Caring for Children with Disabilities in the Medical Home: A Small Group, Distance-Learning, Case-Based Curriculum

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Abstract

Introduction: Children with disabilities and/or special healthcare needs often require a variety of supports and services, many of which are provided through healthcare systems. Despite this, undergraduate medical education (UME) addressing disability is lacking. This curriculum introduced students to the medical home, care coordination, federal education policies and eligibility for special education services for children under the age of 22. Curriculum goals were for students to gain the knowledge of 1) the medical home for children with disabilities and/or special healthcare needs and 2) the federal policies for special education. Case studies and discussions with families, self-advocates, and other professionals about their experiences and expertise addressed some of the medical, social, educational, and issues affecting children with disabilities and their families.

Methods: The curriculum was developed for third and fourth year students consisting of five, 2-hour sessions facilitated through distanced faculty-led, small group discussions. Each session covered a specific case with preparatory assignments. Fourteen medical students participated across four offerings in spring 2020.

Results: Students showed an increase in knowledge in the areas of the medical home, disability law, and educational interventions. Students showed favorable responses to the curriculum structure and pedagogy. Student feedback described increased self-efficacy in navigating systems-level issues and services for patients with disabilities.

Discussion: This curriculum utilized authentic, interprofessional expertise to address a gap in undergraduate medical education related to the care of children with disabilities. The utilization

of technology, case-based driven discussion, and small group de-brief benefitted students with increased knowledge and increased skills.

Educational Objectives:

By the end of the curriculum, students will be able to:

1. Describe how the medical home functions as a model to provide appropriate and effective primary care for children with disabilities and/or special health care needs.
2. Describe the barriers to high quality health care for individuals with disabilities under the age of 22.
3. Describe legislation that addresses special education for children with disabilities.
4. List resources for physicians, families/caregivers, and other members of the medical home to better serve children with disabilities and/or special health care needs and their families.
5. Describe methods physicians can use to advocate for individuals with disabilities.

Disability can have a profound impact on children that carries over through adulthood in healthcare, education, and other systems and services. Disability is not uncommon in the U.S. Data from the National Health Interview Survey estimate that as many as 1 in 6 children ages 3-17 has a developmental disability (Zablotsky et al., 2019). In 2018, over 409,000 children ages birth through two years received early intervention or Birth-to-three services under Part C (U.S. Department of Education et al., 2021). Over 14% (14.1%) of students ages 3-21 received special education services in federally supported special education programs under one or more of the 13 eligible categories under Part B of IDEA during the 2018-2019 school year (U.S. Department of Education, 2021). Children with disabilities grow up to become adults with disabilities with increased risk of disparate health outcomes. Compared to adults without disabilities, adults with disabilities have a lesser likelihood of obtaining a high school diploma, employment, and an annual household income more than $15,000 (Krahn et al., 2015).

Physicians are uniquely positioned to support children with disabilities and special healthcare needs and their families across many settings and services; this often begins with identifying developmental delays and referring for early intervention services and continues through transitioning into adulthood (Lipkin et al., 2015; Rose et al., 2014; Shah et al., 2013). According to the World Report on Disability, physician lack of knowledge about disability can have a negative impact on quality of care of persons with disabilities (PWD) across the lifespan(World Health Organization, 2011).

The American Academy of Pediatrics (AAP) recommends that physicians learn about special education law as well as procedures and programs to support and advocate for children with disabilities or special health care needs and their families (Lipkin et al., 2015; Shah et al., 2013; Vitalone-Raccaro et al., 2019). Providers who have knowledge of special education can work with families and support them during the referral process to access services, monitor progress during well-child visits, and collaborate with special education teams (sometimes referred to as IEP teams or PPT teams) (Hastings et al., 2014; Lipkin et al., 2015; Vitalone-Raccaro et al., 2019), as part of a comprehensive medical home (Adams et al., 2013; Nazarian et al., 2010; Shah et al., 2013) to provide coordinated care (Rose et al., 2014).

Previous studies demonstrate that although pediatricians feel responsible for identifying children to be evaluated for special education eligibility, they feel that a lack of training before and during residency about the process and eligibility criteria for special education is a barrier to providing care for children with disabilities, even if these physicians perceived their role as to assist families in accessing services (Hastings et al., 2014; Shah et al., 2013; Sheppard & Vitalone-Raccaro, 2016; Woodard et al., 2012). The need for education and training about special education and the role of the healthcare provider is well established, however little literature exists on how to incorporate this into UME. Research on UME disability training and curricula often focuses on students' attitudes and beliefs rather than on special education (Shah et al., 2013; Woodard et al., 2012). There is little curricular opportunity for medical students to develop both clinical, interpersonal, and systems-based practice skills to care for PWD and to work with families and schools (Sheppard et al., 2017; Vitalone-Raccaro et al., 2019). There are no validated instruments to measure knowledge of disability and special education in UME that include special education law, services, and source(s) of information related to disability and special (Vitalone-Raccaro et al., 2019). To address this gap, several programs have utilized required clerkships to address attitudes, knowledge, and comfort as well as include parents and

PWD as co-instructors or panelists to incorporate lived experiences (Sheppard et al., 2017; Woodard et al., 2012).

Methods

This curriculum was developed and implemented during the COVID-19 pandemic and therefore was conducted remotely via a password-protected on-line platform (Zoom) for synchronous discussion. It was designed to be given during 2-week enrichment periods built into the first two years of the curriculum at [redacted for blind review]. It was offered four times between April and July of 2020.

Pre- and post- assessments were developed to measure changes in student knowledge (See resources for pre- and post-assessments). The assessments contained seven questions that included a combination of short answer, true/false, select all, and fill in the blanks related to key concepts of the curriculum including medical home, Individuals with Disabilities Education Act (IDEA), Individualized Family Service Plan (IFSP), Individualized Education Program (IEP), and members of a medical home or coordinated care team. The assessments were scored out of 12 possible points (see resources for scoring sheet and answer key). Students completed the pre- prior to receiving preparatory materials. They completed the post- and an evaluation immediately after the final session. All three measures were completed electronically using web-based surveys that were administered through Qualtrics, a third-party online survey company. A total of 14 third and fourth year medical students participated in this curriculum across the four offerings. Data from twelve students (85%) were included in analyses as they completed both pre- and post-assessments.

Clinical and non-clinical faculty members facilitated the curriculum. Additional experts were invited including: self-advocates, parents, a clinical specialist, and other professionals that created an interprofessional learning opportunity for students. Students received the syllabus via email. The syllabus provided hyperlinks to all of the required preparatory materials. These materials included legal statutes and policies, scientific articles, videos, and pertinent websites and other resources. Students prepared for each session by completing the required readings, viewing the required materials, and completing a case study. The cases follow the life-course starting with a child from birth in a hospital setting, navigating birth-to-three services in the home, primary care in an out-patient setting and school settings for special education for a school-age child. Cases were assigned prior to each session and framed that session's discussions. Cases required students to take an interprofessional approach to address the unique needs of the child and family in the case. Students sent their answers to faculty prior to each session for faculty to prepare to review the answers and to prepare to facilitate discussions accordingly. Faculty engaged with invited experts prior to sessions to prepare them to participate in discussions related to the day's topics. Students had the opportunity to ask questions of the experts as a way to incorporate student-motivated learning principles and allow for those with lived experiences to share their expertise.

Table 1 includes information about the schedule, topics, and guests. Expert participation was subject to their availability. Per student recommendation, a developmental-behavioral pediatrician (DBP) was added as another invited expert after the first offering. This clinical specialist introduced developmental theories and developmental systems theories (Sameroff, 2010). In particular, the discussions considered multi-system and multi-factorial impacts and families within an eco-bio-developmental framework. This framework highlights the intersection of nature, nurture, and systems theories that affect child development in social and environmental contexts (Committee on Psychosocial Aspects of Child and Family Health et al., 2012). During this time, the DBP and faculty facilitated a brief conversation about root causes of health inequities and social determinants of health with consideration for how local-level factors ecosystems impact the delivery of special education services. In particular, the group discussed the importance of shifting thinking from a focus on toxic stress and risk factors that impact child development to a focus of relational health and protective factors such as the impact of family (Garner et al., 2021). Further, the inclusion of both a primary care pediatrician and a pediatric specialist provided students with an introduction to the differences in scope of care, types of appointments with children and families, and how each advocates for children in families in similar and different ways.

Table 1.

Schedule of Topics and Invited Experts

Day	Topic	Invited Expert(s)
1	Disability, medical home, & family centered care	Person with disability (self-advocate), Parent
2	Early intervention, birth-to-three, preschool special education (ages 0-5)	
3	Special education (ages 5-22)	Parent
4	Interdisciplinary interagency coordination	
5	Physicians as advocates	Educator, Other Professional, Developmental Behavioral Pediatrician

Results

After completing the curriculum, students showed marked improvement in knowledge. Notably, students showed a 25% increase in accurately describing a medical home, a 92% increase in identifying IDEA, a 75% increase in identifying IFSP, and a 42% increase in identifying IEP. Altogether, students scored on average 60% on the pre-assessment and 76% on the post-assessment. The overall mean rating for pre-test knowledge assessment was 7.17 (*SD* = 1.03). The overall mean rating for post-test knowledge assessment was 9.08 (*SD* = 0.92). The overall mean change in knowledge was statistically significant, t (11) = -7.091, $p < 0.001$, two-tailed.

To capture feedback about the curriculum, students completed a brief evaluation on the facilitators, curriculum content, and curriculum structure using a 4-point scale from strongly disagree to strongly agree. Students were also asked the following three open-ended questions:

1) What did you like most?, 2) How could this be improved?, and 3) What is the most important thing you will take away from this course? Twelve students provided evaluation feedback. All students agreed or strongly agreed that the objectives were made clear and time was well organized (M = 3.67, SD = 0.49; M = 3.73, SD = 0.47 respectively, n = 11). Participants strongly agreed that the presenters were well prepared and organized and were knowledgeable about the subject, and all agreed or strongly agreed that information was presented in a way they could easily understand (M = 3.92, SD = 0.29; M = 3.92, SD = 0.29; M = 3.71, SD = 0.49 respectively). All participants agreed or strongly agreed that they were satisfied with this curriculum and as a result of completing this curriculum their knowledge of the topic had increased (M = 3.92, SD = 0.29; M = 3.92, SD = 0.29 respectively).

Table 2.

Changes in Knowledge

Item	Overall (n = 12)		
	Pre-	**Post-**	**Diff.**
What is a medical home?	50%	75%	25%
True or False			
a. Medical homes are specific to pediatric patients	100%	100%	0%
b. Medical homes should include families	100%	100%	0%
c. A child diagnosed with a disability is eligible for special education services	0%	8%	8%
The medical home should be (select all that apply)	25%	25%	0%
Which federal law makes available free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children?	8%	100%	92%
What is the name of the document based on an in-depth assessment of the child's need and the needs and concerns of the family that contains a) information on the child's present level of development in all areas, b) outcomes for the child and family, and c) services the child and family will receive to help them achieve the outcomes?	8%	83%	75%
What is the name of the document for children ages 3-21 that is individualized, developed by a planning and placement team, reviewed annually, and focuses on special education and related services in schools?	50%	92%	42%
Name 4 people/professions that could be part of a child's care coordination with a disability and/or complex health care needs.	94%	100%	6%

Numerous students reported the organization of content, incorporation of guest speakers, the emphasis on discussion rather than lecture, and learning from family members were key aspects to this learning experience, as they were mentioned in responses to open-ended questions. This feedback was used to make adjustments and modifications to future offerings and provide materials to former students after their session was completed. One example response for each question is provided below. See Table 3 in the Appendix for all responses.

> **What did you like most about the course?:** "I liked how flexible the facilitators [names removed] were in catering the discussion to our curiosities related to the subject material. The resources were certainly comprehensive but not too overwhelming. Having the opportunity to discuss and clarify material covered in the readings was essential. My favorite part of the entire course was hearing from the families themselves, and from [name removed] regarding [pronoun removed] personal stories. These conversations will stick with me and inform my future practice even more so than the knowledge I obtained from reading IDEA parts B and C."
>
> **How could this course be improved?: "**It would be nice to hear more about the transition from childhood into adulthood and how that goes and if there is anything that can be done to improve that."
>
> **What is the most important thing you will take away from this course?: "**I guess the importance of any of these difficult discussions is the "what now" and I think we were all given the resources and the agency to be able to bring this knowledge into advocacy and action going forward, which is critical in giving any of the knowledge we have a voice and to perpetuate change."

Discussion

PWD are a medically underserved population. Findings from implementing this curriculum are similar to those of Sheppard and colleagues (Sheppard et al., 2017); who effectively incorporated special education and family systems material into UME curriculum using both didactic and interactive methods. Including learning opportunities such as this curriculum in UME will better prepare doctors to care for all their patients. This curriculum explored how physicians are advocates for patients with disabilities and their families both within and beyond the exam room. Using cases based on the real experiences of children and families provided specific examples of the complexities of the systems and services available to children with disabilities and special healthcare needs. The details of each case provided opportunities to address issues such as bias in healthcare, communication skills, family makeup, and the social determinants of health and their impacts across health, education, and related systems.

This curriculum demonstrated several benefits. First, it was able to be implemented during the pandemic due to its distanced design. It was interprofessional as it also incorporated the experiences and expertise of faculty and other invited experts. Students were able to explore the complexities of the systems that support children with disabilities and their families across ages and settings. The small group, discussion-based format allowed all students to actively participate and engage with each other, experts, and faculty. Most important, students had the time and space to ask questions to a myriad of experts.

There are several limitations to the generalizability of this curriculum and associated findings. While this curriculum was interprofessional, it was designed within a single institution specifically to fit within the structure of that institution's curriculum. However, the content and distanced aspects of the curriculum are flexible and could be provided as evening or enhancement opportunities over longer periods. Further, while federal laws such as IDEA were examined, there was also an emphasis on state statutes and state infrastructure specific to the institution. Participation was not a required; students self-selected to participate, and likely already had some level of interest in disabilities and/or pediatrics. While not measured in pre- and post- assessments, student evaluation feedback indicates advocacy was an important takeaway and should be measured moving forward. Future offerings could also incorporate a session on the transition from pediatric to adult care, as indicated in student feedback.

This curriculum was adapted from a longer curriculum that was developed for pediatric residents and focused less on providing clinical care to children with disabilities and more on systems level issues (University of Connecticut Center for Excellence in Developmental Disabilities, 2005). One student suggested that including a discussion about how to provide a well-child care visit for a child with disabilities would be helpful. Future offerings of this curriculum could include more clinical-based discussions. Aligning curriculum objectives with disability health care competencies such as the *Core Competencies on Disability for Health Care Education (2019)* would strengthen the evidence-base for including disability in UME. Future offerings could also connect with on-going projects and initiatives such as the National Curriculum Initiative in Developmental Medicine (NCIDM), a multi-year partnership between the American Academy of Developmental Medicine and Dentistry and Special Olympics International (2021), the Center for Dignity in Healthcare for People with Disabilities (2019), and Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs (Association of University Centers on Disabilities, 2021). To measure the long-term effects of increases in student knowledge and skills as applied in practice, future work should also capture how students applied the knowledge and skills gained to impact patient care, expanding from increases in knowledge to changes in practice and then changes in systems to improve care for children with disabilities and special health care needs and their families.

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Table 3.

Evaluation feedback and open-ended questions

Question	Responses
What did you like most about the course?	• Adapted to raise the bar based on the skills and knowledge students brought to the table • I liked how flexible the facilitators [names removed] were in catering the discussion to our curiosities related to the subject material. The resources were certainly comprehensive but not too overwhelming. Having the opportunity to discuss and clarify material covered in the readings was essential. My favorite part of the entire course was hearing from the families themselves, and from [name removed] regarding her personal stories. These conversations will stick with me and inform my future practice even more so than the knowledge I obtained from reading IDEA parts B and C. • -Discussion based. -Guest speakers • I really enjoyed hearing from families, educators, and [specialist], name removed]. I feel like I learned a lot from their personal stories. • The ability to have conversations with a variety of other people about these topics and explore how it has effected their lives. Also, finishing up with a developmental pediatrician was great and tied it all together. • Well organized and very discussion based. • Small numbers which made it easy to ask questions. • I think the openness and assuredness that this was a place we could have these important conversations (and feel like we were given the resources and support to do so), was super welcoming and worked really well for the group and was appreciated by all of us.

Question	**Responses**
	• I enjoyed that we were expected to read outside of class, but that class was discussion based and allowed us to take what we learned from the readings and enhance our understanding. • The passion of the instructors for the material • This course was very well structured with a natural progression of topics and themes that were integrated throughout. Every reading, discussion, and case that we had will help me in the future, both as a pediatrician and as a person. • I loved how every class (including classes with guest speakers) was a "conversation" rather than a "lecture"
How could this course be improved?	• I would suggest scheduling more time for discussion, perhaps 1.5-2 hours for each session. However, that may just be my opinion given we had a chatty group. Being able to see an IEP was helpful just to give context. I know there are a lot of complexities to the IEP that could be discussed, however, I would suggest remembering to cater the discussion to the audience. For example, it was really helpful when concrete tips were shared such as "you as the pediatrician can remind families to request more time to go through the IEP." I found that more helpful than discussing the different kinds of tests, how expensive they are, etc. That felt more related to educators. Perhaps it could be interesting to have a developmental pediatrician such as [names removed] hop on as a guest visitor to hear more about their field, their experiences and their tips regarding how to best advocate and work with their patient population. • No suggestions come to mind right now! Overall it was a great course and we tackled a lot. We could add 10000 different sections on subtopics of each discussion if we wanted and it

Question	Responses
	would still not even bridge the surface, so I think the openness of the conversations was great and will allow the course to grow and change. • Maybe some extra discussion about how to provide well-child care for children with disabilities (like our HEADS discussion). • I would just ask to have a syllabus with all of the assignments beforehand, so that we can complete the assignments earlier. & 24 hours between receiving the assignment and submitting it is a short turn-around time. • My only recommendation is to perhaps hold the course at a different time, since the 6-8pm sometimes presented scheduling conflicts, but I know that may not be feasible given the schedules of facilitators and guests that need to be accommodated. • The REALMs for advocacy day where difficult to work through because they were mostly links to sites. Perhaps having a "guide" like the IEP guide that was provided could be helpful. • Nothing. • It could be helpful to have a 1-2 page document to give to students with some of the main definitions/points of the course. This could be a useful "cheat sheet" in the future in addition to the wonderful resources that we were provided. • It would be nice to hear more about the transition from childhood into adulthood and how that goes and if there is anything that can be done to improve that. • Compiling a resource list throughout the course and sending it out at the end for students to reference later in their careers. • -Guest speaker for half of each session, really got a lot out of these components of class

Question	Responses
What is the most important thing you will take away from this course?	• Ask for help from colleagues, there is no need to re-invent the wheel when advocating for patients. • The most important thing I will take away from this course is always remembering that each person/family is unique and will face different challenges as well as have different goals. The most effective way to serve people with disabilities is to have them lead the discussion regarding their needs and expectations. This course enlightened me in terms of how much work is left to create equity in many facets of our society for people with disabilities. I hope to use the foundation of knowledge I gained from this course to be a more informed advocate for my patients in the future. • -ADVOCATE FOR PATIENTS AND FAMILIES WITH DISABILITIES • How I can help families as a pediatrician navigate through the processes of transitions and IEP meetings. • A greater understanding of the legal aspects of disability and an appreciation for the difficulties families and the whole medical home team face in caring for a child with disabilities. • The difficulties children with disabilities face in healthcare and in school, and how I can make the process easier • How to better approach conversations with parents of children with disabilities. • I guess the importance of any of these difficult discussions is the "what now" and I think we were all given the resources and the agency to be able to bring this knowledge into advocacy and action going forward, which is critical in giving any of the knowledge we have a voice and to perpetuate change.

Question	Responses
	• There are many resources available for children with disabilities and their families. As pediatricians we need to learn how to support our patients/ their families in the way that they need and how to navigate the many resources available to match their specific needs. • Where/how to guide patients with disabilities and their families to make the entire process a little less daunting. • This course has given me the knowledge and language to be able to advocate (at the patient level) and Advocate (at the legislative level) for children with disabilities in my community. I hope to be able to help families at my CLIC or outpatient pediatrics site to navigate a PPT meeting and to understand an IEP. • How interconnected all the professionals in a child with disabilities life are. And how each person plays such an important role in a child's success. This course was amazing, thank you [names removed]!