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Challenges Facing Young Adults with Complex Communication Needs Entering the Adult Health Care System

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Challenges Facing Young Adults with Complex Communication Needs Entering the Adult
Health Care System

May 2019

This evidence project, submitted by

Molly Stark and Christabelle Francis

has been approved and accepted
in partial fulfillment of the requirements for the degree of
Master of Science in Occupational Therapy from the University of Puget Sound.

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Key words: complex communication needs, health literacy, transition, health care system

Abstract

RBarbara Abbott, PhD, OTR/L is a school-based occupational therapist currently working with students grades K-12 in four schools in Kent, WA. The purpose of our project was to identify the most effective service delivery models and/or components of interventions for young adults with complex communication needs to understand their health information. We conducted a systematic review to critically appraise literature published between the years of 1990-2018 to address our research question. Our research yielded a total of seven qualitative and 12 quantitative studies to address our research question. Qualitative data found that individuals with complex communication needs (CCN) experience significant challenges in adulthood with managing and communicating their health needs. Quantitative research identified seven evidence-based interventions that improved health knowledge, health literacy, and health advocacy skills for improving participation in the adult healthcare system. The overarching recommendation from the studies highlighted the importance of promoting self-advocacy and self-determination to navigate the system and manage individual health needs. There is a need for professionals to help prepare these young adults throughout the transition phase from pediatric to the adult healthcare system.

Our subsequent knowledge translation product entailed developing a tri-fold pamphlet intended for school administrators and school-based occupational therapists. It includes qualitative data and evidence based interventions to improve health literacy and self-advocacy skills for young adults with communication challenges in the school setting. Outcomes data collected from school based occupational therapists indicated that the research findings in the pamphlet were widely new information for them. Additionally, they reported positive reactions to the pamphlet. Occupational therapists surveyed agreed that teaching health education is within

their scope of practice in the school setting, and reported an interest in incorporating a health education intervention for students with disabilities into their services. Future research is recommended for developing additional evidence-based interventions for preparing these young adults to advocate for their health needs. Recommendations for future translation of knowledge include catering the information in the pamphlets to specific audiences, such as one pamphlet for occupational therapists and a separate pamphlet for school administrators, with suggestions regarding support for families and educators.

Executive Summary

When this project was founded, Dr. Abbott was the occupational therapist at The Outreach Program (TOP), a post-secondary program for young adults with various diagnoses including Down syndrome, genetic disorders, traumatic brain injury, cerebral palsy, seizure disorders and autism spectrum disorders in Kent, Washington. Dr. Abbott identified her concern that while the program focused mainly on improving academic skills with the students, there was little emphasis on promoting daily living skills. Dr. Abbott recognized this trend and was working to promote functional and skill-based interventions to address the needs of young adults transitioning into independent adulthood. Specifically, Dr. Abbott was interested in gathering evidence for the best methods for preparing young adults with complex communication needs to understand their own health, communicate with health care practitioners during medical visits, and advocate for their health needs. To address this concern, we critically appraised the literature published between 1990-2018 with the question, “what are the most effective service delivery models and/or components of interventions for young adults with complex communication needs to understand their health information?”

We reviewed published literature related to our research question from PubMed, CINAHL, Google Scholar, ERIC, AJOT, and PsycINFO. A final count of 7 qualitative and 12 quantitative articles were retained to address our research question. Based on the evidence we gathered, individuals with communication and cognitive impairments, and delayed processing speed as a symptom of a disability, resulted in inadequate care and ongoing difficulties with navigating the adult healthcare system (Balandin, Hemsley, Sigafos, & Green, 2007; Brown, 2009; Larivière-Bastien, Majnemer, Shevell, & Racine, 2011; McNaughton, Balandin, Kennedy, & Sandmelet, 2010; Morris, Dudgeon, & Yorkston, 2013; Nicolaidis et al., 2015; Williamson et

al., 2017). A lack of basic health knowledge and misunderstandings of health services often resulted in withdrawing from medical appointments (Brown, 2009). Additionally, health care accessibility was impacted by environmental factors such as overstimulating waiting rooms, and decreased availability of adult care providers and services for those with intellectual and/or developmental disabilities (Williamson et al., 2017). To address the challenges this population faces with their health needs, seven evidence-based interventions were found to improve health knowledge, health literacy, and health advocacy skills: the Ask Health diary, the Comprehensive Health Assessment Program (CHAP), Women be Healthy, the 3 Rs, Youth KIT, TRACE online mentor, and VAPT. The overarching recommendations emphasized within the literature were the importance of promoting self-advocacy and self-determination to navigate the system, managing individual health needs and preparing these young adults to transition from the pediatric to adult healthcare system.

Occupational therapists can support these young adults by utilizing the evidence based strategies mentioned to improve health advocacy skills, self determination, health knowledge, accessibility and quality of care, and their overall health. Collaboration with teachers and families is needed to improve their access to health care, while education given to healthcare providers on the use of AAC devices, advocacy for AAC assessments, and employment of communication strategies can address communication barriers between the young adult and members of the healthcare team.

Our knowledge translation approach entailed preparing a trifold pamphlet intended for school based occupational therapists and administrators. It emphasizes the need to provide health education to young adults with special needs and includes evidenced-based interventions that are compatible for teachers, health educators, and occupational therapists to utilize in high school

and transition programs. The pamphlets were distributed to a sample of school based occupational therapists and feedback was gathered through a survey. The responses were both helpful and positive.

CRITICALLY APPRAISED TOPIC (CAT) PAPER**Focused Question**

What are the most effective service delivery models and/or components of interventions for young adults with complex communication needs to understand their health information?

Prepared By

Christabelle Francis, Molly Stark

Date Review Completed

01/29/2019

Professional Practice Scenario

A school occupational therapist is serving students ages 18-21 at a post-secondary transition program. She works to promote functional and skill-based interventions to address the needs of transitioning young adults into adulthood. The school OT wants to know if there are any evidence-based interventions available to teach young adults with complex communication needs (CCN) and/or disabilities to understand and communicate with health care practitioners, and to advocate for their health needs, as they transition from the pediatric to adult healthcare systems.

Search Process**Procedures for the selection and appraisal of articles****Inclusion Criteria**

- Published in a peer-review journal between 1990-2018
- Published in English
- Studies that include participants older than 14
- Adults and young adults with complex communication needs and disabilities that may include but not limited to, cerebral palsy, autism spectrum disorder, TBI, Down syndrome, and seizure disorders
- Types of studies: experimental, qualitative, descriptive, outcome, systematic reviews
- AOTA Level 5 sources: editorials, researched guidelines, case report, expert opinions
- Outcomes may include satisfaction levels, health literacy measures

Exclusion Criteria

- Research articles published before 1990
- *Studies that include participants younger than 14
- Studies that are not written in English
- Information regarding the actual health of individuals with complex communication needs
- Interventions or articles regarding individuals with disabilities reading or literacy levels

*Due to the limited amount of relevant papers found, we expanded our search to include studies with participants from 10 years of age and up.

Search Strategy

Categories	Key Search Terms
Patient/Client Population	<ul style="list-style-type: none"> ● Complex Communication Needs/CCN ● Nonverbal communication needs ● Nonverbal ● Communication impairment ● Communicative disorder ● Communication difficulties ● Verbal communication disorder ● Verbal communication difficulties ● Communication difficulty/difficulties ● Cerebral palsy ● Cerebral Palsy communication ● Autism ● Autism spectrum disorder communication (needs) ● Autistic communication ● Autism communication (needs) ● Augmentative and alternative communication ● Learning disabilities ● English language learners ● Intellectual disability communication ● Disabilities ● Young adults ● Adults in transition ● Adolescents ● Transitioning student
Intervention (Assessment)	<ul style="list-style-type: none"> ● Intervention ● Treatment ● Approaches

	<ul style="list-style-type: none"> • Methods • Tools • Management • Occupational therapy • Self advocacy • Self determination • Service delivery models
Comparison	
Outcomes	<ul style="list-style-type: none"> • Medical information • Patient information • Health information • Medical needs • Health literacy • Health needs • Health knowledge

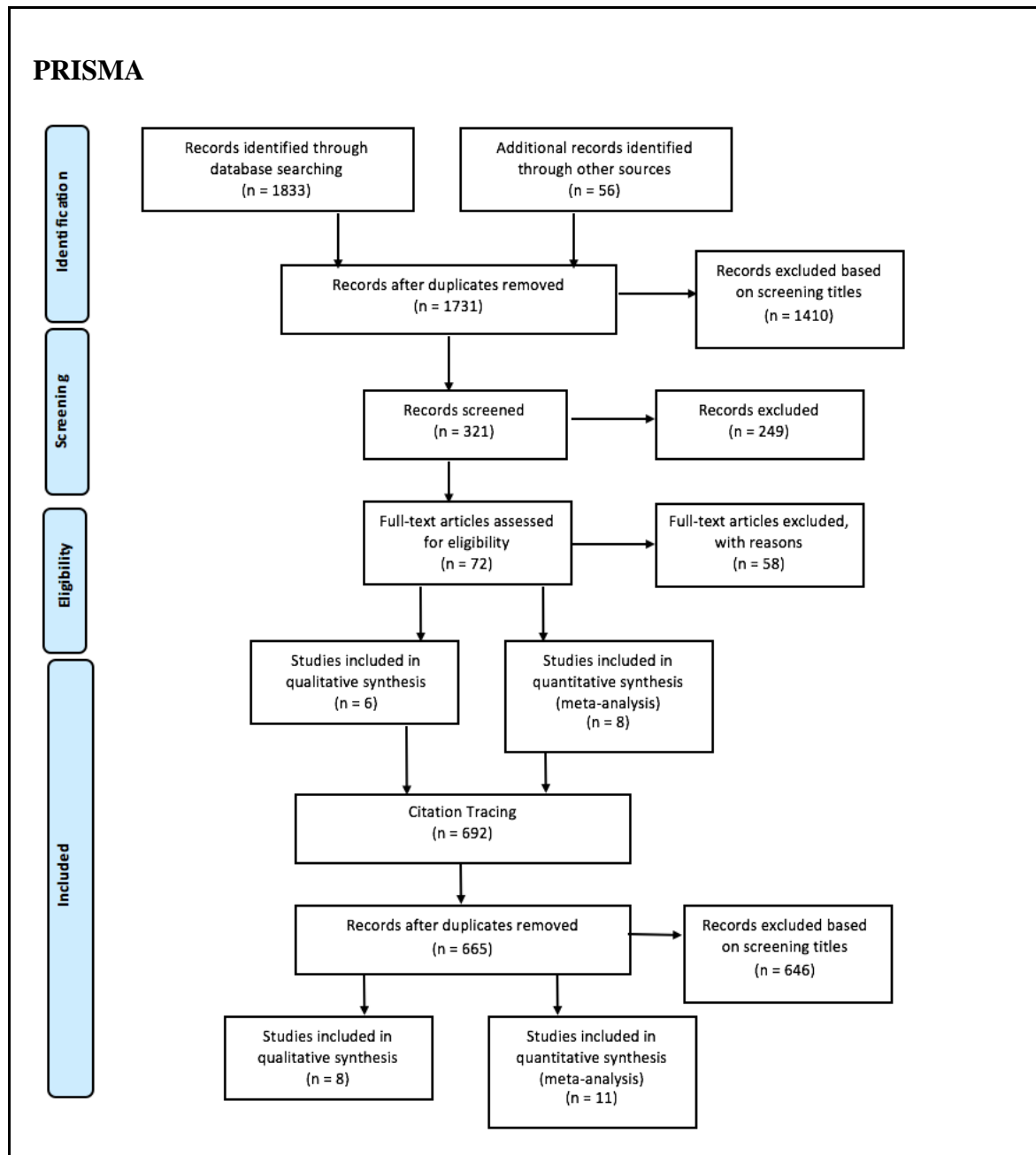
Databases, Sites, and Sources Searched
PubMed
CINAHL
PsycINFO
ERIC
AJOT
Google Scholar

Search Outcomes/Quality Control/Review Process

To address our research question, databases searched included PubMed, CINAHL, Google Scholar, ERIC, AJOT, and PsycINFO. Databases searched were appropriate for our collaborator and setting for gathering medical, educational, occupational and psychological evidence based articles relevant to our question and population of interest. Our initial search involved combining and omitting our key search terms and truncating terms to yield larger results. Due to a lack of results obtained from initial keyword combinations, on-going discussions with our project chair occurred and the decision to expand our keywords was made. Additional keywords included *self advocacy*, *self determination*, *self-expression*, *disability*, *expressive communication*, in regard to interventions, approaches and/or strategies for addressing health literacy within our population of interest. Additional searches did not increase yield of evidence based articles. Conversations with our chair resulted in using the existing search results and grouping articles according to the three most predominant diagnoses for which relevant studies were found in the literature. Further searches were conducted for young adults and adults with cerebral palsy, autism spectrum disorders and learning and/or intellectual disabilities.

Our combined search efforts resulted in 1833 hits. Additional reference checking and database sidebar suggestions identified an additional 56 articles. After removal of duplicates, 1731 articles were retained. After screening titles, 321 articles retained. Upon further exploration of abstracts, 249 were excluded due to the inclusion criteria not being met, or the subject of the articles not being relevant to our question. 72 articles were assessed in greater depth; 56 were excluded due to a focus on interventions regarding reading or literacy levels, were not related to our question or were not evidence based. From the 15 articles retained, citation tracing resulted in an additional 718 articles. Of these, 684 were excluded after screening the titles. Our final count of 8 qualitative and 11 quantitative articles were retained to address our research question.

The researchers in this project independently researched and reviewed the articles, met to discuss all articles in depth and resolve individual discrepancies on what articles would be included. Additional support for search strategies and suggestions came from the University of Puget Sound liaison librarian, Eli Gandour-Rood, University of Washington-Tacoma librarian, and our project chair, Renee Watling.



Results of Search**Table 1. Search strategy of databases.**

Search Terms	Date	Database	# Hits	# Excluded	# Retained
Occupational therapy AND complex communication AND health information	09/27/2018	PubMed	30	29	1
occupational therapy AND complex communication AND health literacy	09/27/2018	PubMed	2	2	0
"complex communication needs" AND "health literacy" AND "occupational therapy"	10/02/2018	PubMed	0	0	0
"complex communication needs" AND "health literacy" AND occupational therapy	10/02/2018	PubMed	0	0	0
occupational therapy AND complex communication needs	10/04/2018	PubMed	44	44	0
health information AND "complex communication" AND interventions	10/04/2018	PubMed	4	3	1
health information AND ccn AND treatment	10/04/2018	PubMed	9	9	0
health information AND nonverbal communication needs AND treatment	10/04/2018	PubMed	29	29	0
Complex communication needs AND health literacy	10/4/2018	CINAHL	0	0	0
Cerebral palsy AND health information	10/4/2018	CINAHL	41	40	1
English language learners AND health information	10/8/2018	CINAHL	2	2	0
Occupational therapy AND complex communication OR ccn) AND Medical information	10/10/2018	CINAHL	0	0	0
Occupational therapy AND Medical information	10/10/2018	CINAHL	0	0	0
occupational therapy AND complex communication AND health literacy	10/10/2018	CINAHL	0	0	0
occupational therapy AND complex communication	10/13/2018	CINAHL	6	6	0
Occupational therapy AND complex	10/13/2018	CINAHL	2	2	0

communication needs					
health information AND "complex communication" AND interventions	10/15/2018	CINAHL	0	0	0
health information AND "complex communication"	10/15/2018	CINAHL	2	1	1
health information AND "complex communication" AND treatment	10/15/2018	CINAHL	0	0	0
Occupational therapy AND (complex communication OR ccn) AND Medical information	10/17/2018	PubMed	15	15	0
Occupational therapy AND (complex communication OR ccn) AND Patient information	10/17/2018	PubMed	20	20	0
Occupational therapy AND (complex communication OR ccn) AND Medical needs	10/17/2018	PubMed	17	17	0
Occupational therapy AND (complex communication OR ccn) AND health knowledge	10/17/2018	PubMed	33	33	0
Occupational therapy AND (complex communication OR ccn) AND health needs	10/17/2018	PubMed	38	37	1
Occupational therapy AND (complex communication OR ccn OR nonverbal) AND health needs	10/17/2018	PubMed	39	39	0
Occupational therapy AND (nonverbal OR nonverbal communication) AND health needs	10/17/2018	PubMed	4	4	0
Occupational therapy AND (nonverbal OR nonverbal communication) AND health information	10/17/2018	PubMed	6	6	0
Occupational therapy AND (nonverbal OR nonverbal communication) AND medical information	10/17/2018	PubMed	5	5	0
Occupational therapy AND (nonverbal OR nonverbal communication) AND patient information	10/17/2018	PubMed	5	5 (1 duplicate)	0
Occupational therapy AND (nonverbal OR nonverbal communication) AND medical needs	10/17/2018	PubMed	1	1	0
Occupational therapy AND (nonverbal OR	10/17/2018	PubMed	0	0	0

nonverbal communication) AND health literacy					
Occupational therapy AND (nonverbal OR nonverbal communication) AND health needs	10/17/2018	PubMed	4	4 (1 duplicate)	0
Occupational therapy AND (nonverbal OR nonverbal communication) AND health knowledge	10/18/2018	PubMed	1	1	0
Occupational therapy AND (communication impairments OR communication disorders) AND health information	10/18/2018	PubMed	57	57 (7 duplicates)	0
Occupational therapy AND (communication impairments OR communication disorders) AND health literacy	10/18/2018	PubMed	5	5	0
Occupational therapy AND (communication impairments OR communication disorders) AND medical information	10/18/2018	PubMed	28	28 (3 duplicates)	0
"Occupational therapy" AND (Autism OR ASD OR Autism spectrum disorder) AND health information	10/18/2018	PubMed	33	33 (3 duplicates)	0
"Occupational therapy" AND (verbal communication disorder) AND health information	10/21/2018	PubMed	2	2	0
Occupational therapy AND (complex communication OR ccn) AND health knowledge	10/21/2018	PubMed	33	33 (3 duplicates)	0
health information AND nonverbal communication AND treatment	10/21/2018	CINAHL	1	1	0
Complex communication needs OR CCN AND intervention OR treatment OR therapy OR techniques AND health information OR patient information OR medical needs	10/21/2018	CINAHL	2	2	0
Complex communication needs OR CCN AND intervention OR treatment OR therapy OR techniques AND health information OR health knowledge OR health needs OR health literacy	10/21/2018	CINAHL	8	8	0
Occupational therapy AND complex communication AND health information	10/26/2018	ERIC, PsycINFO	0	0	0

occupational therapy AND “complex communication” AND “health literacy”	10/26/2018	ERIC, PsycINFO	0	0	0
“Occupational therapy” AND “complex communication”	10/26/2018	ERIC, PsycINFO	10	10 (2 duplicates)	0
health information AND "complex communication" AND intervention	10/26/2018	ERIC, PsycINFO	1	1	0
health information AND "expressive communication" AND intervention	10/26/2018	ERIC, PsycINFO	0	0	0
health information AND "self advocacy" AND intervention	10/26/2018	ERIC, PsycINFO	3	2	1
health information AND "self advocacy" AND treatment OR approach OR method OR tools OR management OR technique OR strategy	10/27/2018	ERIC, PsycINFO	22	21	1
"health information" or "health literacy" or "medical information" or "patient information" or "medical needs" or "health knowledge" AND "self advocacy" or "self determination" AND treatment OR approach OR method OR tools OR management OR technique OR strategy AND disabilit* OR "augmentative and alternative communication" or autism or "cerebral palsy" or "communication difficult*" or "verbal comm*" or "speech impairment"	10/27/2018	ERIC, PsycINFO	15	11 (2 duplicates)	2
("complex communication" OR ccn OR nonverbal OR "communication impair*"), AND ("health knowledge" OR "health info*" OR "health literacy" AND "Intervention OR treatment	10/28/2018	ERIC, CINAHL, PsycINFO,	57	56 (4 duplicates)	1
("young adults" OR "adults in transition" OR adolescents OR transitioning student OR adults) AND "medical information" OR "patient information" OR "medical need" OR "health literacy" OR "health need" OR "health knowledge" AND Intervention OR treatment OR management AND Understand OR interpret OR learn OR explain	10/28/2018	ERIC, CINAHL, PsycINFO	315	313 (7 duplicates)	2
("young adults" OR "adults in transition" OR adolescents OR transitioning student OR adults) AND “self advoc*” OR “self determination” AND ("medical information" OR "patient information" OR	10/28/2018	ERIC, CINAHL, PsycINFO,	0	0	0

[illegible]

determination")) AND (("medical information" OR "patient information" OR "medical need" OR "health literacy" OR "health need" OR "health knowledge")) AND (intervention OR treatment)					
("augmentative and alternative communication" or autism or "cerebral palsy" or "communication difficult*" or "verbal comm*" or "speech impairment")) AND (("self advoc*" OR "self determination")) AND (("medical information" OR "patient information" OR "medical need" OR "health literacy" OR "health need" OR "health knowledge")) AND (intervention OR treatment)	10/29/2018	ERIC, CINAHL, PsycINFO	1	1	0
occupational therap*" AND (intervention or treatment) AND (self advoc* OR "self determination") AND (("young adults" OR "adults in transition" OR adolescents OR transitioning student)	10/29/2018	ERIC, CINAHL, PsycINFO	23	22	1
("Complex communic*" OR "nonverbal commun*" OR "commun* impair*" OR "speech impair*") OR "communic* disorder" OR "verbal communic* disorder" OR "verbal communic* difficult*" OR "cerebral Palsy communic*" OR "Autis* communic*" OR "Augmentative and alternative communication" OR "learn* disab*" OR "intellectual disab* communic*") AND ("intervention OR treatment") AND ("self advoc* OR "self determination") AND ("medical information" OR "patient information" OR "medical need" OR "health literacy" OR "health need" OR "health knowledge"))	10/29/2018	ERIC, CINAHL, PsycINFO	0	0	0
"Complex communic*" OR "nonverbal commun*" OR "commun* impair*" OR "speech impair*") OR "communic* disorder" OR "verbal communic* disorder" OR "verbal communic* difficult*" OR "cerebral Palsy communic*" OR "Autis* communic*" OR "Augmentative and alternative communication" OR "learn* disab*" OR "intellectual disab* communic* OR disabil*") AND ("self advoc* OR "self determination") AND ("medical information" OR "patient information" OR "medical need" OR "health literacy" OR "health need" OR "health knowledge" OR health	10/29/2018	ERIC, CINAHL, PsycINFO	10	10 (6 duplicates)	0

("Complex communic*" OR "nonverbal commun*" OR "commun* impair*" OR "speech impair*") OR "communic* disorder" OR "verbal communic* disorder" OR "verbal communic* difficult*" OR "cerebral Palsy communic*" OR "Autis* communic*" OR "Augmentative and alternative communication" OR "learn* disab*" OR "intellectual disab* communic* OR disabil*") AND ("self advoc* OR "self determination") AND (intervention or treatment or therapy or program or strategy) AND healthcare	10/29/2018	ERIC, CINAHL, PsycINFO	2	2 (1 duplicate)	0
"Complex communic*" OR "nonverbal commun*" OR "commun* impair*" OR "speech impair*") OR "communic* disorder" OR "verbal communic* disorder" OR "verbal communic* difficult*" OR "cerebral Palsy communic*" OR "Autis* communic*" OR "Augmentative and alternative communication" OR "learn* disab*" OR "intellectual disab* communic* OR disabil*") AND ("self advoc* OR "self determination") AND (intervention or treatment or therapy or program or strategy) AND (healthcare OR health	10/29/2018	ERIC, CINAHL, PsycINFO	8	8 (4 duplicates)	0
("Complex communic*" OR "nonverbal commun*" OR "commun* impair*" OR "speech impair*") OR "communic* disorder" OR "verbal communic* disorder" OR "verbal communic* difficult*" OR "cerebral Palsy communic*" OR "Autis* communic*" OR "Augmentative and alternative communication" OR "learn* disab*" OR "intellectual disab* communic*") AND (intervention OR treatment) AND (self advoc* OR "self determination) AND (health)	10/29/2018	PubMed	0	0	0
("Complex communic*" OR "nonverbal commun*" OR "commun* impair*" OR "speech impair*") OR "communic* disorder" OR "verbal communic* disorder" OR "verbal communic* difficult*" OR "cerebral Palsy communic*" OR "Autis* communic*" OR "Augmentative and alternative communication" OR "learn* disab*" OR "intellectual disab* communic*") AND (self advoc* OR "self determination) AND (health)	10/29/2018	PubMed	0	0	0

"augmentative and alternative communication" or aac or "communication impairment" AND "medical information" OR "patient information" OR "medical need" OR "health literacy" OR "health need" OR "health knowledge" AND intervention or treatment or therapy or management or strategy or program or approach	10/29/2018	CINAHL, ERIC, PsycINFO	21	21 (8 duplicates)	0
(young adult OR transitioning student OR adults in transition) AND (complex communication needs OR ccn) AND health information	10/29/2018	CINAHL, ERIC, PsycINFO	52	52 (6 duplicates)	0
(young adult OR transitioning student OR adults in transition) AND (complex communication needs OR ccn) AND health knowledge	10/29/2018	CINAHL, ERIC, PsycINFO	31	31 (3 duplicates)	0
(young adult OR transitioning student OR adults in transition) AND (complex communication needs OR ccn) AND (Service delivery models OR intervention OR tx OR treatment OR approach OR method OR tool) AND (health knowledge OR health literacy OR health information)	10/29/2018	CINAHL, ERIC, PsycINFO	72	72 (4 duplicates)	0
("complex communication needs" OR ccn OR nonverbal OR autism OR "cerebral palsy" OR AAC) AND ("Service delivery models" OR intervention OR tx OR treatment OR approach OR method OR tool) AND ("health knowledge" OR "health literacy" OR "health information")	10/29/2018	CINAHL, ERIC, PsycINFO	66	66 (8 duplicates)	0
("self advoc*") AND "complex communication needs" AND ("health info*")	10/29/2018	CINAHL, ERIC, PsycINFO	2	2	0
"self advoc*" AND "Intervention OR treatment" AND "Health info" AND "young adult"	10/29/2018	Primo	29	29	0
"disabil*" AND "self advoc*" AND intervention OR treatment AND "health information" OR "medical information" OR "health literacy" OR "health knowledge" OR "patient information"	10/30/2018	CINAHL, ERIC, PsycINFO	5	5 (1 duplicate)	0
"disabil*" AND "health knowledge OR health information AND importance of	11/2/2018	ERIC, PsycINFO	224	224 (8 duplicates)	0
"importance of" OR impact OR effect OR influence AND "health literacy" OR	11/2/2018	CINAHL, ERIC,	0	0	0

"patient education" OR "health education" OR "health knowledge" AND disabil AND "young adult" or "adult" or "adolescent"		PsycINFO			
Autism OR asd OR autism spectrum disorders AND health literacy	11/03/2018	CINAHL, ERIC, PsycINFO	36	35 (5 duplicates)	1
Autism OR asd OR autism spectrum disorders AND health literacy or health knowledge AND intervention	11/03/2018	CINAHL ERIC, PsycINFO	94	93 (4 duplicates)	1
Autism OR asd OR autism spectrum disorders AND health literacy or health knowledge AND "young adults" OR adults OR adolescenc*	11/03/2018	CINAHL ERIC, PsycINFO	209	209 (10 duplicates)	0

Table 2. Articles from citation tracing (Google Scholar)

Article	Date	Articles Referenced	Articles Excluded	Articles Retained
Health assessment instruments for people with intellectual disabilities- A systematic review	11/17/2018	6	6	0
Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs	11/17/2018	91	90	1
New voices in women's health: Perceptions of women with intellectual and developmental disabilities	11/19/2018	30	30	0
Randomized control trial of the 3Rs health knowledge training program for persons with intellectual disabilities	11/19/2018	7	7	0
A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication	11/19/2018	185	185	0
Perspectives of adolescents and young adults with cerebral palsy on the ethical and social challenges encountered in healthcare services	11/19/2018	12	11	1

Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: A cluster randomized trial	11/20/2018	167	166	1
Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings	11/20/2018	73	73	0
A health advocacy intervention for adolescents with intellectual disability: A cluster randomized controlled trial	11/20/2018	4	4	0
Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities	11/21/2018	52	52	0
Health transitions for youth with complex communication needs: The importance of health literacy and communication strategies	11/21/2018	7	7	0
Enhancing self-determination in health: Results of an RCT of the ask project, a school-based intervention for adolescents with intellectual disability	11/21/2018	51	51	0
"Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum	11/21/2018	43	41	2
Understanding health disparities for individuals with intellectual disability using photovoice	11/21/2018	43	43	0
Training parents of youth with autism spectrum disorder to advocate for adult disability services: Results from a pilot randomized controlled trial	11/21/2018	9	9	0

Total number of articles used in review from database searches = 14

Total number of articles used in review from reference tracking = 5

Summary of Study Designs of Articles Selected for the CAT Table

Pyramid Side	Study Design/Methodology of Selected Articles	Number of Articles Selected
Experimental	<input type="checkbox"/> Meta-Analyses of Experimental Trials <input checked="" type="checkbox"/> Individual Blinded Randomized Controlled Trials <input type="checkbox"/> Controlled Clinical Trials <input type="checkbox"/> Single Subject Studies	6
Outcome	<input type="checkbox"/> Meta-Analyses of Related Outcome Studies <input type="checkbox"/> Individual Quasi-Experimental Studies w/ Covariates <input type="checkbox"/> Case-Control or Pre-existing Groups Studies <input checked="" type="checkbox"/> One Group Pre-Post Studies	2
Qualitative	<input type="checkbox"/> Meta-Syntheses of Related Qualitative Studies <input type="checkbox"/> Group Qualitative Studies w/ more Rigor <input type="checkbox"/> prolonged engagement with informants <input type="checkbox"/> triangulation of data (multiple sources) <input checked="" type="checkbox"/> confirmation (peer/member-checking; audit trail) <input checked="" type="checkbox"/> comparisons among individuals, w/i a person <input type="checkbox"/> Group Qualitative Studies w/ less Rigor <input type="checkbox"/> Qualitative Study on a Single Person <input checked="" type="checkbox"/> *Narrative literature review <input checked="" type="checkbox"/> *Scoping review	8

Descriptive	<input checked="" type="checkbox"/> Systematic Reviews of Related Descriptive Studies <input type="checkbox"/> Association, Correlational Studies <input checked="" type="checkbox"/> Multiple Case Series, Normative Studies, Descriptive surveys <input type="checkbox"/> Individual Case Studies	3
AOTA Levels I-8 II- 0 III- 2 IV- 1 V- 1 Comments: Six qualitative studies and one narrative literature review were included in the total number of articles, but were not categorized within AOTA levels.		<i>TOTAL number of articles =19</i>

LEARNING DISABILITIES, INTELLECTUAL DISABILITIES, DEVELOPMENTAL DISABILITIES - QUANTITATIVE

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Interventions & Outcome Measures	Summary of Results	Study Limitations
Feldman et al. 2016 <i>Journal of Applied Research in Intellectual Disabilities</i> Canada	Evaluate the 3Rs health knowledge training program for indiv w/ ID	RCT E2 I 8/10	$N=22$; Tx=12 (m age 50.9), 4 groups of 3; Ctrl=10 (m age 53.4) Incl= Dx ID, able to verbally communicate (at least simply) & participate in group training; consent obtained Excl=unknown	I: Tx= Training group; received 3Rs curriculum. # of training sessions $m=13.89$. Ctrl=no training O: m percentage scores on health knowledge tests at pre, post test (2 wks) & follow-up tests (3-6 mo).	Health knowledge post-tests sig higher than ctrl (tx= 78%, ctrl= 43.9%) & follow-up tests (tx= 64%, ctrl= 34.7%).	Small sample size, loss of follow-up data for some control participants
McPherson, et al. 2016 <i>Journal of Applied Research in Intellectual Disabilities</i> Australia	Compare Health Intervention Package w/ usual care; evaluate carer-reported health advocacy skills in adol w/ ID	RCT E2 I 7/10	$N=692$ Tx= $n=345$; 76.4% mainly verbal communicators, 27% mainly nonverbal Ctrl=usual care; $n=247$; 76.7% mainly verbal communicators, 16% mainly nonverbal Incl= Dx of ID, aged 10-18yo, registered at SES or SEU Excl= unknown	I: Health Intervention Package: Ask Project Curriculum Strategy Booklet, Ask Health Diary & CHAP. O: Caregiver report of health advocacy skills, adol's abilities & assessment of their health; use of diary & the CHAP in follow-up survey.	Tx: Likelihood to go to doctor visit without carer, likelihood to explain their health problems to the doctor without carer's help & likelihood to ask questions if they did not understand the doctor sig \uparrow . Carers reported \uparrow adol knowledge & responsibility for own health, and \uparrow in own ability to support adol.	Unable to determine which intervention component is responsible for increases in health advocacy

<p>Lennox et al. 2010</p> <p><i>Journal of Applied Research in Intellectual Disabilities</i></p> <p>Australia</p>	<p>Compare the Ask Health Diary & CHAP for effectiveness in improving healthcare & healthcare engagement for adults w/ ID</p>	<p>RCT</p> <p>E2</p> <p>I</p> <p>6/10</p>	<p>$N=242$; m ages 33-39 4 factorial groups: Usual med care only, CHAP, Ask HD, CHAP + Ask</p> <p>Incl=Dx ID, ≥ 18 yo, lived in private residences either w/ family, alone or w/ other indiv in a shared arrangement, but not with 24-h support Excl= had participated in the previous trial</p>	<p>I: Comprehensive Health Assessment Program & Ask Health Diary. O: Background info, healthcare activity</p>	<p>CHAP: sig \uparrow frequency of hearing & vision screening, receipt of vaccination & weight monitoring. Ask: No sig differences in healthcare activity & epilepsy checks</p>	<p>Due to low recruitment, study was underpowered in ability to detect interaction btw the two main effects</p>
<p>Lennox et al. 2007</p> <p><i>International Journal of Epidemiology</i></p> <p>Australia</p>	<p>Evaluate the effectiveness of CHAP to enhance interactions between adults with ID, their carer & their general practitioner</p>	<p>Cluster RCT</p> <p>E2</p> <p>I</p> <p>6/10</p>	<p>$N= 453$ adults w/ ID; Tx= 234 (ages 19-73, $m=38$yo, $m=141$); ctrl=219, ages 20-67, $m=39.2$ yo, $m=51$)</p> <p>Incl= consent, adult living in 24hr supported accommodation</p> <p>Excl=unknown</p>	<p>I: Tx= 12 mo use of CHAP; Ctrl=12 mo usual care; data collected after 1 year</p> <p>O: Health promotion, disease prevention, case-finding activities & appropriate intervention</p>	<p>Tx group stat sig \uparrow sensory impairments/obesity dx, \uparrow immunizations; \uparrow weight management, \uparrow women preventative screening, \uparrow detection of diseases compared to ctrl</p>	<p>Results not analyzed per ID ages</p>

<p>Lunsky et al. 2003</p> <p><i>Journal of Applied Research in Intellectual Disabilities</i></p> <p>USA</p>	<p>Trial Women Be Healthy for adult women w/ ID</p>	<p>Pre-post study</p> <p>O4</p> <p>III</p> <p>6/6</p>	<p>$N=22$; women, ages 20-65 yo, m age 38 yo</p> <p>$n=18$ White, $n=4$ AfAm</p> <p>Incl= mild-mod ID, had expressed interest in learning more about women's health or had anxiety/fear in the past regarding medical care</p> <p>Excl= limited comprehension, behavioral concerns, discomfort w/ topic</p>	<p>I: 8 wk 90 min sessions group cognitive behavior therapy & assertiveness training; homework & discussion</p> <p>O: Women's Health Interview at pre test, post test, & 10 wk follow-up. Respondents verbalized or pointed to answers.</p>	<p>Post-test: Health knowledge & coping strategies sig \uparrow ($p < 0.005$); health behavior beliefs sig \uparrow ($p < 0.05$).</p> <p>Follow-up: Sig improvements in health knowledge & coping strategies ($p < 0.01$)</p>	<p>Small sample size, inconsistent attendance, curriculum does not serve the needs of women w/ severe disabilities</p>
<p>*Turk et al. 2010</p> <p><i>Journal of Applied Research in Intellectual Disabilities</i></p> <p>UK</p>	<p>To evaluate the effectiveness of implementing a personal health profile (PHP) w/ adults with LD to improve health knowledge/needs & services required/received</p>	<p>RCT</p> <p>E2</p> <p>I</p> <p>7/10</p>	<p>$N=40$ GP practices w/ 201 adults w/ LD; (Tx=21 GP & 102 adults; Ctrl=19 GP & 99 adults)</p> <p>Incl=adults >18yo w/ mild ($IQ = 51-70$), to profound ($IQ \leq 50$) LD</p> <p>Excl= unknown</p>	<p>I: PHP binder w/ general health info, space for patient/carer to document health issues, appts, outcomes & info for professionals on dx</p> <p>O: GP records, The OK Health Checklist, KHPT checklist, CSRI, satisfaction questions, follow-up questions on problems/benefits of using PHP</p>	<p>Tx group: stat sig \uparrow in reporting of problems to GP</p> <p>No stat sig increase in dr visit per year & general knowledge of health</p>	<p>Tx group adherence to PHP use unknown, potential for self-report bias</p>

LEARNING DISABILITIES, INTELLECTUAL DISABILITIES, DEVELOPMENTAL DISABILITIES - QUALITATIVE

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Methods for enhancing rigor	Themes and Results	Study Limitations
Brown 2009 <i>Intellectual and Developmental Disabilities</i> USA	To explore aging, health exp & concerns of women with ID & DD	Grounded Theory/Q3d Focus groups w/ open ended questions	$N=34$, women w/ ID/DD, ages 33-71 Incl= ≥ 30 yo, w, able to respond verbally, Dx ID/DD, consent form	Audio data transcribed verbatim, coded and analyzed w/ Atlas.ti, peer checking	Themes: <i>General aging:</i> most knew age, physical changes, diff understanding physiol changes <i>W's health:</i> general understanding men vs women, unclear relation btw menstruation & reproduction, general understand exams w/o understanding purpose <i>Exp w/ health service professional:</i> unclear why specific tests done/medications taking, lack knowledge of choice w/ dr <i>Health Promotion:</i> limited understanding of unhealthy/high risk behavior <i>Perception of disability:</i> did not identify as having disability/meaning of disability <i>Mental Health:</i> general knowledge of happy vs sad, minimal knowledge on depression/anxiety	Must have adequate verbal comm, 2 researchers may cause bias

<p>St. John et al. 2018 <i>Scandinavian Journal of Occupational Therapy</i> USA</p>	<p>Explore whether use of photovoice (PAR) w/ narrative & focus groups increase depth/ability for indiv w/ ID to describe health concepts.</p>	<p>Narrative/Q3c Semi-structured interview & focus groups</p>	<p>N=2, ages 36(f) & 32(m) w/ ID. Drawn from larger study of adults w/ ID, ages 21-50 no longer enrolled in high school, no limitations on cognitive & verbal ability of participants, needed to have the ability to complete the informed consent/assent process. Excl=unknown</p>	<p>Audio data transcribed verbatim, peer checking, member checking</p>	<p>Themes of “health”: personal identity of health, meaningful occupations (physical activity, responsibility, social engagement, enjoyment, environment) & nutrition Photovoice can be tool used w/ indiv w/ ID to increase depth of comm for understanding adults w/ ID understand meaning of “health”</p>	<p>Small sample size</p>
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LEARNING DISABILITIES, INTELLECTUAL DISABILITIES, DEVELOPMENTAL DISABILITIES - SYSTEMATIC REVIEW

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Number of Papers Included, Incl/ Excl Criteria	Data Comparison Measures	Summary of Results	Limitations
Bakker-van Gijssel et al. 2017 <i>Research in Developmental Disabilities</i> Netherlands	Systematically review the quality of health assessment instruments for indiv w/ ID	Systematic review D1 I	<i>N</i> =29 Incl= articles about health assessments part of comprehensive health assessment instrument for adults w/ ID; peer reviewed in literature btw 01/2000 – 05/2016 Excl=screening for ID, screening of children w/ ID, syndrome specific health monitoring, screening for specific ID-related syndromes, diseases, cause of ID, for specific issues (hearing impairment), psychiatric disorders, specific PT/OT screening instruments	Compared development, clinimetric properties & effectiveness of tools from search	20 assessment instruments for adults w/ ID. None met all criteria (development, clinimetric, content, effectiveness). “Stay well and Healthy!” & “CHAP” potentially better than others. “Preventive care checklist for adults w/ DD” & “Scottish health check programme for adults with learning disabilities” promising & need further investigations	Researchers unable to obtain complete instrument details on “Health toolkit”; subjective scoring on assessments may have resulted in bias

LEARNING DISABILITIES, INTELLECTUAL DISABILITIES, DEVELOPMENTAL DISABILITIES - SCOPING REVIEW

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Number of Papers Included, Incl/ Excl Criteria	Summary of Results & Recommendations
*Williamson et al. 2017 <i>OTJR: Occupation, Participation and Health</i> USA	Review the literature on health care for adults w/ IDD to identify opportunities for occupational therapy research and practice to improve healthcare accessibility	Scoping review utilizing the EHP theory V	N=37 Incl: articles published after 2006, in English, address health care access, pertaining to adults with IDD; studies conducted in the US. Excl: articles that address health promotion, articles not discussing health care access, & articles w/ pediatric samples.	Person: <i>Comm skills</i> (n=7) Expressive & receptive comm chall, hc providers comm w/ caregiver vs adult w/ IDD, caregiver's diff w/ making medical decisions for adult not able to comm, emo reg; <i>Adherence to health care recomm</i> (n=3) Diff understanding/following medical recomm, organizational diff; ↓ <i>knowledge about health services</i> (n=5) women w/ IDD less likely to complete preventive screenings. Environment: ↓ <i>knowledge/education on treating adults w/ IDD</i> (n=13), hc institutions not trained to work w/ IDD population, physicians report feeling uncomfortable treating indiv w/ Down syndrome & ASD, misconception of ASD result in hesitation to disclose dx; <i>Lack of preventive care opportunities</i> (n=3) more likely to exp secondary conditions due to ↓ mobility/education, women w/ IDD have less health education; <i>Financial barriers</i> (n=4) diff w/ insurance companies approving services, providers not up to date w/ insurance regulations, employment, providers not compensated for extra time to assess & treat patients w/ ASD; <i>Physical environment</i> (n=3) <i>barriers to access</i> =overstimulated waiting rooms, office locations that require use of elevators; <i>Facilitators to access</i> = natural lighting; <i>Family context</i> (n=4) less likely to receive services if live w/ families, lack of emo support; family members, peers, disability professionals can participate in exams & support health decision-making; <i>Health care service transitions</i> (n=4) Lack of adult care providers & services, need for improvement w/ transition, discomfort due to lack of knowledge w/ condition; <i>Health literate education efforts</i> (n=4) education materials tailored to adults w/ IDD increased health knowledge & preparedness, establish procedures using

				diff comm strategies.
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CEREBRAL PALSY - QUALITATIVE

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Methods for enhancing rigor	Themes and Results	Study Limitations
Balandin, S. et al. 2007	Explore the exp of patients w/ CP and CCN in hospital. Identify comm barriers &	Phenomenology / Q3d Semi-structured interview	N=10, ages 35-61 w/ CP & CCN (m=5, f=5) n=6 used dysarthric speech w/ no interpreter; n=4 used	Comparisons btw & among individuals	Themes: <i>Comm barriers & its consq:</i> lack of method or opportunities to comm, nurses' lack of understanding or unresponsiveness to comm attempts, patients' changing health & anxiety; diff	Study focused on patients in variety of wards but results may have differed if participants had

<i>Applied Nursing Research</i> Australia	effective comm strategies to improve the hospital comm exp		AAC Incl= inpatients for \geq 3 days in the past 2 years; adults who are their own informants Excl=unknown		in participation in health management, gaining assistance for basic care. <i>Strategies for improving comm:</i> patients use repair strategies (repeat msg, spell words, turn to family to interpret msg); nurses took time to listen/respond; nurse training to comm w/ AAC & other comm strategies	exposure to nurses w/ AAC exp. Small sample size & heterogenous sample
Larivière-Bastien et al. 2011 <i>Narrative Inquiry in Bioethics</i> Canada	Identify & understand challs adults w/ CP exp w/ healthcare services	Phenomenology /Q3d Questionnaire & semi-structured interview	N=14, ages 18-25 ($m= 20.9$) w/ CP; n=3 w/ mild speech diff; n=3 w/ mod speech diff Incl= CP, signed informed consent form, understand & answer questions from the interview Excl=unknown	Audio taped interview, transcribed verbatim, thematic coding approach piloted/revised pre-study, member checking	Themes: <i>Challs w/ health system:</i> perceived unfairness in services delivered, feelings of injustice, lack adequate health resources, lack of access to health facilities, inadequate preparation to receive adults w/ CP unaccompanied to medical appts. <i>Consultation chall:</i> conflation of motor & cognitive disability, impersonal attitudes, lack of empathy & active listening <i>Suggestions:</i> desirable attributes of physicians, increasing research on different aspects of CP, increase support for indiv w/ CP	Small sample size; no indiv w/ severe ID, severe speech diff, or nonverbal, severe CP, comorbidities. No info on positive exp

AUTISM SPECTRUM DISORDER - QUANTITATIVE

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Interventions & Outcome Measures	Summary of Results	Study Limitatio ns
*Hillier, et al. 2017 <i>Advances in Autism</i> USA	Examine the healthcare exp of young adults w/ ASD within the US healthcare system	Case series D3 IV 2/3	Grp 1: Adults w/ ASD (n=16, age 19-29, m=88%, f=6%, other=6%). Incl: Proof of prior ASD dx Grp 2: Parents of grp 1 & parents of adults w/ ASD (n=50, m age 54, m=10%, f=90%). Incl: age 18+ Grp 3: Comparison grp of age & gender matched undergraduate students w/o ASD (n=42, m=98%, other=2%). Excl: Dx of ASD Grp 1 & 2: recruited via email list of past/current members of SSG run by author.	I=20 min online questionnaire about hc exp. O=hc utilization, autonomy of hc, quality of hc received, outcomes of hc	<i>Hc utilization:</i> Grp 1 visited PCP more frequent vs Grp 3; Grp 3 more likely to have private insurance vs Grp 1. <i>Autonomy of hc:</i> Grp 1 report higher levels of ind w/ managing hc visits vs grp 2; grp 3 sig ↑ vs grp 1 (appts alone: grp 3=88%, grp 1=40%; fill out paperwork independently: grp 3=60%, grp 1=20%). <i>Quality of hc received:</i> Grp 1 sig ↑ vs grp 2 (understanding & explaining problems/symptoms to PCP: grp 1=73%, grp 2=46%; follow-up tests ind, following instruction after visit); sig difference btw grp 1 & 3 (follow medical instruction: grp 3=90%, grp 1=60%). <i>Outcomes of hc:</i> Grp 1 less positive about PCP ability to effectively comm w/ them vs grp 3.	Small sample size, uneven group size results in less power & type II error more likely

<p>Taylor, et al. 2017 <i>Journal of Autism and Developmental Disorders</i> USA</p>	<p>Determine efficacy of VAPT to train parents of youth w/ ASD to advocate for adult disability services</p>	<p>RCT E2 I 6/10</p>	<p>N=41; Parents of youth w/ ASD 2 year pre/post high school grad (tx=20, ctrl=21); (m=1; f=40)</p> <p>Incl= youth w/ ASD, family willing/able to participate in tx, 12 consecutive wks, willing to be randomized.</p> <p>Excl= don't live in TN</p>	<p>I: Tx= 12 wk, 30 hr advoc training (including instruction, family sharing activities, case study & group discussion) via person/webcast/vid eo on adult service delivery system; Ctrl=received list of local disability resources</p> <p>O: <i>Adult service system knowledge; Advoc skills/comfort; Parental empowerment</i></p>	<p><i>Adult service system knowledge:</i> Tx group=↑ 95%, Ctrl=↑48%; <i>Advoc skills/ comfort:</i> Tx=↑30%, Ctrl=no changes, <i>Empowerment:</i> Tx=↑65%, Ctrl=↑29%</p> <p>Parents attending sessions in person correlated w/ higher level advocacy & empowerment</p>	<p>Info control group received unknown; unknown if parents who viewed from home watched full session; unknown if knowledge/skills gained during treatment were used in future; parent self report possibly biased</p>
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AUTISM SPECTRUM DISORDER - QUALITATIVE

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Methods for enhancing rigor	Themes and Results	Study Limitations
Nicolaidis. et al. 2015 <i>Autism</i> USA	To gain understanding of exp adults w/ ASD had w/ hc & obtain insider recommendations	Phenomenological/Q3c Online survey & semi-structured indiv interview (telephone, email, in-person or messenger)	<i>N</i> =55; 39 w/ ASD (<i>m</i> =22, <i>f</i> =17, <i>m</i> age=35) & 16 adults w/ exp supporting adults w/ ASD in hc setting(<i>m</i> =1, <i>f</i> =15, <i>m</i> age=52) Incl=US resident, ≥18yo, comm in written/spoken English/ASL; Dx ASD, Aspergers, PDD-NOS	Thematic analysis w/ Text Analysis Markup System Software, peer checking	Themes: <i>Factors associated w/ ASD dx:</i> chall w/ comm skills, sensory diff, body awareness, lack of consistency, slower processing, nonverbal comm & general organization <i>Provider-level factors:</i> lack knowledge of ASD, had incorrect assumptions of patients skills/needs, don't allow comm in writing, confusing language. Success w/ providers open to accommodations & incorporating supporters <i>System impact on ASD hc:</i> limit access informal/formal supports, complexities hc system, accessibility to facilities, ASD stigma, societal issues <i>Recommended support:</i> info on navigate hc system, aids for visits, tools to follow dr recomm, credible medical info/links, hc rights info	No comparison on patient and supporter views; no comparison of results of indiv participants w/ varying strengths & chall

COMPLEX COMMUNICATION NEEDS - SYSTEMATIC REVIEW

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Number of Papers Included, Incl/ Excl Criteria	Methodology & Pattern Analysis	Summary of Results & Recommendations	Study Limitations
Finke et al. 2008 <i>Journal of Clinical Nursing</i> USA	Systematically review the research on comm btw nurses & patients w/ CCN	Systematic review D1 I	N=12 4 primary databases searched Incl= published in a peer-reviewed journal btw 1990–2007, in English, primary research methodology examining at least one nurse/patient. Comm factor: importance, barriers, supports, recomm for improvements. Excl= any material that described nurse-patient communicative interactions w/out use of primary research methodology or w/out data reported as findings. Participants: Nurses, patients, unpaid caregivers	Research methods in papers: qual interview/ questionnaire, cross-sectional experiment, obs, narrative analysis Analysed for patterns in: importance of comm btw nurses & patients w/ CCN; barriers to comm btw nurses & patients; the supports for comm btw nurses & patients; & recomm to improve comm btw nurses & patients.	n=9, <i>Lack of comm</i> : affect patient recovery & LOS in hospital, patient's experiment lack of control/self-determination, basic care needs unmet n=11, <i>Barriers</i> : task-focused interactions assoc w/ physical needs & medical care ineffective at meeting needs, lack of AAC training or access to comm tools n=11, <i>Supports</i> : follow written directives for comm, look for nonverbal cues, share comm info w/ other medical staff n=4, <i>Recomm</i> : Training w/ AAC use & implications of severe comm impairment <i>AAC strategies</i> : determine mode of comm, allow time for patient to comm, confirm message is understood, use AAC to support comprehension if required, advocate AAC assessment	None reported

COMPLEX COMMUNICATION NEEDS - QUALITATIVE

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Methods for enhancing rigor	Themes and Results	Study Limitations
*Morris et al. 2013 <i>Disability and Rehabilitatio n Assistive Technology</i> USA	To explore the experiences of adults who use AAC systems to comm w/ hc provider	Phenomenolo gical, Q3d Indiv one-on- one interviews (N=12) and online focus group (n=4)	N=12 w/ CP (n=5), DD (n=1), ALS (n=3), HNC (n=1), PLS (n=2); 31-69yo (m=45.7) Incl=use AAC > 6- months, consent	Video/audio recording view ≥3x, verbatim transcription, coded in nVivo 8, peer checking	General feeling that comm diff did not impact care, importance of bringing caregiver Themes: <i>Plan/Prepare appt:</i> used written documents w/ dx info/questions <i>Time barriers impact care,</i> <i>exp inappropriate assumptions of</i> <i>dx/cognitive abils, importance of</i> <i>patient-provider</i> <i>rapport/relationship, importance of</i> <i>abil to make own decisions,</i> <i>ineffective comm at apt negatively</i> <i>impacts treatment plan adherence</i>	Small sample size

COMPLEX COMMUNICATION NEEDS - NARRATIVE LITERATURE REVIEW

Author Year Journal Country	Purpose of Paper	Type of Literature	Recommendations/Strategies
McNaughton et al. 2010 <i>Journal of Pediatric Rehabilitation Medicine</i> USA	Identify changes w/ transition from child to adult health services, & how to teach adolescents w/ CCN to develop health literacy & patient-provider comm skills.	Narrative literature review	Strategies to promote health literacy & patient-provider comm: Health passports; take AAC tools to health consultations; introduce self & comm system; use approp vocabulary; practice health-related language; role-play; access to approp supports (interpreters, comm boards); develop self-determination & self advocacy skills

CHRONIC HEALTH CONDITIONS - MIXED METHODS

Author Year Journal Country	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Interventions & Outcome Measures	Summary of Results	Study Limitations
*Gorter et al. 2015 <i>BMJ Open</i> UK	To assess use, utility and impact of Youth KIT &/or TRACE to support youth w/ chronic conditions during transition to adult hc	Mixed Method O4/Phenomenological Q2d III 3/6	<i>N</i> =50 young adults w/ chronic health conditions (20 different dx) transferring to adult hc within 1 year; <i>m</i> age=19.9 Incl=abil to use intervention tools, English speaking Excl= youths who fully depend on caregivers for ADLs & comm	I: Youth KIT (tool to promote goal setting/self management) &/or TRACE (online transition mentor) O: Pre/Post transition data on frequency of use, utility & impact of transition intervention, goal achievement, post transfer qual interview	Use/utility of Youth KIT most helpful pretransition, use ↓ post-transfer; TRACE: easy to understand, data included not relevant to population; both most helpful for goal setting, stat sig increase in setting/meeting individual health related goals; minimal use post transition	No indiv w/ comm diff, no long term understanding of impact

* articles obtained through citation tracing

Key to Abbreviations

Abbreviation	Full Phrase
#	number
&	and
↑	increase/increased
↓	decrease/decreased
>	greater than
≥	greater than or equal to
≤	less than or equal to
3Rs	Rights, Respect and Responsibility
AAC	augmentative and alternative communication
abil/s	ability/abilities
activs	activities
ADL	activities of daily living
adol	adolescents
advoc	advocacy
AfAm	African American
Amer	American
ALS	amyotrophic lateral sclerosis
appt/s	appointment/s
ASD	autism spectrum disorder
ASL	American Sign Language
approp	appropriate
btw	between
cardio	cardiovascular
comm	communication
chall/s	challenge/challenges
CHAP	Comprehensive Health Assessment Program
conseq	consequences
ctrl	control group
CP	cerebral palsy
CSRI	Client Services Receipt Inventory
DD	developmental disabilities
diff	difficulty/difficulties
doc	documentation
dr	doctor
dx	diagnosis
EHP	ecology of human performance
emo	emotional
exam	examination
excl	exclusion
Exp	experience/s
f	female
GP	general practitioner
grp/s	

hc	group/s
HD	healthcare
HNC	health diary
hep	head and neck cancer
hr	hepatitis
I	hour
ID	intervention
IDD	intellectual disability/ies
immun	intellectual and/or developmental disabilities
incl	immunization
incorp	inclusion
ind	incorporated
indiv	independence
info	individual/s
KHPT	information
LD	Knowledge of Health Problems and Terminology Checklist
LOS	learning disability
m	length of stay
<i>m</i>	male
MC	mean
min	multiple choice
mo	minute
mod	months
msg	moderate
<i>N</i>	messages
<i>n</i>	total number of cases
O	number of cases (in a subsample)
OT	outcome
PDD-NOS	occupational therapy
PHP	pervasive developmental disorder not otherwise stated
physiol	Personal Health Profile
PLS	physiological
PT	primary lateral sclerosis
RCT	physiotherapy
recomm	randomized control trial
SESs	recommendations
SEUs	Special Education Schools
sig	Special Education Units
SSG	significant
stat	social skills group
x	statistically
TN	times
TRACE	Tennessee
tx	TRACE online mentor
qual	treatment group
US	qualitative
vac	United States

VAPT	vaccination
vs	Volunteer Advocacy Program-Transition
w	versus
w/	women
w/out	with
wk/s	without
yo	week/s
Youth KIT	years old
yr/s	Keeping It Together for Youth
	year/s

Summary of Key Findings.**Summary of Experimental Studies**

Four evidence-based interventions were found to improve health knowledge, health literacy, and health advocacy skills of young adults and adults with learning disabilities. McPherson, et al., (2016) found that a Health Intervention Package*, consisting of a classroom-based health education, the Ask health diary* and CHAP*, increased health knowledge and advocacy skills among adolescents with ID including self-advocating for own health needs during interactions with healthcare providers, and assuming responsibility for their own health (McPherson et al., 2016). Augmentation of communication and health documentation efforts improved access and quality of care (McPherson et al., 2016). Women with mild to moderate ID had significant improvements in health knowledge, coping strategies, and health behavior beliefs following 8-weeks of Women Be Healthy* (Lunsky, Straiko & Armstrong, 2003). The 3Rs* (Rights, Respect, and Responsibility) health knowledge training program improved health knowledge among individuals with intellectual disabilities through small group interventions incorporating visual materials and a game format (Feldman et al., 2016). Implementation of the personal health profile for adults with LD resulted in an increase in the number of health problems reported to general practitioners compared to the control group; however, did not improve health literacy skills or increase medical visits as was hypothesized (Turk et al., 2010).

The Youth KIT* and TRACE online mentor* were found to be helpful for young adults in setting goals prior to the transition to adult healthcare, however, neither intervention was shown to have a long lasting impact. The Volunteer Advocacy Program-Transition (VAPT)* showed positive results for educating and involving parents of young adults with ASD in the shift from pediatric to adult services (Taylor, Hodapp, Burke, Waitz-Kudla & Rabideau, 2017).

Note. Interventions marked with * are described in Appendix A

General themes from subjective accounts highlight that communication impairments, cognitive impairments and delayed processing speed as a symptom of a disability resulted in inadequate care, ongoing difficulties when navigating the adult healthcare system and during general visits (Balandin, Hemsley, Sigafoos, & Green, 2007; Brown, 2009; Larivière-Bastien, Majnemer, Shevell, & Racine, 2011; McNaughton, Balandin, Kennedy, & Sandmelet, 2010; Morris, Dudgeon, & Yorkston, 2013; Nicolaidis et al., 2015; Williamson et al., 2017). Adults with cognitive impairments reported that a lack of basic health knowledge often resulted in withdrawing from routine visits due to confusion on what certain examinations were for and what services were medically necessary (Brown, 2009). Others reported general feelings of injustice resulting in increased anxiety over medical conditions and displeasure with the health system when engaging with professionals who underestimated their cognitive abilities or needs (Balandin et al., 2007; Larivière-Bastien et al., 2011; Morris et al., 2013; Nicolaidis et al., 2015). Additionally, environmental factors such as overstimulating waiting rooms, financial barriers, and decreased availability of adult care providers and services for those with intellectual and/or developmental disabilities (IDD) continue to impact health care accessibility (Williamson et al., 2017).

The overarching recommendation from the studies on adults with various disabilities highlighted the importance of self-advocacy and self-determination to navigate the system and manage individual health needs (McNaughton, Balandin, Kennedy, & Sandmelet, 2010; Morris et al., 2013). Many individuals felt unprepared for routine doctors' visits and stressed the importance of preparing in advance by arriving to visits with written medical information and questions, aids to express themselves, caregivers to assist as necessary and the individual capacities to advocate for themselves (Larivière-Bastien et al., 2011; McNaughton et al., 2010; Morris et al., 2013; Nicolaidis et al., 2015). Many individuals in the studies desired that healthcare providers and professionals prepare and supply additional health related aids, tools to navigate the healthcare system and information to prepare more thoroughly for their appointments (Balandin et al., 2007; Larivière-Bastien et al., 2011; McNaughton et al., 2010; Morris et al., 2013; Nicolaidis et al., 2015). Additionally, time barriers and medical professionals' lack of knowledge on certain disabilities hinder patient-

provider relationships and further delay individuals with communication challenges from seeking out and receiving the care he/she needs (Balandin et al., 2007; Larivière-Bastien et al., 2011; Nicolaidis et al., 2015; Williamson et al., 2017).

Summary of Descriptive Studies

In a review of 20 different health assessments available for people with intellectual disabilities, Bakker-van Gijssel et al (2017) found two of highest quality: Stay Well and Healthy-Health Risk Appraisal (SWH-HRA) and the Comprehensive Health Assessment Programme (CHAP). In a review of 12 studies regarding communication between nurse and patients with complex communication needs, Finke, Light and Kitko (2008) found interactions were hindered as nurses lacked training and understanding on augmentative and alternative communication device use. A case series that examined accessibility of healthcare for those with ASD within the US healthcare system, Hillier, Galizzi, and Ferrante (2017) found that those with ASD overestimated their ability to manage their healthcare and were significantly less independent in managing their healthcare than their peers without ASD.

Implications for Consumers

Consumers with communication challenges should pursue opportunities to further advance their general knowledge of health, what it means to be “healthy”, work to understand his/her disability, and gather information on the healthcare system as a whole (Brown, 2009; Larivière-Bastien et al., 2011; McNaughton et al., 2010; St. John, Hladik, Romaniak, & Ausderau, 2018). Suggestions include engaging with material that describes and defines basic health related needs and the aging process and asking questions of their medical providers when they are unclear of the purpose of an examination or the medication they are prescribed (Brown, 2009).

Consumers should advocate for their needs by preparing for medical visits, creating health passports or written information and questions, being prepared to clarify and describe individual needs and utilize communication devices with medical

professionals (Balandin, Hemsley, Sigafoos, & Green, 2007; Larivière-Bastien, Majnemer, Shevell, & Racine, 2011; McNaughton et al., 2010). Consumers should incorporate parents and/or caregivers in the advocacy process when navigating the healthcare systems and during routine visits as this may alleviate some of the challenges faced during medical appointments (Larivière-Bastien, et al., 2011; Nicolaidis et al., 2015; Taylor et al, 2017). Finally, using tools such as the Youth KIT and TRACE may be helpful for setting and meeting health related goals during the transition from pediatric to adult healthcare (Gorter et al., 2015).

Implications for Practitioners

Occupational therapists can support young adults with ID/IDD, ASD, or CCN, as they transition from the pediatric to adult health care system by utilizing evidence based strategies that can improve health advocacy skills, self determination, health knowledge, accessibility and quality of care, and their overall health. Occupational therapists can collaborate with teachers to implement a classroom-based health education program utilizing health diaries and CHAP booklets; employ a curriculum addressing women's health and preparation for medical visits through cognitive behavior therapy and assertiveness training; implement an advocacy program to educate parents on adult disability services, healthcare and advocacy; and involve young adults in the healthcare decision-making and design of health programs (Lennox, et al., 2012; Lunskey, Straiko, & Armstrong, 2003, McPherson et al., 2016, Williamson et al., 2017). Other avenues of support include training for individuals with CCN on how to a) navigate the healthcare system, b) develop strategies and work with healthcare providers to modify the physical and sensory environments for medical visits, and c) utilize tools to support follow through with health provider's recommendations (Nicolaidis. et al., 2015; Hillier, et al., 2017, Williamson et al., 2017). To address communication barriers, occupational therapists can train healthcare providers on the use of AAC devices, how to advocate for AAC assessments, and to employ communication strategies with key members involved in the healthcare of the young adult (Finke, Light, & Kitko, 2008). Lastly, Williamson et al. (2017) suggests that including IDD-specific information on health provider

licensing exams can encourage education on working with adults with IDD in health care programs.

Implications for Researchers

Further research is needed to develop more evidence-based programs to prepare young adults with complex communication needs to transition from the pediatric to the adult healthcare system. Research should include those with severe disabilities and larger sample sizes. Additionally, strategies and recommendations for removing communication barriers need to be researched to determine their feasibility and effectiveness. Currently, there is no evidence in the literature that health checks, such as the Ask Health Diary and CHAP, result in increased autonomy for individuals with intellectual disabilities, and further research is needed to determine which component of the Health Intervention Package is responsible for the greatest gains (McPherson, 2017). Practitioners need researchers to assess the efficacy of health transition programs and utility of developing appropriate policies to ensure smooth transitions from pediatric to adult health services (McNaughton et al., 2010). There is a need for research on effective health care provider readiness training, promoting health care involvement with adults with IDD, and self determination for informed consent in health care decision-making (Williamson et al., 2017). The effect of environmental facilitators and barriers including the physical environment, race/ethnicity, financial and family context issues need to be explored in depth.

Bottom Line for Occupational Therapy Practice/ Recommendations for Best Practice

Occupational therapists need to develop evidence based interventions to effectively prepare young adults with complex communication needs for adult health services. Evidence suggests teaching this population self-advocacy and self-determination skills is vital to best engage in the adult health care system (Lennox et al., 2016; McPherson et al., 2016). Implementing an Ask Health Diary may be an effective means for preparing a young adult with complex communication needs to increase their self-advocacy skills in regard to their health (Lennox et al., 2016; McPherson et al., 2016).

Occupational therapists should incorporate education and training for young adults about their health, the human body and the health care system in their practice using formal and informal tools to prepare this population for adult healthcare (Feldman et al., 2016; Lennox et al., 2007, 2010, 2016; McPherson et al., 2017). Additionally, occupational therapists should include caregivers in the transition process and implement health diaries or Comprehensive Health Assessment Programs into services to further assist adults with disabilities in engaging in ongoing medical care (Lennox et al., 2007; McPherson et al., 2016).

References

- Bakker-van Gijssel, E. J., Lucassen, P. L. B. J., Olde Hartman, T. C., van Son, L., Assendelft, W. J. J., & van Schrojenstein Lantman-de Valk, H. M. J. (2017). Health assessment instruments for people with intellectual disabilities-A systematic review. *Research in Developmental Disabilities, 64*, 12–24. doi:10.1016/j.ridd.2017.03.002
- Balandin S., Hemsley B., Sigafos J., & Green, V. (2007). Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs. *Applied Nursing Research, 20*, 56–62. doi:10.1016/j.apnr.2006.03.001
- Brown, A. A. (2009). New voices in women's health: Perceptions of women with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 47*, 337-347. doi:10.1352/1934-9556-47.5.337
- Feldman, M. A., Owen, F., Andrews, A. E., Tahir, M., Barber, R., & Griffiths, D. (2016). Randomized control trial of the 3Rs health knowledge training program for persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 29*, 278–288. doi:10.1111/jar.12186
- Finke, E. H., Light, J., & Kitko, L. (2008). A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *Journal of Clinical Nursing, 17*, 2102–2115. doi:10.1111/j.1365-2702.2008.02373.x
- Freeman, M. (2015). Development and evaluation of the Youth KIT: Keeping It Together™ for Youth (the ‘Youth KIT’) to assist youth with disabilities in managing information. *Child Care Health Development, 41*, 222-229. doi:10.1111/cch.12199
- Gorter J. W., & Punthakee, Z. (2010) Transition to Adulthood with Cyber guide Evaluation (TRACE) [Online]. Ontario, Canada. Retrieved from <http://abilityonline.org/>

- Gorter, J. W., Stewart, D., Cohen, E., Hlyva, O., Morrison, A., Galuppi, B., ... TRACE Study group. (2015). Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: A mixed-methods longitudinal prospective cohort study. *British Medical Journal Open*, 5, 1-12. doi:10.1136/bmjopen-2014-007553
- Hillier, A., Galizzi, M., & Ferrante, K. (2017). Healthcare experiences of young adults with autism spectrum disorder. *Advances in Autism*, 3, 206–219. doi:10.1108/AIA-06-2017-0014
- Larivière-Bastien, D., Majnemer, A., Shevell, M., & Racine, E. (2011). Perspectives of adolescents and young adults with cerebral palsy on the ethical and social challenges encountered in healthcare services. *Narrative Inquiry in Bioethics*, 1(1), 43–54. doi:10.1353/nib.2011.0001
- Lennox, N., Bain, C., Rey-Conde, T., Purdie, D., Bush, R., & Pandeya, N. (2007). Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: A cluster randomized trial. *International Journal of Epidemiology*, 36, 139-146. doi:10.1093/ije/dyl254
- Lennox, N., Bain, C., Rey-Conde, T., Taylor, M., Boyle, F. M., Purdie, D. M., & Ware, R. S. (2010). Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings. *Journal of Applied Research in Intellectual Disabilities*, 23, 303–311. doi:10.1111/j.1468-3148.2009.00533.x
- Lennox, N., Ware, R., Carrington, S., O'Callaghan, M., Williams, G., McPherson, L., & Bain, C. (2012). Ask: A health advocacy program for adolescents with an

- intellectual disability: A cluster randomised controlled trial. *Biomed Central Public Health*, 12, 750. doi:10.1186/1471-2458-12-750
- Lennox, N., McPherson, L., Bain, C., O’Callaghan, M., Carrington, S., & Ware, R. S. (2016). A health advocacy intervention for adolescents with intellectual disability: A cluster randomized controlled trial. *Developmental Medicine & Child Neurology*, 58, 1265–1272. doi:10.1111/dmcn.13174
- Lunsky, Y., Straiko, A., & Armstrong, S. (2003). Women be healthy: Evaluation of a women’s health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 247–253. doi:10.1046/j.1468-3148.2003.00160.x
- McNaughton, D., Balandin, S., Kennedy, P., & Sandmel, T. (2010). Health transitions for youth with complex communication needs: The importance of health literacy and communication strategies. *Journal of Pediatric Rehabilitation Medicine*, 3, 311–318. doi:10.3109/07434618.2015.1036458
- McPherson, L., Ware, R. S., Carrington, S., & Lennox, N. (2017). Enhancing self-determination in health: Results of an RCT of the Ask project, a school-based intervention for adolescents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 360–370. doi:10.1111/jar.12247
- Morris, M. A., Dudgeon, B. J., & Yorkston, K. (2013). A qualitative study of adult AAC users’ experiences communicating with medical providers. *Disability and Rehabilitation: Assistive Technology*, 8, 472–481. doi:10.3109/17483107.2012.746398
- Nicolaidis, C., Raymaker, D., Ashkenazy, E., McDonald, K., Dern, S., Baggs, A., . . . Boisclair, W. (2015). “Respect the way I need to communicate with you”:

Healthcare experiences of adults on the autism spectrum. *Autism*, 19, 824-831.

doi:10.1177/1362361315576221

St John, B., Hladik, E., Romaniak, H., & Ausderau, K. (2018). Understanding health disparities for individuals with intellectual disability using Photovoice.

Scandinavian Journal of Occupational Therapy, 25, 1-11.

doi:10.1080/11038128.2018.1502349

Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017).

Training parents of youth with autism spectrum disorder to advocate for adult disability services: Results from a pilot randomized controlled trial. *Journal of Autism and Developmental Disorders*, 47, 846–857.

doi:10.1007/s10803-016-2994-z

Turk, V., Burchell, S., Burrha, S., Corney, R., Elliott, S., Kerry, S., ... Painter, K. (2010). An evaluation of the implementation of hand held health records with adults with learning disabilities: A cluster randomized controlled trial. *Journal of Applied Research in Intellectual Disabilities*, 23(2), 100–111. doi:10.1111/j.1468-3148.2009.00518.x

Williamson, H. J., Contreras, G. M., Rodriguez, E. S., Smith, J. M., & Perkins, E. A.

(2017). Health care access for adults with intellectual and developmental disabilities: A scoping review. *OTJR: Occupation, Participation and Health*, 37, 227–236. doi:10.1177/1539449217714148

Involvement Plan

On February 15, 2019 at 11:30 a.m., we held a meeting with our research collaborator, Dr. Barbara Abbott, to discuss the next steps for the research project. Dr. Abbott informed us that she no longer was working at The Outreach Program (TOP) in Kent, Washington. She had transitioned to working in four schools in the Kent School District splitting her time between an elementary school, a middle school, a private academy and an online high school program. Her caseload included students in general education or contained classrooms diagnosed with autism, Down syndrome, intellectual disabilities, attention deficit hyperactivity disorder and severe anxiety. While she no longer works at the post-secondary transition program for which the project was founded, Dr. Abbott confirmed that our research project was still very relevant to the concerns she had in her new settings.

Dr. Abbott emphasized that the schools she currently works in continue to lack proper, structured education programs for teaching young adults with complex communication needs how to best understand their health information. She highlighted that while the population she primarily works with are younger, the research we gathered was applicable to her current needs and her desire to distribute knowledge. At a district-wide level, students with special needs in the Kent School District typically do not receive health, nutrition, or sexual education courses as administrators do not believe the material is relevant or would be understood by this population. Additionally, she reported that occupational therapists with whom she works rarely address these concerns due to disagreements regarding what is within the scope of occupational therapy practice.

Dr. Abbott asked us to create an electronic two page Powerpoint Publisher tri-fold pamphlet with a summary of our research. The intended audiences were education stakeholders and colleagues. She indicated that due to the nature of communicating with stakeholders, which

often entails a 15-minute presentation at most, an electronic pamphlet that could be updated with new research and printed for further distribution would be the most appropriate medium for translating our research into a project. The desired pamphlet would incorporate qualitative data to provide subjective accounts of individual experiences with the adult health care system and health knowledge, statistical information regarding IDEA laws and state compliance with health and sexual education standards, as well as quantitative evidence to provide the most applicable evidence-based interventions for addressing this problem area. This pamphlet would benefit her practice, students with CCN, and the field of occupational therapy.

Dr. Abbott indicated that one of the largest barriers to the knowledge translation project would be the consideration and acceptance of this information by the occupational therapists with whom she works. Dr. Abbott expressed that many occupational therapists she engages with do not agree that improving health literacy is within the occupational therapy scope of practice in the school setting. She reported that there are a large number of occupational therapists who are not familiar with the AOTA Occupational Therapy Practice Framework and that many approach occupational therapy in the school districts with interventions focused on handwriting and other fine motor skills. Dr. Abbott expressed that these challenges extend to school administrators who often have limited perspectives on occupational therapist roles in the school districts. She indicated that she has had to advocate for interventions or education curriculum regarding health knowledge with her administrators due to their expressed perspectives that interventions regarding health information are not within the field of school occupational therapy. In the hopes of mitigating these challenges, Dr. Abbott emphasized that a brief, yet, comprehensive pamphlet that can be easily distributed to and viewed by stakeholders and occupational therapists would be the ideal platform for our project. She indicated the need for a combination of the information found in both quantitative and qualitative articles.

The initial plan was to send the final product to school administrators in the Kent School District; however, Dr. Abbott indicated it could be applicable to other school districts, education service districts and the Washington Occupational Therapy Association (WOTA). In order to monitor outcomes, we planned to develop a short survey for the recipients of the pamphlet. Questions would be structured to gather input on whether the information provided in the pamphlet was new, altered recipients' perspectives on their students, and if the interventions provided would be applicable for implementation in the school district.

Target dates for the completion of tasks/products.

Task/Product	Deadline Date	Steps w/ dates to complete project
Draft #1 of Electronic Pamphlet	3/5/2019	2/25/2019 - Decide on relevant information to include in pamphlet 2/28/2019 - Decide on layout/placement of information 3/5/2019 - Submit draft #1 3/12/2019 - Meet with Renee to discuss draft #1
Draft #2 of Electronic Pamphlet	3/15/2019	Week of 3/11 - Meet with Dr. Abbott to discuss draft of pamphlet - Revise electronic pamphlet if needed based on feedback from Dr. Abbott 3/27/2019 - Meet with Renee to discuss draft #2
Draft #3 of Electronic Pamphlet - Final	3/29/2019	Submit to Renee for final review of electronic pamphlet
Design Outcome Survey	4/4/2019	3/30 - 4/4/2019 - Secure audience for survey - Design outcome survey

		- Meet with Renee re: survey design if needed
Assess Data in Outcome Survey	4/15/2019	4/5 - 4/10/2019 - Submit survey and electronic/print copy of pamphlet to intended audience
AOTA Conference Proposal	4/16/2019	4/9 - 4/15/2019 - Work on AOTA conference proposal
Final Report and CAT	4/30/2019	Week of 4/22 - Meet with Renee to discuss final report 4/30/2019 - Submit final report & CAT to Renee

Knowledge Translation

Pamphlet

In order to synthesize research findings and prepare a double-sided tri-fold pamphlet, the student researchers began brainstorming to identify what information from that already gathered would be applicable to both school-based occupational therapists and school administrators. They also identified where current gaps regarding health education for students with special needs existed. It became clear that the layout of the pamphlet must be professional in nature, concise, and incorporate additional school-related statistics capture the attention of administrators, the main stakeholders who could approve implementation of the research findings in a school setting. To highlight the current trends and realities at both national and statewide levels, the student researchers gathered information regarding IDEA laws, statistical information related to law compliance, and data of individuals with disabilities. Information included nationwide statistics on the percentage of states currently not meeting the requirements in IDEA transition planning goals, the percentage of states not in compliance with IEP requirements, as well as Washington state statistics on the percentage of individuals over the age of 18 with at least one disability. Furthermore, the pamphlet also comprised a description of the

Health and Physical Education Standards adopted by the Washington State Public Schools, and the Healthy Youth Act that calls for appropriate sexual education regardless of gender, race, sexual orientation and disability status as part of WA State law.

When collaborating on the layout of content throughout the pamphlet (see Appendix B), the student researchers selected that information they believed would be the most logical to convey the purpose and intent of the pamphlet. The first section of information presented to the reader includes the results gathered from the literature regarding the lack of health education for individuals with disabilities. It also includes information about Section 504 which protects students from disability discrimination and ensures equal access to educational opportunities to all. These were decided to be the best introduction of information to draw the audience in.

The inside left panel of the pamphlet includes state and nationwide statistics and laws, followed by the middle panel with results found within the literature regarding health education benefits for individuals with disabilities. The right panel consists of descriptions and cost of relevant evidence-based interventions that would be appropriate for use among young adult students to improve health knowledge, accessibility to healthcare, self-advocacy and coping skills, and overall health status. Logistics such as cost and ease of delivery were taken into account when deciding which of the interventions with strong evidence to recommend. The pamphlet also includes identification of various professionals who would be able to teach health education to students with disabilities using the recommended interventions.

Challenges

A significant challenge faced in the knowledge translation process was determining how to condense 19 articles of research onto one double sided pamphlet for an audience of school administrators and school-based occupational therapists. The student researchers decided to include those interventions with the strongest evidence and that were cost effective and most

feasible to deliver. Another unforeseen challenge was locating a particular educational curricula that was documented in the literature, the 3Rs health training program for individuals with intellectual disabilities. The student researchers discovered a free sexual education curriculum on the internet with the same name, 3Rs. However, through communication with the authors of the 3Rs program that was included in the CAT, and the director of the 3Rs sexual education program, it was clarified that the programs were not affiliated with each other. Also, the authors of the 3Rs health training program mentioned that the training kits had gone out of print due to technical reasons. This resulted in the student researchers excluding this strong evidence-based intervention from the pamphlet. The back and forth email communication with the separate parties posed a time constraint in the completion of the product.

Interim Dates of Completion (2019)

Task/Product	Completed Date	Steps to achieve final product
Draft #1 of Trifold Pamphlet	4/1/2019	<ul style="list-style-type: none"> - Discuss layout and content of pamphlet, then delegate tasks between each other - Submit draft of pamphlet to project chair/mentoring professor for review
Draft #2 of Trifold Pamphlet	4/14/2019	<ul style="list-style-type: none"> - Review feedback of pamphlet from project chair/mentor - Revise pamphlet according to feedback - Gain approval from project chair/mentor on final draft of pamphlet
Design Outcomes Survey	4/16/2019	<ul style="list-style-type: none"> - Identify quantitative and qualitative questions to include in survey - Secure intended audience for survey - Send outcome survey to project chair/mentor for review

Monitor Outcomes	4/22/2019 - 4/26/2019	<ul style="list-style-type: none"> - Send 10 hard copies of final pamphlet and survey to research collaborator - Leave pamphlets and surveys in pediatric clinical instructors' shared office to gather potential respondents
Assess Data in Outcome Survey	4/26/2019	<ul style="list-style-type: none"> - Assess quantitative and qualitative data from completed surveys

Outcome Monitoring

Consistent with the initial plan to survey recipients of the pamphlet to determine its effectiveness in conveying information, the student researchers developed an eight question survey (see Appendix C) intended primarily for school-based occupational therapists. The introduction to the survey directed the recipients to review the pamphlet and complete the survey questions after viewing the information. The respondents were asked to provide their level of occupational therapy credentials, number of years in occupational therapy practice, number of years in school-based occupational therapy practice and the age of the students worked with. The respondents were then asked to complete seven questions on a five-point Likert scale, with “1” as strongly disagree and “5” as strongly agree.

The survey questions asked whether the information was new to the respondents, whether the information changed respondent perspective on the population he/she worked with, if the material was laid out in a clear manner. It also asked if the respondent believed teaching health education was within the scope of occupational therapy, if the respondent would be interested in sharing information from the pamphlet with colleagues and/or school administrators, if the respondent would utilize the information to inform his/her practice, and if the respondent was

interested in incorporating one or more of the listed interventions for students with disabilities into the school day. A final open-ended question was included to allow for additional comments.

Dr. Abbott delivered both hard and electronic copies of the pamphlet to occupational therapists within the Kent School District, WOTA Community Transitions in Practice and AOTA Transition Community of Practice. Since the student researchers did not have direct access to the potential respondents of the surveys delivered by Dr. Abbott, she distributed and collected surveys from that audience herself. The total number of recipients of the pamphlet Dr. Abbott delivered is unknown to the student researchers. Upon agreement between Dr. Abbott and the student researchers, hard copies of the pamphlets and surveys were also distributed to school-based occupational therapists working as clinical instructors (CIs) for the University of Puget Sound's Occupational Therapy onsite clinic. There were six recipients of the pamphlet and survey that the student researchers delivered to the CIs. The CIs reviewed the pamphlets, completed surveys, and placed them in an envelope that was located in the shared CI office in the pediatric clinic at University of Puget Sound. A total of 13 surveys were returned from Dr. Abbott and two surveys were collected from the CIs, amounting to 15 surveys in total.

Effectiveness of Task and Product

To evaluate the effectiveness of the knowledge translation process, the student researchers reviewed and analyzed the 15 completed and returned surveys from occupational therapists who have had experience working in the school system and who had reviewed the pamphlet. Fourteen of the 15 surveys returned were from occupational therapists currently working in the school system. Of the 15 returned, the occupational therapists' years of general practice ranged from two to 45 years with an average of 19 years. The years of school-based practice ranged from three months to 30 years with an average of 11.7 years. It should be noted

that the occupational therapist with three months experience was a respondent not currently working in the school system; the lowest number of years spent working by a currently practicing school-based occupational therapist was two years. All respondents reported a range of ages of students worked with and in total, these ages ranged from 2 to 22 years old. While the total number of surveys returned was small, due to the average range of years working as an occupational therapist and years of experience working in a school system, the student researchers concluded that the survey responses would provide informed replies important for considering the effectiveness of the knowledge translation project.

Statistical analyses of the survey responses indicated the pamphlet fulfilled many of the aims of the knowledge translation project. In response to the question, “the information in the pamphlet is new to me,” 40% of respondents disagreed and 27% agreed. The other 33% were neutral about the information being new to them. The next question asked respondents whether the information in the pamphlet changed their perspective on the student populations they worked with. Thirty-three percent of the respondents agreed, 27% disagreed, and 33% were neutral about it; one respondent did not answer this question. The outcomes on both of these questions suggest that the occupational therapists may have had some prior knowledge about the discrepancy between health education needs of students with special needs and the health education opportunities available in schools for this specific population.

The occupational therapists surveyed overwhelmingly agreed that “teaching health education is within the scope of occupational therapy,” as reported by 87% of respondents. Whereas 13% of respondents were neutral about the statement. This positive perspective of respondents was surprising. Dr. Abbott had mentioned that the majority of school based occupational therapists delivered occupational therapy interventions related to handwriting and fine motor skills. Based on the response to this question, currently practicing school-based

occupational therapists in our sample believe health education to be within the scope of their services, however, they may not have had the tools to deliver this service. Furthermore, the disparity in occupational therapists providing interventions to improve health literacy of students may be due to the lack of awareness of school administrators that teaching health information is within the scope of occupational therapy. This further aligns with Dr. Abbott's need to advocate for interventions or education curricula regarding health information with her school administrators.

In response to the statement, "I would be interested in sharing this information with colleagues and/or school administrators," 93% of respondents agreed, and 7% were neutral. Similarly, in response to the statement, "I would be interested in incorporating a health education intervention for students with disabilities during the school day," 93% of respondents agreed, and 7% were neutral. Outcomes on both of these statements indicate that occupational therapists could be a potential source of information dissemination and advocacy to other school educators and administrators on the importance of providing accessible health education to students with disabilities.

Overall, the feedback received regarding the pamphlet was widely positive. In response to the statement, "the material was laid out in a clear manner," 87% of respondents agreed and 13% were neutral. In regard to the statement, "I would utilize the information in this pamphlet to inform my practice as a school-based occupational therapist," 87% agreed, and 13% were neutral. This suggests that the information included in the pamphlet for school-based occupational therapists was relevant and could potentially be used in their practice.

Lastly, the respondents were provided an opportunity for open-ended feedback on the pamphlet. Comments affirmed the usefulness of the pamphlet such as "this pamphlet describes essential components of health education for individuals with a disability clearly and in a

meaningful manner” and “I see the benefit of this concept.” Other comments included, “I really like how this provides no or low-cost resources to support health education for this population,” “this information is very valuable,” and “thanks for addressing this unmet need.” Some respondents asked for suggestions beyond of the scope of the research project such as “any advice on how to talk with parents about the importance of knowledge and advocacy?” Others provided suggestions such as linking the facts in the pamphlet to the reference list, as well as condensing or expanding upon different information provided.

Overall, both quantitative and qualitative outcomes of the survey were relatively positive with valuable information that can be used to further refine the knowledge translation products in the future. Although the sample size was small, the majority of occupational therapists surveyed reported believing that teaching health education is within their scope of practice. Yet, as Dr. Abbott had mentioned, that has not been the focus of occupational therapy interventions in the school settings, and students with disabilities are typically excluded from accessing appropriate health education curricula in their classrooms. An overwhelming majority of the respondents reported being interested in incorporating a health education intervention for students with disabilities during the school day. This establishes the relevancy and usefulness of the pamphlet as a strong advocacy tool that could be used to inform school administrators in considering health education interventions to teach students with disabilities. The surveyed occupational therapists also agreed that they would share the information on the pamphlet with their colleagues and school administrators. This suggests that occupational therapists can be pioneers in addressing this unmet need of young adult students with disabilities to improve their health advocacy skills, self-determination skills, access to quality health care, and overall health.

Analysis of the Overall Process

This year long research project was one filled with learning opportunities, challenges, barriers, successes and at last, accomplishments. Beginning the process as a group of four researchers and breaking off into two groups of two, we initially felt disappointment, concern and overwhelmed with the vast amount of work that we knew was in store for our future. Then, as new researchers presented with a new and abstract research topic with little available evidence, we experienced anxiety and panic as to how to proceed and develop a project that would provide our collaborator with the answers she was looking for. Fortunately, our project chair, Dr. Watling, was there to help and guide us with her expertise through the process of refining our question and assisting with our research strategies. With her guidance and our growing knowledge of the research process, we were able to locate and comb through thousands of articles and develop a more critical eye towards the evidence we uncovered.

Our skills as new researchers were further refined and improved in the process of synthesizing all of the articles and evidence we had found into our final paper. With various diagnoses and conditions addressed in both our qualitative and quantitative data, we initially struggled to generalize our evidence into concise summaries. With dedication, we developed the skills to recognize patterns in the articles, identify high levels of evidence and effectively consolidate our findings into our paper with success. After presenting our findings to our collaborator, hearing her positive feedback, and ideas for our knowledge translation, we recognized that our work and the evidence we had found was in fact beneficial to her practice and population she worked with.

Our knowledge translation project again presented both unique challenges and opportunities. Sifting through all of our research and determining appropriate information to include onto a double-sided trifold brochure for education stakeholders and school-based

occupational therapists pushed us to develop the skills needed to turn our research into a product for practical use. The process was challenging yet allowed us to further develop a critical eye for evidence in practice, and with these challenges came successes. Receiving the positive feedback on our outcome surveys, we realized that our research provided new and impactful evidence to even highly experienced practitioners. To see that the evidence based interventions we discovered may be utilized by practitioners was incredibly rewarding. We came to recognize that researching topics not commonly focused on in occupational therapy practice can help develop and advance our profession as a whole. We learned a great deal from this process and are certain the research skills we developed throughout the year will benefit us moving forward into our careers as evidence-informed practitioners.

Recommendations for the Future

The information that had been gathered in the tri-fold pamphlet was for a broad audience that includes educators, occupational therapists, school administrators, and other education professionals. To increase the effectiveness of the pamphlet, future student researchers can cater the product for specific audiences. For example, if the intended audience is solely occupational therapists, sections that mention how occupational therapists can support educators in the implementation of health education, how they can advocate and support assessments on assistive technology, and collaboration strategies with educators within existing transition programs can all be valuable components to include. It would also be beneficial to indicate which interventions would be most appropriate for augmentative and alternative communication (AAC) use to address the needs of students with communication barriers. The information can also be tailored for members of the Individualized Education Plan (IEP) team. For example, family members can be informed on the use and benefits of health diaries during medical visits, and ways to support

the young adult student to increase health advocacy skills during their interactions with health professionals. Speech language pathologists, occupational therapists, and/or assistive technology evaluators can collaborate with each other in assessing and implementing AAC device use for the young adult as part of transition planning goals with a focus to increase health literacy skills and self-determination.

The layout of the trifold pamphlet only allows a limited amount of information that can be included before becoming overcrowded. Depending on the audience of the pamphlet, future student researchers should make a deliberate determination regarding which components of information to highlight and which to exclude. This can help the layout of the product to be less visually stimulating, and improve the clarity of information for the audience. Additionally, creating a manual with further information on the interventions referenced, as well as other interventions included in the CAT but not mentioned in the pamphlet, can be useful for school administrators, occupational therapists, and other education professionals to consider.

If school administrators in the Kent school district decide to adopt one or more of the health education interventions for implementation in classrooms, future student researchers can help with collecting outcome measures following the interventions. Researchers can perform statistical analyses of the information, and determine the interventions' effectiveness on improved health literacy and health advocacy skills. They can also present the information to educational stakeholders to convey the importance in continued funding and support of these interventions.

References

- SHAPE America. (2018, May 9). Washington state advocacy toolkit. Retrieved from https://www.shapeamerica.org/advocacy/State-Toolkits/Washington_Toolkit.aspx
- SHAPE America. (2015). Appropriate practices in school-based health education. Retrieved from <https://www.shapeamerica.org/uploads/pdfs/Appropriate-Practices-in-School-Based-Health-Education.pdf>
- University of Queensland. (2016, October 7). The ask health diary and app. Retrieved from <https://qcidd.centre.uq.edu.au/resources/ask-health-diary-and-app>niquest. (2019). *Chap form*. Retrieved from <https://eshop.uniquet.com.au/chap-form-clinical-use/>
- Uniquet. (2019). Chap form. Retrieved from <https://eshop.uniquet.com.au/chap-form-clinical-use/>

Appendix A

Descriptions of Interventions in CAT Tables

3Rs: A health knowledge training program designed specifically for individuals with intellectual disabilities and verbal skills. Teaches concepts related to the human body, organs, biological systems, and how to keep systems healthy. The teaching methods are based on behavioral and universal design learning principles that include: adapting teaching style to the learner, breaking down concepts, providing examples and feedback, and role playing. Pain and time scales were used to teach participants how to describe their pain and when it started. It included pictures of people experiencing different types of pain to describe specific types of pain (e.g. heartburn). They were also taught how to recognize and redress health rights violations in the context of respect for others' health rights and responsibility to their own well-being. The participants also designed their own health diary to share important information about themselves with their healthcare professional (Feldman et al., 2016).

Ask Health Diary: A health advocacy tool designed for ongoing use, completed by the person, advocate, or family members (Lennox et al., 2007).

CHAP: a one-off health review tool completed by care provider & person prior to general practitioner (GP) consultation. It is a 21 page booklet: Part 1=medical history completed by carer, Part 2= GP completed (review medical history, targeted exam and assist carer to complete health action plan) (Lennox et al., 2007).

Health Intervention Package: School-based intervention to promote health advocacy and self-determination among adolescents with ID. It consists of a classroom-based health education, Ask

Health Dairy (hand-held health record) and CHAP health check. The Ask Health Diary includes: personal details, health advocacy tips, medical record, practical tips and information on unrecognized conditions for medical staff (McPherson et al., 2017).

Volunteer Advocacy Program-Transition: 12-week workshop series to train parents of youth with autism spectrum disorder to advocate for adult disability services (Taylor et al., 2017).

Women Be Healthy: Eight-week curriculum that include health education, coping skills training, exposure to medical setting, and assertiveness and empowerment training for adult women with ID (Lunsky et al., 2003).

Youth KIT (Keeping It Together for Youth): Tool designed and developed for youth with physical and developmental disabilities to promote organization, goal setting, and self-management in domains including personal information, social information, social activities, school information, work information, budget/financial information, personal care and life skills, transportation, medical and health information, obtaining and sharing information (Freeman, 2015).

TRACE online mentor: A website designed by an occupational therapist (mentor) for youth and young adults with chronic conditions and disabilities to discuss transition issues. TRACE was available to participants through one-on-one chats, message postings, group chats, and email. Mentor and study coordinators promoted group chats during individual chats, study visits, and email announcements. Group and individual chats were offered in the evening (Gorter & Punthakee, 20).

Appendix B

Trifold Pamphlet

The Need for Health Education

Research shows that without proper education, individuals with disabilities are:

- Less likely to go to routine doctor visits and preventative screenings
- More likely to have medical conditions and complications
- Twice as likely to report sexual assault than non-disabled individuals
- Widely unable to identify health needs, the function of prescribed medications and purpose of health examinations
- At higher odds of unmet healthcare needs related to both physical and mental health
- Lacking basic health knowledge related to their own bodies



References

[Blocks]. Retrieved from <https://www.istockphoto.com/photos/old-childrens-building-blocks?page=5&sort=mostpopular&mediatype=photography&phrase=old%20childrens%20building%20blocks>

[Female patient and doctor]. Retrieved from <http://nahic.ucsf.edu/wp-content/uploads/2016/06/>

Lunskey, Y., Straiko, A., & Armstrong, S. (2003). Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 247–253. doi:10.1046/j.1468-3148.2003.00160.x

Lunskey, Y., Straiko, A., & Armstrong, S.C. (2002). Women be healthy: A curriculum for women with mental retardation/developmental disabilities. [Revised by S.M. Haverkamp, C. Klutts-Hile, & P. Dickens]. Chapel Hill, NC. Retrieved from <https://www.cds.hawaii.edu/sites/default/files/downloads/resource/s/womenshealth/WomenBeHealthy.pdf>

McPherson, L., Ware, R. S., Carrington, S., & Lennox, N. (2017). Enhancing self-determination in health: Results of an RCT of the Ask project, a school-based intervention for adolescents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 360–370. doi:10.1111/jar.12247

SHAPE America. (2018, May 9). Washington state advocacy toolkit. Retrieved from https://www.shapeamerica.org/advocacy/State-Toolkits/Washington_Toolkit.aspx

SHAPE America. (2015). Appropriate practices in school-based health education. Retrieved from <https://www.shapeamerica.org/uploads/pdfs/Appropriate-Practices-in-School-Based-Health-Education.pdf>

[Student and educator]. Retrieved from <http://nahic.ucsf.edu/wp-content/uploads/2016/06/>

University of Queensland. (2016, October 7). The ask health diary and app. Retrieved from <https://qcidd.centre.uq.edu.au/resources/ask-health-diary-and-app>

Uniquet. (2019). *Chap form*. Retrieved from <https://eshop.uniquet.com.au/chap-form-clinical-use/>

Uniquet. (2019). *Chap form*. Retrieved from <https://eshop.uniquet.com.au/chap-form-clinical-use/>

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Health Education Needs Of Students with Disabilities



Providing health education in schools to **all** students today...

Prepares **all** students for the future.

Section 504 of the Students with Disabilities Act protects students from disability discrimination and requires all students with disabilities have educational opportunities **equal** to those provided to those without disabilities.

Is your district in compliance?

The Facts

Nationally:

- Nearly **90%** of states are not meeting the requirements of transition planning under the IDEA (NCD, 2000).
- Nearly **45%** of states are not in compliance with IEP requirements (NCD, 2000).
- The Every Student Succeeds Act (ESSA) identifies school health and physical education (HPE) as part of a student's well-rounded education, requiring stakeholder engagement to implement comprehensive and effective school district plans (Shape America, 2018).

In Washington:

- **22.2%** of individuals over the age of 18 have at least one disability (CDC report)
- In 2016, **Washington State Public Schools adopted the "Health and Physical Education Standards" which includes:**
 - Providing **foundational knowledge** for students to be healthy and well throughout life
 - Supporting the development of healthy members of society
 - Prioritizing the needs of **each** student by using inclusive language
 - Emphasizing instructional understanding and application of the Whole Child Approach
- WA State law (Healthy Youth Act: RCW 28A.300.475): Any school that provides sexual education must use methods appropriate for

Does your district meet the standards?

With the Right Tools

With proper health education, individuals with disabilities demonstrate increased:

- Health knowledge
- Knowledge about their own bodies
- Likelihood to go to doctor for routine exams
- Confidence and likelihood to explain personal needs to doctors
- Ability to ask questions regarding medication and their body
- Self-advocacy skills for addressing their needs
- Coping strategies during uncomfortable procedures



THE GOOD NEWS

Appropriately designed, low cost, easy to use, and evidence-based materials exist for teaching health education to individuals with disabilities.

Tools That Work

Ask Health Diary: A health advocacy app designed to be completed by the individual with intellectual disabilities, advocate, and/or family members. It can help increase knowledge and ownership of personal and health information, prepare for upcoming medical appointments, and improve health status.
Cost: \$1.49

Health Intervention Package: A comprehensive classroom-based education program that includes the use of the Ask health diary and CHAP, a health review tool proven to improve health and healthcare accessibility
Cost: Cost of CHAP & Ask Health Diary App
CHAP: \$10 per user AUD during 12-month license period. Commercial use license required.

Women Be Healthy: Designed for women with intellectual and developmental disabilities, this 8-week curriculum can help develop self-advocacy skills by increasing health knowledge and teaching coping skills for doctor visits through assertiveness and empowerment training.
Cost: Free

A student-centered approach to health education is the most effective instructional strategy (SHAPE America, 2015).

Training and Teaching

Recommended tools are compatible for teachers, health educators, occupational therapists, and other education professionals to teach students with disabilities in high school and transition programs.

Appendix C

Outcome Survey

After reviewing the “Health Education Needs of Students with Disabilities”, please take the time to complete the following survey. This survey should take approximately 5-10 minutes to complete. Answers will be used for research purposes only.

Level of occupational therapy credential:

Years in school-based OT practice:

Years of OT practice: _____

Age of students worked with: _____

	Strongly disagree 1	2	3	4	Strongly agree 5
1. The information in this pamphlet is new to me.					
2. The information in this pamphlet has changed my perspective on the populations I work with.					
3. The material was laid out in a clear manner.					
4. I believe teaching health education is within the scope of occupational therapy.					
5. I would be interested in sharing this information with colleagues and/or school administrators.					
6. I would utilize the information in this pamphlet to inform my practice as a school-based occupational therapist.					
7. I would be interested in incorporating a health education intervention for students with disabilities during the school day.					

8. Do you have any additional comments?

Thank you for your time.

If you have any further questions, please contact Molly Stark, OTS (MStark@pugetsound.edu),
or Christabelle Francis, OTS (christabellefrancis@pugetsound.edu)

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