care team coordination':ab,ti,kw OR 'care team coordinator*':ab,ti,kw OR 'continuum of care':ab,ti,kw OR 'care continuum':ab,ti,kw OR 'patient care continuity':ab,ti,kw OR 'continuity of care':ab,ti,kw OR 'care continuity':ab,ti,kw OR 'case management':ab,ti,kw OR 'care management':ab,ti,kw OR 'health management':ab,ti,kw OR 'healthcare management':ab,ti,kw
3. 'adult'/exp OR 'adult*':ab,ti,kw OR 'young adult*':ab,ti,kw OR 'middle aged':ab,ti,kw OR 'aged':ab,ti,kw OR 'elderly':ab,ti,kw OR 'geriatric':ab,ti,kw OR 'old age':ab,ti,kw OR 'aging':ab,ti,kw OR 'ageing':ab,ti,kw OR 'adult person*':ab,ti,kw OR 'adult people':ab,ti,kw OR 'adult individual*':ab,ti,kw OR 'adult population':ab,ti,kw OR 'adult patient*':ab,ti,kw OR 'aged person*':ab,ti,kw OR 'aged people':ab,ti,kw OR 'aged adult*':ab,ti,kw OR 'aged individual*':ab,ti,kw OR 'aged population':ab,ti,kw OR 'aged patient*':ab,ti,kw OR 'aging person*':ab,ti,kw OR 'aging people':ab,ti,kw OR 'aging adult*':ab,ti,kw OR 'aging individual*':ab,ti,kw OR 'aging population':ab,ti,kw OR 'aging patient*':ab,ti,kw OR 'ageing person*':ab,ti,kw OR 'ageing people':ab,ti,kw OR 'ageing adult*':ab,ti,kw OR 'ageing individual*':ab,ti,kw OR 'ageing population':ab,ti,kw OR 'ageing patient*':ab,ti,kw OR 'old person*':ab,ti,kw OR 'old people':ab,ti,kw OR 'old adult*':ab,ti,kw OR 'old individual*':ab,ti,kw OR 'old population':ab,ti,kw OR 'old patient*':ab,ti,kw OR 'older person*':ab,ti,kw OR 'older people':ab,ti,kw OR 'older adult*':ab,ti,kw OR 'older individual*':ab,ti,kw OR 'older population':ab,ti,kw OR 'older patient*':ab,ti,kw
4. 'randomized controlled trial'/exp OR 'controlled clinical trial'/exp OR 'observational study'/exp OR 'cohort analysis'/exp OR 'epidemiology'/exp OR 'comparative study'/exp OR 'treatment outcome'/exp OR 'follow up'/exp OR 'time factor'/exp OR 'randomized':ab,ti,kw OR 'randomised':ab,ti,kw OR 'placebo':ab,ti,kw OR 'randomly':ab,ti,kw OR 'trial':ab,ti,kw OR 'groups':ab,ti,kw OR 'epidemiolog*':ab,ti,kw OR 'prevalence':ab,ti,kw OR 'chang*':ab,ti,kw OR 'evaluat*':ab,ti,kw OR 'reviewed':ab,ti,kw OR 'prospective':ab,ti,kw OR 'retrospective':ab,ti,kw OR 'baseline':ab,ti,kw OR 'cohort':ab,ti,kw OR 'consecutive':ab,ti,kw OR 'compare*':ab,ti,kw OR 'compara*':ab,ti,kw OR 'case series':ab,ti,kw
5. #1 AND #2 AND #3 AND #4

CINAHL

Total Results: 384

1. TI ((MM "Down Syndrome") OR (MM "Intellectual Disability") OR (MM "Developmental Disabilities") OR (MM "Mentally Disabled Persons")) OR down syndrome OR trisomy 21 OR intellectual disabilit* OR intellectual delay* OR intellectual disorder* OR developmental disabilit* OR developmental delay* OR developmental disorder* OR cognitive disabilit* OR cognitive delay* OR cognitive disorder* OR learning disabilit* OR learning delay* OR learning disorder* OR neurodevelopmental disabilit* OR neurodevelopmental delay* OR neurodevelopmental disorder* OR persons with mental disabilit*) OR AB ((MM "Down Syndrome") OR (MM "Intellectual Disability") OR (MM "Developmental Disabilities") OR (MM "Mentally Disabled Persons")) OR down syndrome OR trisomy 21 OR intellectual disabilit* OR intellectual delay* OR intellectual disorder* OR developmental disabilit* OR developmental delay* OR developmental disorder* OR cognitive disabilit* OR cognitive delay* OR cognitive disorder* OR learning

- disabilit* OR learning delay* OR learning disorder* OR neurodevelopmental disabilit* OR neurodevelopmental delay* OR neurodevelopmental disorder* OR persons with mental disabilit*)
2. TI ((MM "Case Management") OR (MM "Continuity of Patient Care") OR care coordination OR coordinated care OR coordinating care OR integrated care OR transitional care OR coordination of care OR integration of care OR care coordination model* OR care coordination program* OR care coordination service* OR care coordination mechanism* OR care coordinator* OR care team* OR care team coordination OR care team coordinator* OR continuum of care OR care continuum OR patient care continuity OR continuity of care OR care continuity OR case management OR care management OR health management OR healthcare management) OR AB ((MM "Case Management") OR (MM "Continuity of Patient Care") OR care coordination OR coordinated care OR coordinating care OR integrated care OR transitional care OR coordination of care OR integration of care OR care coordination model* OR care coordination program* OR care coordination service* OR care coordination mechanism* OR care coordinator* OR care team* OR care team coordination OR care team coordinator* OR continuum of care OR care continuum OR patient care continuity OR continuity of care OR care continuity OR case management OR care management OR health management OR healthcare management)
 3. TI ((MH "Adult+") OR adult* OR young adult* OR middle aged OR aged OR elderly OR geriatric OR old age OR aging OR ageing OR adult person* OR adult people OR adult individual* OR adult population OR adult patient* OR aged person* OR aged people OR aged adult* OR aged individual* OR aged population OR aged patient* OR aging person* OR aging people OR aging adult* OR aging individual* OR aging population OR aging patient* OR ageing person* OR ageing people OR ageing adult* OR ageing individual* OR ageing population OR ageing patient* OR old person* OR old people OR old adult* OR old individual* OR old population OR old patient* OR older person* OR older people OR older adult* OR older individual* OR older population OR older patient*) OR AB ((MH "Adult+") OR adult* OR young adult* OR middle aged OR aged OR elderly OR geriatric OR old age OR aging OR ageing OR adult person* OR adult people OR adult individual* OR adult population OR adult patient* OR aged person* OR aged people OR aged adult* OR aged individual* OR aged population OR aged patient* OR aging person* OR aging people OR aging adult* OR aging individual* OR aging population OR aging patient* OR ageing person* OR ageing people OR ageing adult* OR ageing individual* OR ageing population OR ageing patient* OR old person* OR old people OR old adult* OR old individual* OR old population OR old patient* OR older person* OR older people OR older adult* OR older individual* OR older population OR older patient*)
 4. TI ((MH "Randomized Controlled Trials") OR (MH "Nonexperimental Studies") OR (MH "Prospective Studies") OR (MH "Controlled Before-After Studies") OR (MH "Historically Controlled Study") OR (MH "Comparative Studies") OR (MH "Epidemiological Research") OR (MH "Treatment Outcomes") OR (MH "Time Factors") OR randomized OR randomised OR placebo OR randomly OR trial OR groups OR epidemiolog* OR prevalence OR chang* OR evaluat* OR reviewed OR prospective OR retrospective OR baseline OR cohort OR consecutive OR compare* OR compara* OR case series) OR AB ((MH "Randomized Controlled Trials") OR (MH "Nonexperimental Studies") OR (MH "Prospective Studies") OR (MH "Controlled Before-After Studies") OR (MH "Historically Controlled Study") OR (MH "Comparative Studies") OR (MH "Epidemiological Research") OR (MH "Treatment Outcomes") OR (MH "Time Factors") OR randomized OR randomised OR placebo OR randomly OR trial OR groups OR epidemiolog* OR prevalence OR chang* OR evaluat* OR reviewed OR prospective OR retrospective OR baseline OR cohort OR consecutive OR compare* OR compara* OR case series)
 5. #1 AND #2 AND #3 AND #4

Web of Science

Total Results: 3,284

1. TI=(down syndrome or trisomy 21 or intellectual disabilit* or intellectual delay* or intellectual disorder* or developmental disabilit* or developmental delay* or developmental disorder* or cognitive disabilit* or cognitive delay* or cognitive disorder* or learning disabilit* or learning delay* or learning disorder* or neurodevelopmental disabilit* or neurodevelopmental delay* or neurodevelopmental disorder* or persons with mental disabilit*) OR AB=(down syndrome or trisomy 21 or intellectual disabilit* or intellectual delay* or intellectual disorder* or developmental disabilit* or developmental delay* or developmental disorder* or cognitive disabilit* or cognitive delay* or cognitive disorder* or learning disabilit* or learning delay* or learning disorder* or neurodevelopmental disabilit* or neurodevelopmental delay* or neurodevelopmental disorder* or persons with mental disabilit*)

2. TI=(care coordination or coordinated care or coordinating care or integrated care or transitional care or coordination of care or integration of care or care coordination model* or care coordination program* or care coordination service* or care coordination mechanism* or care coordinator or care team* or care team coordination or care team coordinator or continuum of care or care continuum or patient care continuity or continuity of care or care continuity or care management or health management or healthcare management) OR AB=(care coordination or coordinated care or coordinating care or integrated care or transitional care or coordination of care or integration of care or care coordination model* or care coordination program* or care coordination service* or care coordination mechanism* or care coordinator or care team* or care team coordination or care team coordinator or continuum of care or care continuum or patient care continuity or continuity of care or care continuity or care management or health management or healthcare management)
3. TI=(adult* or young adult* or middle aged or aged or elderly or geriatric or old age or aging or ageing or adult person* or adult people or adult individual* or adult population or adult patient* or aged person* or aged people or aged adult* or aged individual* or aged population or aged patient* or aging person* or aging people or aging adult* or aging individual* or aging population or aging patient* or ageing person* or ageing people or ageing adult* or ageing individual* or ageing population or ageing patient* or old person* or old people or old adult* or old individual* or old population or old patient* or older person* or older people or older adult* or older individual* or older population or older patient*) OR AB=(adult* or young adult* or middle aged or aged or elderly or geriatric or old age or aging or ageing or adult person* or adult people or adult individual* or adult population or adult patient* or aged person* or aged people or aged adult* or aged individual* or aged population or aged patient* or aging person* or aging people or aging adult* or aging individual* or aging population or aging patient* or ageing person* or ageing people or ageing adult* or ageing individual* or ageing population or ageing patient* or old person* or old people or old adult* or old individual* or old population or old patient* or older person* or older people or older adult* or older individual* or older population or older patient*)
4. TI=(randomized controlled trial or controlled clinical trial or observational study or cohort studies or controlled before-after studies or historically controlled study or comparative study or epidemiology or treatment outcome or follow-up studies or time factors or randomized or randomised or placebo or randomly or trial or groups or epidemiolog* or prevalence or chang* or evaluat* or reviewed or prospective or retrospective or baseline or cohort or consecutive or compare or compara* or case series) OR AB=(randomized controlled trial or controlled clinical trial or observational study or cohort studies or controlled before-after studies or historically controlled study or comparative study or epidemiology or treatment outcome or follow-up studies or time factors or randomized or randomised or placebo or randomly or trial or groups or epidemiolog* or prevalence or chang* or evaluat* or reviewed or prospective or retrospective or baseline or cohort or consecutive or compare or compara* or case series)
5. #1 AND #2 AND #3 AND #4

APA PsycINFO

Total Results: 270

1. TI ((MM "Down's Syndrome") OR (DE "Intellectual Development Disorder") OR (MM "Developmental Disabilities") OR down syndrome OR trisomy 21 OR intellectual disabilit* OR intellectual delay* OR intellectual disorder* OR developmental disabilit* OR developmental delay* OR developmental disorder* OR cognitive disabilit* OR cognitive delay* OR cognitive disorder* OR learning disabilit* OR learning delay* OR learning disorder* OR neurodevelopmental disabilit* OR neurodevelopmental delay* OR neurodevelopmental disorder* OR persons with mental disabilit*) OR AB ((MM "Down's Syndrome") OR (DE "Intellectual Development Disorder") OR (MM "Developmental Disabilities") OR down syndrome OR trisomy 21 OR intellectual disabilit* OR intellectual delay* OR intellectual disorder* OR developmental disabilit* OR developmental delay* OR developmental disorder* OR cognitive disabilit* OR cognitive delay* OR cognitive disorder* OR learning disabilit* OR learning delay* OR learning disorder* OR neurodevelopmental disabilit* OR neurodevelopmental delay* OR neurodevelopmental disorder* OR persons with mental disabilit*)
2. TI ((MM "Case Management") OR (DE "Continuum of Care") OR care coordination OR coordinated care OR coordinating care OR integrated care OR transitional care OR coordination of care OR integration of care OR care coordination model* OR care coordination program* OR care coordination service* OR care coordination mechanism* OR care coordinator* OR care team* OR care team coordination OR care team coordinator* OR continuum of care OR care continuum OR patient care continuity OR continuity of care OR care continuity OR case management OR care management OR health management OR healthcare

- management) OR AB ((MM "Case Management") OR (DE "Continuum of Care") OR care coordination OR coordinated care OR coordinating care OR integrated care OR transitional care OR coordination of care OR integration of care OR care coordination model* OR care coordination program* OR care coordination service* OR care coordination mechanism* OR care coordinator* OR care team* OR care team coordination OR care team coordinator* OR continuum of care OR care continuum OR patient care continuity OR continuity of care OR care continuity OR case management OR care management OR health management OR healthcare management)
3. TI (adult* OR young adult* OR middle aged OR aged OR elderly OR geriatric OR old age OR aging OR ageing OR adult person* OR adult people OR adult individual* OR adult population OR adult patient* OR aged person* OR aged people OR aged adult* OR aged individual* OR aged population OR aged patient* OR aging person* OR aging people OR aging adult* OR aging individual* OR aging population OR aging patient* OR ageing person* OR ageing people OR ageing adult* OR ageing individual* OR ageing population OR ageing patient* OR old person* OR old people OR old adult* OR old individual* OR old population OR old patient* OR older person* OR older people OR older adult* OR older individual* OR older population OR older patient*) OR AB (adult* OR young adult* OR middle aged OR aged OR elderly OR geriatric OR old age OR aging OR ageing OR adult person* OR adult people OR adult individual* OR adult population OR adult patient* OR aged person* OR aged people OR aged adult* OR aged individual* OR aged population OR aged patient* OR aging person* OR aging people OR aging adult* OR aging individual* OR aging population OR aging patient* OR ageing person* OR ageing people OR ageing adult* OR ageing individual* OR ageing population OR ageing patient* OR old person* OR old people OR old adult* OR old individual* OR old population OR old patient* OR older person* OR older people OR older adult* OR older individual* OR older population OR older patient*)
 4. TI ((MH "Randomized Controlled Trials") OR (MH "Nonexperimental Studies") OR (MH "Prospective Studies") OR (MH "Controlled Before-After Studies") OR (MH "Historically Controlled Study") OR (MH "Comparative Studies") OR (MH "Epidemiological Research") OR (MH "Treatment Outcomes") OR (MH "Time Factors")) OR randomized OR randomised OR placebo OR randomly OR trial OR groups OR epidemiolog* OR prevalence OR chang* OR evaluat* OR reviewed OR prospective OR retrospective OR baseline OR cohort OR consecutive OR compare* OR compara* OR case series) OR AB ((MH "Randomized Controlled Trials") OR (MH "Nonexperimental Studies") OR (MH "Prospective Studies") OR (MH "Controlled Before-After Studies") OR (MH "Historically Controlled Study") OR (MH "Comparative Studies") OR (MH "Epidemiological Research") OR (MH "Treatment Outcomes") OR (MH "Time Factors")) OR randomized OR randomised OR placebo OR randomly OR trial OR groups OR epidemiolog* OR prevalence OR chang* OR evaluat* OR reviewed OR prospective OR retrospective OR baseline OR cohort OR consecutive OR compare* OR compara* OR case series)
 5. #1 AND #2 AND #3 AND #4

Appendix B. Data Extraction Table

First Author, Year of Publication, Country, and Language	Purpose (Direct Quote)	Population/Sample Size	Methodology	Care Coordination Effort	Impact of Care Coordination	Relevant Findings
<p>Williamson (2018) United States, English</p>	<p>To understand how family caregivers and their roles were recognized in MLTSS for adults with IDD in Kansas</p>	<p>N=31 Kansas stakeholders (n=13 statewide/regional representatives; n=7 service coordination providers; n=11 family caregivers)</p>	<p>"In-depth semi-structured telephone interviews"</p>	<p>MLTSS was a managed care approach to the delivery of long-term services through Medicaid. Kansas transitioned to the MLTSS approach, referred to as KanCare. The aim was to increase access to services through improved care coordination. With KanCare, families worked with a case manager and care coordinator.</p>	<p>Impact not specifically addressed</p>	<p>Interviews highlighted individual experiences regarding care coordination through KanCare, including issues with communication, care coordinator caseload, and conflict of interest</p>
<p>Martin (2019) Canada, English</p>	<p>To pilot a novel, enhanced model of care coordination for complex patients with IDD</p>	<p>9 clients with IDD</p>	<p>Not listed, as this was not a research study, but a program description.</p>	<p>This pilot program was tailored to adults with IDD and facilitated services across health and social sectors. It utilized a health links care coordinator that created a coordinated care plan (CCP) with patients and their caregivers.</p>	<p>Impact not specifically addressed</p>	<p>Faced challenges in patient recruitment, involving primary care providers in care coordination, and collaboration</p>