Care Coordination for Children with Special Health Care Needs: A Scoping Review to Inform Strategies for Students with Traumatic Brain Injuries

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ABSTRACT

BACKGROUND: Chronic and complex medical issues, including traumatic brain injuries (TBIs), have significant educational implications. The purpose of this study was to identify and summarize the literature on care coordination strategies among healthcare professionals, educators, and caregivers for children with special healthcare needs (CSHCN). Clarifying factors that influence care coordination for CSHCN can inform future studies on care coordination for students with TBI. Improved understanding of these factors may lead to better communication, reduction of unmet needs, more efficient service access, and improved long-term outcomes for children.

METHODS: A scoping review was conducted, guided by PRISMA-ScR methodology. Five databases (CINAHL, PSYCINFO, EMBASE, ERIC, PubMed) were searched to identify relevant studies that focused on care coordination and educational settings.

RESULTS: Twelve articles met inclusion criteria. Care coordination interventions for CSHCN used in educational settings focused on relationship-building strategies, clear procedures and roles, and education of members of the school community.

CONCLUSIONS: Findings highlight strategies to coordinate care for CSHCN and factors that may moderate effects of these interventions. Key stakeholders should now study these strategies specifically in children with TBI.

Keywords: traumatic brain injury, chronic illness, complex medical condition, scoping review, care coordination

Care Coordination for Children with Special Healthcare Needs:

A Scoping Review to Inform Strategies for Students with TBI

A traumatic brain injury (TBI) is not a singular event; rather, it is a chronic disease process that can lead to lifelong changes in one's health and well-being[1,2]. Children who have sustained TBIs may experience a range of cognitive, physical, academic, emotional, and behavioral challenges[3-5]. The transition from a hospital or rehabilitation facility back to school can be particularly challenging. Beyond that transition, many students experience persistent issues related to their TBI that interfere with success in school. Multiple stakeholders are responsible for supporting the educational needs of students with TBI, including family members and caregivers, healthcare providers, educators, and school personnel. Coordination of services among these systems of care can help maximize child outcomes[6].

In 2014, there were approximately 2.87 million TBI-related emergency department visits, hospitalizations, and deaths in the United States, including over 837,000 among children[7]. Injuries that previously may have been fatal are increasingly survived but result in chronic difficulties. Greater injury severity is associated with increased need for school support services[8]. Health status and school performance are linked to overall short-term and long-term quality of life outcomes for children with a chronic medical condition[9]. TBIs are particularly difficult for school-age youth because in addition to difficulties with memory, coordination, language, and emotional regulation, TBIs can affect students' relationships and participation in the classroom and extracurricular activities[10-12]. A student who previously was previously social and maintained good grades may now struggle to comprehend and retain information. She may lose friends due to mood swings and communication difficulties. Her teachers may perceive her as

inattentive because she struggles with focus and work completion. These problems can be compounded by the fact that a TBI is often an invisible injury[13,14], meaning that the difficulties children experience are less often obvious physical problems. Rather, challenges are typically subtle cognitive and communication related impairments making them harder to "see." When children who have sustained TBIs return to school, their teachers may not understand their educational needs, particularly if there is a lack of communication between medical providers, caregivers, and educational professionals.

Care coordination involves organizing patient care activities between two or more care providers[15]. It can both prevent and address obstacles to effective and efficient care. Coordinated care can include interdisciplinary communication, coordination of treatment activities, and service integration across institutions. Much of the care coordination literature focuses on coordination among medical providers,[16-18] such as establishing a "medical home" for students with chronic conditions such as asthma[19-21], cerebral palsy[22, 23] or chronic respiratory failure[24, 25]. There is, however, no established model of care coordination for children with TBI, which contributes to risk for poor long-term outcomes[26]. The development and dissemination of best practice guidelines for care coordination is a critical area for improvement in TBI management. Strong coordination of care that includes the educational setting as a key partner can help ensure efficient and effective services, including an adaptation of the learning environment in a way that accommodates physical, cognitive, and emotional needs [27]. This includes coordinating with school-based related service providers who are allied health professionals, such as speech pathologists, occupational therapists, and physical therapists. Although there is expert opinion literature on improving educational services for children with TBIs[29-31], as well as a small number of studies examining issues related to hospital-school transition and school

reintegration[32-34], few empirical studies specifically examine care coordination between medical and educational providers for students with TBIs. One study[35] evaluated the STEP model, a systematic hospital-school transition protocol for children hospitalized for TBI; however, there were no significant differences for students in the usual care versus intervention groups on special education eligibility, support services provided, or academic accommodations at one month or one year post-discharge. The authors proposed that the lack of effects may have been related to the timing of treatment, dosage/intensity of intervention, outcome measures, and/or fidelity of program delivery. Further, because many of the children in the "usual care" group received inpatient rehabilitation programming, they received fairly robust transition services, not very dissimilar to those received by students in the intervention group. Because medical-to-educational care coordination for students with TBI is a major gap in the literature, and to inform future studies that might explore this issue, we sought to synthesize the literature related to care coordination for children with special health care needs (CSHCN). The goal of this work is to help inform future work with children who have TBIs. Ineffective care coordination for children with TBIs can be a significant barrier to effective transition and intervention[36,37] and few studies have provided strong direction in how to address the problem. In 2017, Breneol et al.[38] conducted a scoping review on strategies to support transitions from hospital to home for children with medical complexity. Our study builds on this work by including the school as a critical part of the transition process and models of support. This project is part of a larger scoping review on care coordination; this manuscript specifically addresses the literature related to medical-educational care coordination. Our other reviews examine the care coordinator role and tools for care coordination in CSHCN. Thus, the aim of this scoping review was to identify and summarize literature on care coordination models that include the educational setting for

CSHCN, with the overall goal of making recommendations for future studies focusing on improving care coordination for children with TBIs. The research question guiding this scoping review was: What factors improve hospital-to-school care coordination for CSHCN? It is expected that findings of this review will be helpful to educators, healthcare professionals, caregivers, and other researchers involved in studying and treating a variety of chronic health conditions, including TBIs.

METHODS

This scoping review uses the PRISMA framework for scoping reviews (PRISMA-ScR) described by Tricco et al.[39].

Data Sources and Search Strategy

In January 2020, an interactive process between the first and third author, a group of related professionals, and a medical librarian discussed this review and generated ideas for key word searches. After iterative search trials to explore results using the selected search terms, the group selected those included in this review for the final terms. The medical librarian conducted searches of the following databases: Ovid MEDLINE, CINAHL, EMBASE, ERIC, and PsycINFO. Search terms are in Table 1.

Insert Table 1 about here

Following the initial search, titles and abstracts were exported into Rayyan QCRI, a web-based application for systematic reviews[40]. After duplicates were removed, 4 research volunteers evaluated 2096 titles and abstracts to identify papers that warranted additional review. Each

abstract was reviewed independently by 2 reviewers, and when the reviewers did not agree, the third author served as an additional reviewer.

In the second review stage, 286 articles were fully screened. Each of the studies was assigned to two persons who independently rated the inclusion criteria. In cases of disagreement, a third reviewer independently reviewed the paper to determine eligibility.

Inclusion and Exclusion Criteria

To be included in the final scoping review, studies had to meet the following criteria: (a) involved care for persons under age 25 with a chronic medical condition, (b) were published since 2009, (c) included an examination of at least 1 intervention related to care coordination for CSHCN, and for this manuscript specifically, related to hospital-school transition. Researchers excluded papers that were (a) not published in English, (b) not related to a pediatric chronic medical condition, (c) expert opinion, dissertations, presentation/conference abstracts, or review articles (i.e., scoping reviews, systematic reviews), and (d) did not include a care coordination intervention that was relevant or applicable to children with TBI.

Data Extraction

Based on the goals of this review, researchers used a data extraction spreadsheet to record relevant variables from each included study. Researchers recorded data on (1) year of publication and location of study, (2) study aims, design, and population, (3) care coordination interventions and outcomes, (4) study results, and (5) additional notes or findings of interest. Each study was assigned to one researcher to review and tabulate. Twenty percent of articles were reviewed by a second researcher to ensure reliability in data extraction. Overall, point-by-point agreement was 88%. Consistent with scoping review methodology, researchers did not assess the scientific level of evidence of the intervention studies included in this review.

RESULTS

The initial search yielded 2498 total articles. After duplicates were removed, 286 titles

and abstracts were identified for further review. In the second stage of review, 62 articles met

inclusion criteria for the overall care coordination scoping review, with 12 articles meeting full

criteria to be included in this review (see Table 2). Of the remaining 50 articles, 19 articles were

included in the care coordination tools scoping review and 31 articles included in the care

coordination roles paper (see Figure 1).

Insert Table 2 about here

Insert Figure 1—PRISMA diagram—about here

Because the goal of our scoping review was to identify studies that implemented any type

of care coordination intervention for CSHCN, "school" was not specifically included as a search

term in the initial search strategy. As the research group evaluated included papers, they

determined that papers discussing hospital-to-school transitions offered a unique opportunity to

examine this aspect of care coordination specifically. Thus, since the medical-educational

transition is an important part of pediatric care coordination for CSHCN that needs additional

attention, the research team completed a secondary hand-search of reference lists and database

suggestions related to "school" and "care coordination," with the plan to add any additional

papers that examined hospital-school care coordination for CSHCN specifically. However, this

hand-search yielded no additional articles related to medical-educational care coordination for CSHCN.

The 12 articles selected for this scoping review were published between 2009 and 2019. Six of the articles have been published since 2015, suggesting that the data collected for this care coordination review is recent and this area of research is developing. Study designs included qualitative and quantitative design. Six of the studies used quantitative methods; three studies used qualitative methods; the last three studies were mixed-methods, using both quantitative and qualitative methods. Eight of the 12 studies took place in the United States, two of the studies took place in Canada, and the remaining two studies took place in Britain and Australia. The majority of the studies' participants were school-aged children and youth; the only study that did not contain school aged participants investigated parent perspectives of care coordination for CSHCN. For a description of the purpose and sample population of each study, see Table 2. For a description of each study's procedures, interventions, and results, see Table 3. Five of the articles in this review discussed care coordination studies that involve the school as a hub of service implementation; the others addressed coordinating services between families and schools.

Care Coordination Interventions for CSHCN Involving the School

We identified three major care coordination intervention strategies involving the schools: 1) developing strong relationships, 2) establishing clear procedures and roles, and 3) providing education.

Relationship-building to facilitate care coordination. Of the 12 articles included in this review, seven implemented relationship-building strategies into their intervention. One article assessed the importance of including families[41]and two other articles examined the process of

including students as key partners in care coordination between medical and educational teams[42,43]. Rowlandson and Smith[41] found that when families were included as a key partner in care coordination, they reported positive experiences regarding diagnosis and assessment processes. Including students in the care coordination process is also important and can take different forms. Two of the included articles explained common themes that arose when including students in this process. Specifically, in order to have effective coordinating relationships that include positive child involvement, major factors include: maintaining good communication, working to better understand the child, strengthening the relationship with the child, and creating an atmosphere where the child is the focus[42,43].

Four articles[44-46,21] assessed the importance of establishing reciprocal referral relationships between medical providers and schools, assessing student/family needs, and providing access to services and care when needed. Coughey et al.[44] found that families who use Link Line, a care coordination service that established referral relationships and connections between school districts and local hospitals, were less likely to have emergency department and hospital visits the following year. Connections between schools and hospitals were made through Link Line, a telephone-based care coordination system that encouraged users to call at any time. When families called Link Line, asthma care coordinators would link families with appropriate services[44]. When care coordination assesses for and responds to individualized needs for students with asthma, researchers found a decrease in school absences and emergency department visits[46]. Findley et al.[45] evaluated the effectiveness of developing reciprocal relationships within a community-based care coordination model for children with asthma and also found a decrease in emergency department visits and hospitalizations and an increase in caregiver confidence in the ability to control asthma and reduce triggers. Lastly, the setting in which a support organization

is located affects the accessibility of care. Kelly et al.[21] found that the relationship between care

coordination implementation teams and the organizations that are providing student support,

along with the amount of support these organizations are providing, were important factors

contributing to the care coordination of students with asthma. Having relationships and support

for students from participating organizations helped to influence the integration of care

coordinators into clinical care teams and the identification of student participants[21].

Clear procedures and roles to facilitate care coordination. Ten of the 12 included

studies implemented interventions to establish clear procedures and roles to facilitate hospital-

educational care coordination for CSHCN. Salm[42] found that developing clear expectations for

all members of the team helped to foster collaboration and an understanding of what each team

member brings to the partnership. Clear procedures and roles can also come in the form of

designating school personnel to lead care coordination for CSHCN and providing a liaison in the

form of a care coordinator can improve care coordination between medical and school personnel.

One article designated specific school personnel as a liaison for students with autism spectrum

disorder, attention deficit hyperactivity disorder, or a dual diagnosis of the two. Researchers

found an increase in the ability to gather information from multiple areas of the child's life,

better coordination between families and use of interventions between home and school, and

higher satisfaction levels from parents and students who have been engaged in the program[41].

Having a care coordinator from the healthcare environment serve as a liaison can be an

alternative to having school personnel take on this role. Findley et al.[45], Kelly et al.[21], and

Liptzen et al.[47] showed that when community based care coordinators serve as liaisons, families

have an increase in communication with medical providers overall, an increase in their personal

ability to communicate with providers, and an increase in access to these providers.

Within the ten articles that examined the identification of clear procedures and roles to

best support care coordination, four articles also discussed effective use of technology and

paperwork/forms to assist in this care coordination intervention. These studies demonstrated that

enhancing communication via phone calls led to decreased rates of unplanned

hospitalizations[48,44]. However, telephone-based communication may not always be feasible and

instead a streamlined electronic process and online forms can also be used effectively. In one

study, such forms, physical or virtual, streamlined the process of care coordination and improved the workflow of care for patients[49]. Hamburger et al.[46] also included the use of forms by way of medication administration care plans, and this study concluded that there were positive associations regarding the care provided. Medication tracking and care plan forms help provide data if medical providers are considering altering medication type and/or dosage, and this is useful for school personnel. Medication administration care plans can also help home caregivers because they will have a document to refer to when caring for their child.

   Education to facilitate care coordination between hospitals and schools. One article included education as a potential intervention to improve medical-educational care coordination for CSHCN[47]. Professional development for educators and educational programs for students with asthma improved the effectiveness of care coordination between medical and school providers. Researchers found that after teaching students' peers about asthma and its treatments, students better understood how inhalers are used and had a better general understanding of asthma. A significant increase in school-developed action plans and availability of rescue medications were also reported after the educational intervention was administered to staff and students.

DISCUSSION

   The purpose of this scoping review was to identify and summarize the existing literature focusing on care coordination among medical professionals, educators, and caregivers for CSHCN. This is important because information gathered from this summarization of the literature can help develop future studies on care coordination for students who have sustained TBIs, where there is a substantial lack of research but a persistent need. The care coordination

interventions described in this scoping review as implemented in studies focusing on CSHCN emphasized different aspects of care coordination between medical and school settings, but all had the common themes of supporting students and families and improving the long-term outcomes of students with CSHCN.

Our scoping review looked globally at care coordination for CSHCN, yet our search only identified 12 studies that have explored specific strategies to improve hospital-to-school care coordination for medically vulnerable students with a variety of chronic diagnoses. The need to research care coordination that includes school personnel is clear. Little research examines how the care of students who have sustained a TBI is coordinated as they transition from full-time care in a hospital or at home back to school. Because of the chronic, complex, and potential long-term needs of students with TBI, it is likely that they would benefit from well-developed care coordination programs in a similar way that students with asthma and other chronic medical conditions have been shown to benefit.

The results of this scoping review highlighted the importance of establishing strong relationships between medical and school personnel involved with the care of a CSHCN. One barrier to relationship-building within care coordination can be the number of people involved in the process. A care coordinator can initiate relationships and foster the connections made between families and different care providers from various settings, such as schools and hospitals. This is particularly important for students with TBI because of the sudden nature of the condition, occurring in a child who may have had no previous educational or medical needs. Whereas families of students with specialized healthcare needs often have years to develop relationships with medical and educational service providers, a TBI often requires that parents immediately get up-to-speed on issues related to health insurance, service providers, and special

education. Trusted professionals can help with this difficult process. This conclusion is supported by Hafeez et al.[50] which found that by incorporating a care coordinator into the process of organizing care for children with epilepsy they were able to provide support in a variety of contexts. It is likely that establishing this type of support for students and families with TBI may also be beneficial.

The establishment of clear procedures and roles between hospital and educational providers was another major strategy emphasized in the studies included in this scoping review. When all members of the care team know what to do, the needs of the child and family can be appropriately addressed. For example, streamlining paperwork can ensure that there is a clear record of what the family needs and what services have already been provided[49]. This can make problem solving more effective in the future. These procedures can also incorporate technology to make collaboration more efficient, particularly when there are numerous collaborators from a variety of settings. Because students with TBI often experience rapid recovery post-injury, this can be particularly helpful for progress monitoring and quick communication of necessary intervention modifications.

Although education was a less prominent theme, providing education to school personnel about a child's specific medical condition can ensure that key stakeholders understand the child's unique needs in the school setting. Evidence for providing education about medical conditions of CSHCN to school personnel supports expert opinion related to the importance of educating stakeholders about TBI[32,51]. Studies identified in this scoping review indicate that future research should implement this strategy for children with TBI and monitor the effects of this care coordination strategy. Further, if medical providers can educate teachers and peers about the implications of TBI, it could positively affect post-TBI issues that emerge at school, such as

challenges with behavior, communication, and attention. It is helpful when professional

development in TBI for educators includes training in evidence-based interventions, supervised

practice with new skills, and continued mentoring, feedback, and consultation in the school

setting[51]. Education efforts can expand beyond the members of a care coordination team. This

includes educating teachers about the effects of TBI on a student's classroom performance[32]

and educating the peers at school about how they can support their classmate[47].

Limitations

As a scoping review, this work seeks to synthesize existing research on a broad topic;

therefore, no definitive conclusions or recommendations can be made to directly change clinical

and educational practice at this time. Past research on hospital-to-school care coordination for

CSHCN allows us to consider how to design future research studies focusing on children with

TBI. More studies are needed to test specific questions regarding the effectiveness of care

coordination strategies for students with TBIs. As with all scoping reviews, it is possible that

relevant articles were missed based on our search strategies. We used additional strategies, as

discussed, to supplement our search with hand searches to identify any relevant literature missed

in our initial search. We also limited our search to the last ten years to focus on the most relevant

and timely studies. Because most of the studies we found were published in the last five years,

we believe that we have captured the relevant, published literature on this topic. Only literature

written in English was included in this review; this limits the scope of the reviews included to

only one language.

Conclusions and Implications for Future Research

This review described the current state of literature on care coordination between

hospitals/medical providers and schools for CSHCN, with the aim of synthesizing this literature

and considering how it could be applied in future studies to support students with TBIs. This scoping review investigated the common themes and previously studied interventions focusing on care coordination between families, healthcare professionals, and schools. The studies included in this scoping review highlight the importance of identifying a care coordinator to assure successful communication amongst all parties when trying to enhance care coordination for CSHCN. Overall, this review indicates that relationship-building strategies, clear procedures and roles, and education of both professionals and students/families can help improve care coordination, thereby fostering better outcomes for teams and students. Based on the strategies that have been found successful in studies of CSHCN, future studies should investigate these specific care coordination strategies for students with TBI. Researchers should consider methods to take the above examples from care coordination studies in CSHCN and study them for children with TBI.

IMPLICATIONS FOR SCHOOL HEALTH & EQUITY

The data collected in this care coordination scoping review inform practitioners of the strategies that are most effective in supporting CSHCN and their families between medical and school settings. While research is needed to confirm that the implementation of these strategies will improve the success of students with TBI, the major strategies discussed above---relationships, clear procedures and roles, and education---align with expert opinion and reinforce strategies with which educators are already familiar. For example, strong relationships and frequent check-ins with a care coordinator may be particularly beneficial for students with TBI due to the rapid changes that can take place after a young person experiences brain injury. Providing education to those who serve children as they transition back into the school setting would likely also be beneficial for educators, families, and children. Initial programs have been

developed[52] and could be studied prospectively. TBI symptoms can vary from person to person, so providing key individuals with a basic understanding of the signs and symptoms of TBI, and evidence-based procedures to address limitations in the classroom, can help to support students in their transition back to school. In response to this review, and to improve the health, equity, and academic success of students with TBI, some practical strategies schools could immediately consider include the following:

- Identify a team member at each school building who will be the point person to communicate with medical or outside providers for children with TBI. Gather information about goals and needs. A school nurse, psychologist, or speech-language pathologist are examples of appropriate professionals who could fill this role.

- Establish clear procedures that will be followed to screen for TBI in students at all key entry or transition points, such as entry to a school district, beginning of kindergarten, middle school, high school. Communicate necessary information to all key team members as the student progresses in school (different building or different sets of teachers, for example). Work with appropriate professionals and use online resources to compile a list of simple strategies that can be used in the classroom to support a child with TBI.

- Consider identifying small groups of staff members each year who take part in online training focused on the effect of TBI in students. The Centers for Disease Control and Prevention offers several free trainings that are less than 1 hour, and there are many other available resources as well. Focusing on educating school personnel on the effects of TBI can help to address students' needs in the classroom.

Obstacles to care coordination can include legal barriers such as confidentiality of records and parent consent. Practical barriers also include setting, parent involvement, and resources such as time and insufficient personnel[53,21]. Recognizing the barriers and facilitators of care coordination can help to better serve the child and family's needs when implementing different strategies such as, using technology effectively[44], implementing professional development for students and faculty[45], and incorporating the family unit as a key partner[41]. Understanding these positive and negative factors can also influence future research evaluating the implementation of different care coordination strategies for all students with medical needs, including those who have sustained TBIs.

HUMAN SUBJECTS APPROVAL STATEMENT

Not applicable, as this is not a research study involving human subjects.

CONFLICT OF INTEREST DISCLOSURE STATEMENT

All authors declare they have no conflicts of interest.

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Table 1. Search Terms

Research component	Research terms
#1 care coordination	(interdisciplinary communication) OR (interdisciplinary collaboration) OR (complex care manag*) OR (care coordination) OR (teacher communication) OR (interprofessional collaboration) OR (interprofessional communication)
#2 diagnoses	(medically complex child*) OR (special health care need*) OR (chronic medical condition*) OR (chronic medical illness) OR (complex care) OR (complex medical)
#3	#1 AND #2
Additional hand search	(school*) AND (care coordination)

Table 2. Purpose, Scope, Origin, and Sample Population of Included Studies

Authors/Year/Location	Purpose	Sample Population	Diagnosis Studied
Cady, et al. (2009) United States	Evaluate the effect of USK program on hospital resource utilization	43 participants; age 2-17 years old	Special healthcare needs which include a major diagnosis of a genetic syndrome/congenital anomaly, neurodegenerative disease, cerebral palsy, gastrointestinal diagnosis, immunodeficiency diagnosis, or other major diagnosis with healthcare needs
Coughey et al. (2010) United States	Evaluate the effectiveness of telephone-based care coordination program to improve asthma management	59 participants in the treatment group; 236 participants in control group; age 3-12 years old	Asthma
Findley et al. (2011) United States	Describe the efficacy of a community-based care coordination model for serving children with asthma	2,092 participants; age 0-18 years old	Asthma
Giroux et al. (2019) Canada	Understand parents' roles in and perceptions of interprofessional collaboration between their child's healthcare professionals and educators	23 participants; Age 36->51 years old	Chronic illnesses including cancer, connective tissue disorders, digestive conditions, diabetes, and neurological disorders
Hafeez et al. (2017) United States	Describe the content of a care	9 participants in individual interviews	Epilepsy

	coordination intervention for children with epilepsy	and 1 focus group with 7 participants; age not specified	
Hamburger et al. (2015) United States	Evaluate outcomes of youth with asthma receiving care coordination in the context of a formal medical home program	967 participants; age birth-24 years old	Asthma
Kelly et al. (2015) United States & Puerto Rico	Assess the influence of various settings on the structure of care coordination activities, the strengths of implementing care coordination for asthma in a given setting, and the primary challenges that arise	805 participants; age 0-18 years old	Asthma
Liptzen et al. (2016) United States	Develop a program to improve asthma control and reduce absences for children in Denver Public Schools	252 participants; Elementary and middle school age	Asthma
Matiz et al. (2015) United States	Evaluate the IT tools developed as part of the launch of a patient-centered medical home model focused on asthma in four pediatric	1217 participants; Age 4-18 years old	Asthma

	academic practices in a large, urban setting		
Rowlandson & Smith (2009) Isle of Wight	Construct coordinated approach to assessment and diagnosis of Autism Spectrum Disorder utilizing current recommended guidelines of good practice; To provide coordinated planning for intervention using a Team Around the Childe approach; Coordinate the work of all service to provide a consistent and appropriate 24 hour management program	593 diagnosed participants; age 4-19 years old	ASD, ADHD, ADHD with a comorbid diagnosis, or a dual diagnosis of ASD and ADHD
Salm (2017) Canada	Develop a deeper understanding of how preservice and in-service professionals experience interprofessional collaboration and competency development as	350 participants; High School age	Mental health disorders comorbid with intellectual disabilities

	a means to support		
Ziviani et al. (2013) Australia	Gain a better understanding of the perceptions of Evolve Behavior Support Services frontline and managerial staff delivering services to participants in out-of-home-care with disability and complex behaviors	21 participants; Children and Youth	Staff who worked with children and young people with disabilities and complex psychological and/or behavioral problems

Table 3. Summary of Included Studies

Authors/Year/Location	Who is Implementing Services	Study Design	Description of Intervention/ Program	Outcome Measures	Results/Findings
Cady, et al. (2009) United States	Advanced Practice Nurses	Quantitative	Telephone-based, comprehensive care coordination and case management	Number of unplanned or emergency hospitalizations after enrollment in program	Rates of unplanned inpatient days declined; telephone-based care coordination is a promising approach
Coughey et al. (2010) United States	Asthma care coordinators	Quantitative	Link Line, a telephone based care coordination and system integration program staffed by two asthma care coordinators	Markers of Morbidity (emergency department visits, hospitalizations, office visit claims)	Intervention group was significantly less likely to attend unplanned office visits and less likely to have an emergency department visit compared to themselves prior to enrollment
Findley et al. (2011) United States	Community health workers or school-based nurses	Quantitative	Five community programs were examined: Establishment of asthma management goals with family; Facilitation of interactions with the	Confidence in controlling asthma, steps to reduce triggers, creating an asthma action plan, appropriate use of medication, emergency department visits and hospitalizations, school absences	Programs improved management behaviors and decreased morbidity across sites

			health care system; Clinical or social service referrals to address family needs; Culturally competent tailored education; Building social support; Assistance in reducing home environmental triggers		
Giroux et al. (2019) Canada	Parents, health professionals, and education professionals	Quantitative and Qualitative	Recognizes parents' contribution as coordinators	Level of parental engagement with health professionals; level of parental engagement with educational professionals; level of communication between health professionals and educators as perceived by parents	Parents reported they could effectively communicate their child's health and educational needs with health and educational professionals; statistical analysis determined moderately increased challenges presenting information across professions
Hafeez et al. (2017) United States	Care coordinators	Qualitative	Required care coordinators to have one in-person contact with	N/A	Facilitators and barriers of care coordination included

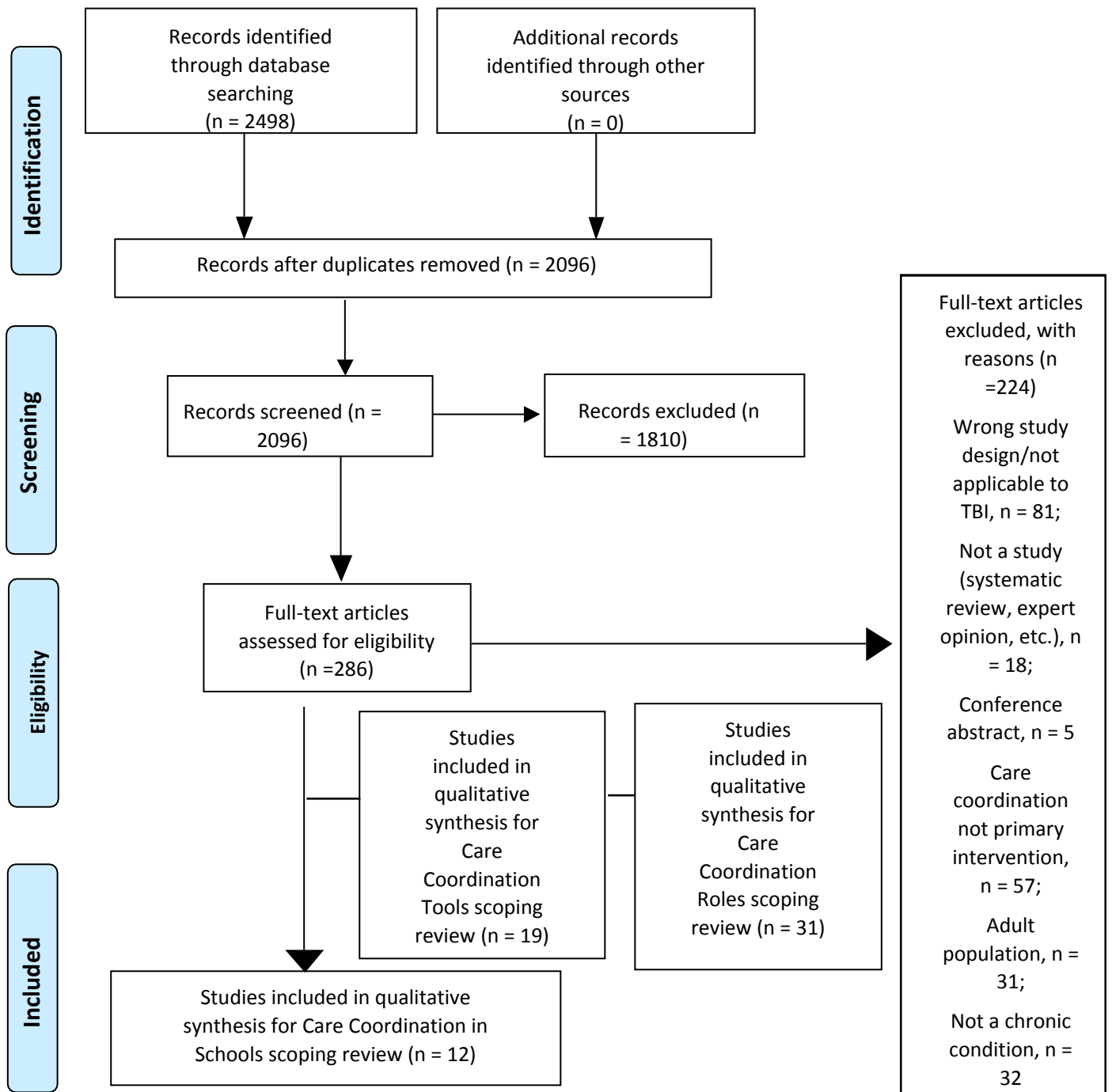|			patients every three clinic visits, and were asked to use a modified version of a care coordination checklist		parents, physicians, the health system, payers, and community
Hamburger et al.(2015) United States	Personal health care professionals/care coordinators	Quantitative	The Pennsylvania Medical Home Initiative-Educating Practices in Community-Integrated Care practices medical home adoption, implementation, and evaluation; Coordinators created and maintained asthma action/care plans and reviewed plans with families/patients	Healthcare utilization (hospital, emergency department, acute care, follow-up visits); quality of life measures (missed school/parental work days)	Significant decrease in school absences, emergency department visits, and acute care visits
Kelly et al. (2015) United States & Puerto Rico	Asthma care coordinator (nurses, health educators, and community health workers)	Qualitative	Asthma Care coordinator provided link between care delivered outside and inside of the health care office	Differences in programs across settings; strengths and challenges to implementing care coordination in specific settings	The ability to use data sources, leverage infrastructure, readily communicate with health care providers, and integrate

					new components of care played a key role in instituting improvements
Liptzen et al. (2016) United States	Asthma counselors	Quantitative	The Step-Up Asthma Program	Open Airways for Schools and Kickin' Asthma scores; inhaler technique scores; number of urgent care visits; number of hospitalizations; number of missed school days	Students had improved asthma knowledge scores and inhaler techniques, and fewer exacerbations which was sustained over the year following the program enrollment
Matiz et al. (2015) United States	Medical providers	Quantitative	Forms were used to disseminate referral orders, medication administration information; "asthma slots" were added to the scheduling system to allow for weekly appointments for patients with care plan changes	Emergency department visits and inpatient admissions between baseline and each year	Asthma outcomes can be improved with provider use of locally developed IT tools that support patient care; IT tools improved workflow across the entire medical home and for all patients with asthma
Rowlandson & Smith (2009) Isle of Wight	Government of Isle of Wight	Qualitative and	Multi-agency team was developed to	Diagnostic and assessment process; type of	Referrals have increased

		Quantitative	deliver care coordination	referral; diagnosis after full assessment; satisfaction of outcome of parents and child	from schools and general practitioners; increased ASD, ADHD, and communication problem awareness; time from assessment to diagnosis to planning process was decreased from 2 years to 5-6 months
Salm (2017) Canada	Schools, social workers, and mental health workers	Qualitative	Creation of care coordination team	Developing a clear understanding of the six CIHC competencies	For students being a part of the team enhanced the scope and depth of understanding of students with dual diagnoses and competency; for the team they described themselves as highly collaborative and interdependent
Ziviani et al. (2013) Australia	Evolve Behavior Support Services	Quantitative and Qualitative	Evolve Interagency Service was used to provide services to patients in	General and agency/stakeholder specific issues and benefits of collaboration	Overall, staff described a greater level of collaboration with partner agencies;

	out-of-home care		there was a relatively greater success in collaboration with interagency government partners compared to other stakeholders

Figure 1 Prisma 2009 Flow Diagram