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Medical student program to learn from families experiencing developmental disabilities

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Patients and families experiencing developmental disabilities (DDs) may lack trust in physicians due to negative experiences in healthcare. DDs include conditions impairing physical, learning, language, or behavior areas, beginning during the developmental period and impacting daily functioning ('Developmental Disabilities'). Medical students generally do not receive standard training to effectively communicate with and diagnose patients with DDs. ARIE is a program for medical students to meet and learn from these patients and their families. Students learn about these families' experiences during home visits, guided by standardized interview questions and surveys about families' trust in physicians. Families did not appear to strongly trust physicians, with no significant changes after the program. Families shared they experienced physicians' lack of empathy and knowledge when caring for patients with DDs. Families wanted future physicians to be empathetic and informed when treating children with disabilities. Students reported increased comfort and confidence in interacting with patients with DDs as well as their families after completing the training program. Implementing a service-learning model focused on DDs at other medical schools, incorporating training with communication techniques and home visits, can increase students' confidence and experiences when engaging with patients with DDs and their families.

Keywords: Medical students, developmental disabilities, medical education

Introduction

Caring for vulnerable populations is a crucial component of practicing medicine. Unfortunately, a national standard for training medical students to work with patients experiencing developmental disabilities (DDs) does not exist, which may contribute to health disparities for these patients (Haverkamp *et al.* 2016) (Peacock *et al.* 2015). DDs include conditions impairing physical, learning, language, or behavior areas, beginning during the developmental period and impacting daily functioning ('Developmental Disabilities' 2022). Patients with disabilities may have different barriers to accessing and actively participating in their healthcare (Lunsky, Emery, and Benson 2002). Additionally, surveys have shown that healthcare providers report feeling overwhelmed and unprepared to address the specific needs of patients with Autism Spectrum Disorder (ASD) and DDs (Boreman *et al.* 2007). Another problem lies in negative attitudes society and even healthcare providers have towards

disabilities, (Wilson and Scior 2014) contributing to lower quality of care (Tervo *et al.* 2002). Despite this negative perception, healthcare providers have expressed the need for more training in diagnosing and treating patients with disabilities (Bruder *et al.* 2012).

More can be done to enhance medical student knowledge about disabilities in early stages of training. A study by Woodard *et al.* showed significant changes in the knowledge, attitudes, and comfortability of medical students towards disabilities following the implementation of a 6-week module with lectures, disability-related community site visits, and model patients with disabilities. At Wayne State University School of Medicine (WSUSOM), prior to 2019, medical students were not required to have disability training. Beginning in 2019, all second-year medical students gained exposure to this patient population through a half-day seminar as part of their pre-clinical curriculum focused on health disparities. It informed students about disability-related resources, equipment, and organizations in the local Detroit metropolitan area. Students also listened to first-hand accounts from community members with physical

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or developmental disabilities regarding their experiences within social and healthcare systems. Similar to the module described by Woodard *et al.*, the ARIE program was designed to offer WSUSOM students more experiences with persons who have disabilities. It inspired the creation of the mandatory half-day seminar in the pre-clinical curriculum.

ARIE, named after an anonymous donor, is a student organization at WSUSOM that partners with the Michigan Developmental Disabilities Institute (MI-DDI) to give first- and second-year medical students opportunities in their pre-clinical years to interact with families with children experiencing DDs. MI-DDI operates as one of 67 University Centers for Excellence in Developmental Disabilities in the United States and works to create a sense of community and greater quality of life for these patients. This partnership attempts to bridge the gap in medical education between future physicians and this underserved population by advocating for interdisciplinary education, disability studies research, and community support and services ('Michigan Developmental Disabilities Institute' 2020). Resources include information about disability research and policy, education, employment, family support, and financial services.

While attempting to bridge this gap in medical training, ARIE also sought to affect perceptions of trust towards physicians among families experiencing DDs in the program. Trust is a necessary part of the doctor-patient relationship. Patients need to trust doctors while sharing private information in efforts to improve their own health (Hall *et al.* 2001). Poor trust in a physician is associated with less health-seeking behavior and a poorer view of self-health status (Mohseni and Lindstrom 2007) while higher trust in physicians is associated with greater health-seeking behavior (Trachtenberg *et al.* 2005). Trust in physicians can be affected by the perceptions of their physicians' communication skills, clinical skills, and attitudes (Chandra and Mohammadnezhad 2020). It can be influenced by the doctor having personal involvement with the patient and taking opportunities to get to know the patient beyond just their medical needs (Gopichandran and Chetlapalli 2013). ARIE helps students directly engage with children with DDs and their families to build interpersonal connections which may contribute to perceptions of trust.

In fall 2018, medical students in ARIE visited families in their homes to gain insight into the day-to-day life of a child with a DD as well as their family dynamics. During the visits, students assessed families' trust in physicians and how caring for their children shapes their lives. Additionally, these visits allowed students to gain experiences interacting with this patient population. We hypothesized that at the conclusion of these visits, families would perceive increased trust in

physicians while students would feel more comfortable and confident when treating patients with disabilities.

Methods

This study fit Wayne State University's Institutional Review Board Category 1 for exemption. Interested WSUSOM students signed up to join the ARIE program during a student resources fair at the beginning of the academic year. ARIE was an option for students to fulfill their service-learning requirement as part of the medical school curriculum. First- and second-year medical students serving as program coordinators assigned forty students in pairs to families of children with DDs enrolled in MI-DDI. Students were matched to families based on access to transportation and geographic proximity to participating families in various areas of south-east Michigan.

Students attended a 1-hour training session hosted by MI-DDI, where they were taught how to adjust their communication techniques appropriately when interacting with those experiencing DDs. This included highlighting person-first language – a way of communicating with or referring to people with disabilities that focuses on the individual rather than the disability. It includes mindful language such as using “people with disabilities” instead of saying “handicapped” when referring to children in the program (Dunn and Andrews 2015). Students practiced using person-first language as well as other communication techniques they could use during home visits. The trainer also shared feedback from families regarding their experiences with medical students from previous ARIE cohorts. In general, families shared that they enjoyed interacting with medical students and hoped these encounters would have a positive impact on the students' future patients. Families suggested having access to the survey questions in advance so they could have more time to think of their responses before the visit. Additionally, students were led through a case study that illustrated a model home visit conducted through the ARIE program. The case study focused on a home visit with medical students in the ARIE program attempting to interview parents with three young children at home, one of whom has Down syndrome. The children repeatedly require their parents' attention, and the oldest child is asked to assist the parents. The parents convey difficulties in finding affordable childcare, especially when having one child with special needs. Students were challenged to think of unique difficulties and relationship dynamics such families may have when raising a child with a disability and how this may relate to their healthcare experiences. Students also discussed the importance of support groups and resources for these families and effective communication from healthcare professionals.

Following orientation, 40 first- and second-year medical students conducted two home visits and interviews with families of children with DDs over the course of three months. Medical school faculty answered students' and families' questions or concerns prior to and after visits through phone or email. Student coordinators followed up with the medical students in the program to assess their home visit experiences and fielded appropriate concerns to faculty.

At the first two-hour visit, students administered a survey ([Appendix A](#)) to their assigned family, an 11-question trust scale adapted from the Wake Forest Physician trust scale (Hall *et al.* 2002) that examined general trust families of children with DDs had towards physicians. The authors of this scale deemed it to be both valid and reliable (Hall *et al.* 2002). A 5-point Likert scale was used with 1 being strongly disagree and 5 being strongly agree. Families also completed a demographics survey in which they were asked about their child's date of birth and gender. Parents were asked about their marital status, languages spoken, race, home address, contact information, and employment status. Students additionally interviewed families about their children's specific diagnoses and their experiences caring for a child with a DD using the ARIE Family Interview Questions ([Appendix B](#)). After completing survey and interview questions, students tried to build personal relationships with the families, learning about their daily routines and challenges they may face while taking care of their child. Furthermore, students provided families with resources for health care services and support groups in the local Detroit metropolitan area.

During the second home visit, students strengthened their relationships with the families with activities such as having a movie night, playing board games, helping with homework, etc. At the conclusion of the program, all families and students were invited for an end-of-the-year celebration. Families and children connected with each other at a local facility over shared activities and food, and representatives from both WSUSOM ARIE and MI-DDI attended the celebration and provided the families with more extensive resources. At this time, the families completed the post-visit survey, which was the same 11-question trust scale they completed at the beginning of the first home visit with medical students. As an incentive to participate in the program, families were provided with a \$25 VISA gift card at each family visit. Families were also given either a \$10 Google Play gift card or a toy depending on their child's age at both visits. Families were given another \$25 gift card at the conclusion of the program regardless of their attendance at the end-of-the-year party.

Of the 20 families participating in our program, 16 completed the first-visit survey and interview questions, and 11 completed the post-visit survey with medical

students. Eight families completed the program and both the first- and post-visit surveys. Due to scheduling conflicts, some families were not able to complete the program, which allowed for new families to join after the program had already started. Other families did not finish the surveys. When analyzing data, families were assigned de-identifying codes to avoid using their names. The means and standard deviations for first- and post-visit survey responses from families were calculated.

Qualitative data analysis was additionally performed for responses students collected from two of the Family Interview Questions ([Appendix B](#)), namely #19 addressing families' difficulties working with the medical field, and #29 addressing what families would like future medical practitioners to know about parenting a child with special needs. The Framework Method (Gale *et al.* 2013) was the base used for thematic analysis of the responses with an inductive approach. Themes were generated from the responses rather than selected prior to the study. Two researchers independently identified and then discussed recurrent overarching themes within the responses. Each response was assigned to only one appropriate theme after agreement from both researchers. The responses were organized in a table in one column with the theme assigned to each response in another column. Frequencies of themes among responses were calculated as percentages. Links between themes were discussed. Additionally, racial/ethnic profiles and diagnoses in our study population were found based on data families provided in the demographics survey.

In addition to the family surveys, medical students were surveyed before and after the program with the Medical Students Perceptions of Disability and Definitions and Criteria Associated with Disabilities Assessments (MSPDA) ([Appendix C](#)). A 5-point Likert scale was used with 1 being strongly disagree and 5 being strongly agree. This survey was based off questions numbered 3, 4, 6, 8, and 12 from the survey instrument: Medical Student Attitudes Toward Persons with Disabilities (Symons *et al.* 2012) that used a 4-point Likert scale. These survey items were chosen as they were believed to capture the main themes assessed in the original survey. This survey gauged students' perceptions of their comfort and confidence when interacting with people with disabilities and perceptions of attitudes of people with disabilities. A 5-point Likert scale was adapted instead of using a 4-point scale so medical students had more options to choose from in terms of their attitudes and perceptions. Of the 40 medical students in the program, 31 completed the pre-program survey while 28 completed the post-program survey. Twenty-three students completed both the pre- and post-program surveys. The means and standard deviations for pre- and post-program survey responses from students were calculated. Paired t-tests were used for statistical analysis of the students' survey responses.

Table 1. Questions and average values of responses for the first and post-visit 11-question trust scale for general physician trust.

11-question Trust Scale for General Physician Trust				
Survey Questions:	First Visit Means (and standard deviations) for all families	First Visit Means (and standard deviations) only for the 8 families that completed first and post-visit surveys	Post-Visit Means (and standard deviations) for all families	Post-Visit Means (and standard deviations) only for the 8 families that completed first and post-visit surveys
1. Doctors in general care about their patients' health just as much or more as their patients do.	3.88 (0.62)	3.88 (0.35)	3.45 (0.82)	3.75 (0.71)
2. Sometimes doctors care more about what is convenient for them than about their patients' medical needs.	3.44 (1.09)	3.50 (0.93)	3.82 (0.75)	3.63 (0.74)
3. Doctors are extremely thorough and careful.	3.50 (0.89)	3.63 (0.92)	3.18 (0.87)	3.25 (1.04)
4. You completely trust doctors' decisions about which medical treatments are best.	3.19 (1.05)	3.25 (1.16)	3.09 (1.04)	3.25 (1.16)
5. Doctors are totally honest in telling their patients about all of the different treatment options available for their condition.	3.25 (0.93)	3.25 (0.21)	3.27 (1.01)	3.50 (1.07)
6. Doctors think only about what is best for their patients.	3.44 (1.09)	3.38 (1.06)	3.45 (0.82)	3.63 (0.92)
7. Sometimes doctors do not pay full attention to what patients are trying to tell them.	3.56 (1.26)	3.75 (0.89)	3.55 (1.04)	3.25 (1.04)
8. Doctors always use their very best skill and effort on behalf of their patients.	3.75 (0.86)	3.75 (0.89)	3.45 (0.82)	3.75 (0.71)
9. You have no worries about putting your life in the hands of doctors.	3.13 (1.20)	3.00 (1.20)	3.09 (1.22)	3.50 (1.07)
10. A doctor would never mislead you about anything.	3.13 (1.02)	3.00 (1.07)	2.91 (0.83)	3.13 (0.83)
11. All in all, you trust doctors completely.	3.13 (1.09)	3.00 (1.07)	2.82 (1.33)	3.25 (1.28)
Averages of all responses:	3.40 (0.25)	3.40 (0.93)	3.28 (0.28)	3.44 (0.96)

Results

The results from the 11-question trust scale for general physician trust showed that families of children with DDs did not strongly trust physicians in general (Table 1) with no significant changes in scores when comparing responses given during the first home visit and upon completion of the program. The results of the medical students' surveys- Medical Students Perceptions of Disability and Definitions and Criteria Associated with Disabilities Assessments (MSPDA)- are included in Table 2. A statistically significant difference was found between some pre- and post-program responses, included in 95% confidence intervals (CI) with $p < 0.05$. After visiting the families, medical students reported feeling significantly more confident when working with patients who have a disability (95% CI: 0.26, 0.83), more comfort being around a person who has an intellectual disability (95% CI: 0.33, 0.84), more confidence communicating with a patient's family member(s) (95% CI: 0.25, 0.75), and more comfort interacting with a person with an intellectual disability in the community on his or her own (95% CI: 0.34, 1.0). There was not a significant difference in students' perceptions about people with disabilities potentially feeling sorry for themselves and resenting those without disabilities.

The racial and ethnic profiles for participating families were as follows: 59% White- Non-Hispanic, 18% Hispanic, 17% Black- Non-Hispanic, and 6% American Indian/Alaskan Native. Of the 16 families who completed the Family Interview Questions, diagnoses were as follows: 6 identified their child as having autism, 4 having Down syndrome, 3 having multiple diagnoses, 1 having cognitive impairment, 1 having fetal alcohol syndrome, 1 having attention deficit hyperactivity disorder, 1 having a speech issue, and 1 having epileptic encephalopathy.

Qualitative data analysis for selected Family Interview Questions is presented here. Responses to Family Interview Question #19, "Have you encountered any difficulties working with the medical field? Please share some of your experiences." are shared in Table 3 along with the theme assigned to each response. Of the 14 responses received, the following themes were present: 21.4% lack of empathy, 21.4% physicians' lack of knowledge caring for patients with disabilities, 14.3% difficulty obtaining care with Medicaid, 14.3% communication barriers, 14.3% no difficulties encountered, 7.1% resources and funding, and 7.1% medication side effects. Responses to Family Interview Question #29,

Table 2. Questions and average values of responses for the pre- and post-program surveys given to medical students participating in the ARIE program.

Medical Students Perceptions of Disability and Definitions and Criteria Associated with Disabilities Assessments (MSPDA)					
Survey Questions:	Pre-Program Means (and standard deviations) for all students	Pre-Program Means (and standard deviations) only for the 23 students that completed pre- and post-program surveys	Post-Program Means (and standard deviations) for all students	Post-Program Means (and standard deviations) only for the 23 students that completed pre- and post-program surveys	95% Confidence Intervals
1. I feel confident working with patients who have a disability.	3.88 (0.55)	3.88 (0.61)	4.41 (0.50)	4.42 (0.50)	(0.26, 0.83)
2. I feel confident communicating with a patient's family member(s).	4.21 (0.49)	4.17 (0.48)	4.66 (0.48)	4.67 (0.48)	(0.25, 0.75)
3. I would be comfortable interacting with a person with an intellectual disability who was in the community on his or her own (i.e., without staff members or caretakers).	3.78 (0.21)	3.75 (0.68)	4.38 (0.56)	4.42 (0.58)	(0.34, 1.00)
4. I am comfortable being around a person who has an intellectual disability.	4.22 (0.66)	4.21 (0.66)	4.76 (0.44)	4.79 (0.41)	(0.33, 0.84)
5. Most people with disabilities feel sorry for themselves.	1.59 (0.80)	1.50 (0.66)	1.59 (0.68)	1.58 (0.72)	Not significant
6. Most people with disabilities resent people without disabilities.	1.66 (0.79)	1.54 (0.66)	1.41 (0.50)	1.42 (0.50)	Not significant

“As future medical practitioners, what would you like us to know about parenting a child with special needs?” are shared in Table 4 along with the theme assigned to each response. Of 15 respondents, the following themes were present: 33.3% be empathetic, 13.3% be informed about treating children with disabilities, 13.3% ask questions, 13.3% treat all children with equal value, 6.7% for families with children that have disabilities experience stress, 6.7% parent is child's advocate, 6.7% be aware of challenges in medical care for child, and 6.7% listen.

Discussion

We concluded that families of children with DDs did not strongly feel trust towards physicians when considered as a collective group. These perceptions did not change significantly during the program. Several families cited multiple experiences contributing to this, including difficulty finding a physician who was mindful of their child's disability and the social and economic challenges this created for them. One family shared that their child “had 5 physicians in the past 10 years because some doctors didn't accept her Medicaid, one doctor would not even examine her, and another doctor had moved away” (Table 3).

Comments students gathered from surveying the families also highlighted the importance of effective communication between physicians and others in the healthcare system. In one firsthand account, an ARIE family discussed difficulties in communication between medical office staff and insurance companies. The family said this miscommunication extended to “doctors

[who] also may not respond to verify medications for insurance” (Table 3). Poor communication can affect the relationships between families and physicians caring for their children with disabilities (Sharkey *et al.* 2016). The study led by Sharkey, *et al.*, explored experiences of inpatient hospital staff and families to evaluate communication between healthcare providers and families that had children with disabilities while hospitalized. Authors share parents' experiences, stating that good communication with providers can create good rapport. This was suggested to help with trust in the healthcare team.

When considering other reasons for patient distrust in physicians, one may stem from suffering a poor health outcome under a physician's supervision. In a recent study, patients with intellectual disabilities were found to have a significantly greater risk of developing mental and/or physical health problems compared to those without intellectual disabilities (Young-Southward *et al.* 2017). One mother in the program cited an experience where, “Misdiagnosis, overmedication, and non-responsiveness led to terrible medication side effects because providers did not bother to check all medications [her] child was on” (Table 3). Lack of DD training in medical school may lead to such negative outcomes. The authors of a 2012 study found that this lack of training can lead to decreased availability of physicians for adults with an intellectual disability (Wilkinson *et al.* 2012) which can impede quality of and access to care (Abrams *et al.* 2011). Not only did patients feel like their physicians could not assist them with their needs, but all participating physicians

Table 3. Responses to family interview question #19.

All responses as recorded by participating medical students to the survey question in the family interview: Have you encountered any difficulties working with the medical field? Please share some of your experiences.	Themes found in each response:
1. Not really.	No difficulties encountered
2. Having primary insurance helps with avoiding issues with Medicaid coverage.	Difficulty obtaining care with Medicaid
3. Not particularly. [Mom] has experienced that not getting certain diagnoses for [her son] has made it difficult to access certain resources and funding.	Resources and funding
4. Yes, [mom] said that when she was pregnant and the test came back that [her son] had Down syndrome, almost every doctor assumed she would be terminating the pregnancy. She said there was only one physician that gave her hope that a child with Down syndrome can live a healthy life. As time has gone on, acceptance by healthcare professionals has gotten better, but she feels there is still room for improvement.	Lack of empathy
5. The Orthopedic Surgery department at the Children's hospital claimed she was "wasting her time" trying to accommodate for her child when trying to get ankle braces for her child.	Lack of empathy
6. Misdiagnosis, overmedication, and non-responsiveness led to terrible medication side effects because providers did not bother to check all the medications the child was on. For example, the provider did not regularly check [the son's] prolactin levels when he was on a medication known to increase them. This led to gynecomastia.	Medication side effects
7. Their pediatric physician works better. Sometimes well-liked physicians move or retire and the family must find new ones. There was also an instance of a person in the emergency room being uninformed about [her son's] needs.	Physicians' lack of knowledge caring for patients with disabilities
8. Yes. The mother of this child has a medical background, so she felt she has a better knowledge of certain procedures compared to parents who do not have a medical background. She has also noticed how many physicians lack empathy. In particular, she had a very bad experience with an ENT Specialist who treated [her daughter].	Lack of empathy
9. Office staff and communication between offices and the insurance company has been very difficult. It is hard to get different things signed off on and sent to the offices. It has created problems with insurance when they needed a lot of things re-approved. Doctors also may not respond to verify medications for insurance. During inpatient stays, there are issues with plans changing while physicians are rotating.	Communication barriers
10. Some physicians are not aware of the things that need to be screened for in children with Down syndrome. This can make visits difficult because the mother feels that she sometimes has to be the one keeping track of things. Additionally, people need to remember that [her son] can answer many questions in the interview himself.	Physicians' lack of knowledge caring for patients with disabilities
11. [Her daughter's] "physical health is pretty good," but it has been hard finding a doctor that accepts their Medicaid insurance and finding a counselor that can suit her needs. [Her daughter] had 5 physicians in the past 10 years because some doctors didn't accept her Medicaid, one doctor would not even examine her, and another doctor moved away.	Difficulty obtaining care with Medicaid
12. [The mother] experienced difficulties with the healthcare system when [her son] was very young. She noticed that there was an issue with his speech but when she told his doctor, he dismissed it. It was only after [her son] started kindergarten that teachers notified [the mother] about [the son's] speech problem. Although she attributes the mistake to the doctor's old age, [the mother] feels like [her son] could have started speech therapy sooner if the physician had taken her concerns seriously.	Physicians' lack of knowledge caring for patients with disabilities
13. There is some difficulty in communicating within the field. EMRs are a huge benefit, however, [the mother] would appreciate more open communication and clear explanation by providers. She seemed particularly frustrated with how long it took to get a diagnosis when [her son] first developed symptoms.	Communication barriers
14. [The mom] says she has had great doctors and staff helping her with [her son]. If she believes the care her son was getting wasn't the best, she would never go back to the same place.	No difficulties encountered

claimed they did not feel adequately prepared to care for adult patients with intellectual disabilities (Wilkinson *et al.* 2012). Another mother in our program described how a physician she interacted with was unaware of conditions that needed to be screened for in her child with Down syndrome. This lack of knowledge added extra burden to her because she felt she needed to be diligent about advocating for her child's care when ideally, she should have been able to be confident in the physician's competency. Families in our study often cited lack of physicians' knowledge caring for patients with disabilities related to issues they encountered in healthcare. It was also a perspective they wanted medical students to be made aware of (Tables 3 and 4).

How can we better prepare physicians to competently treat patients with disabilities? The answer lies in medical education. Medical students are not regularly exposed to this vulnerable population in their training, limiting their interpersonal skills as physicians when treating such patients (Ioerger *et al.* 2019). A recent study shows that due to lack of knowledge or comfort in treating patients experiencing ASD, primary care physicians tend to refer these patients to other healthcare professionals like psychologists with more training in the area (Golnaz and Watson 2019). Additionally, the study shows that physicians may feel uncertain when attempting to diagnose patients experiencing ASD due to inadequate training during their time as medical

Table 4. Responses to family interview question #29.

All responses as recorded by participating medical students to the survey question in the family interview: As future medical practitioners what would you like us to know about parenting a child with special needs?	Themes found in each response
1. Don't say, "I'm sorry". Say, "I'm here and I will support you", connecting people to support [as soon as possible] and with moms with similar situations.	Be empathetic
2. Be empathetic, understanding, calm, allow/expect more time for talking to families; be sure to take the time to speak to caregivers separately because there are sometimes matters that have to be talked about separately.	Be empathetic
3. "I would like you to know that we as parents and caregivers have a lot of stress to deal with. Anything you can do to help is appreciated, a referral, a pat on the back. We have to constantly be patient and understanding. Know that every child is different and that there are unique challenges to living with somebody with a disability, it is not the same as seeing the child for a limited chunk of time in your office."	Be empathetic
4. "Having a child with special needs is challenging, but it is certainly not terrible." Parents and practitioners need to be extremely in tune with the child's health and be able to notice little changes in their behaviors in order to identify vulnerabilities or things that are not normal. There should be a list of things to keep an eye out for in their development, and when to be paying attention to these things.	Be informed about treating children with disabilities
5. Listen to what patients say and when patients say they need help, listen.	Listen
6. They are just like any other child, don't make them feel like they are different and cannot live a good life.	Treat all children with equal value
7. No experience is the same for all parents. Do not make assumptions. Do not be dismissive. Be compassionate.	Be empathetic
8. Don't be afraid to ask questions. Don't be offended if parents don't go to support group (not helpful for [her daughter]). Ask "What do I need to do to help you?" Be willing to do things like write letters to schools for example.	Ask questions
9. There will always be challenges, but in different forms. Give all the children the same opportunities and avoid labeling. There should be more emphasis that people with disabilities are worthy of medical attention.	Treat all children with equal value
10. It's exhausting, you have to be with your children at all times. There is a lot of stress, no breaks, and it affects everyone.	Families with children that have disabilities experience stress
11. [Her son] is the happiest part of her life, and she wants people to know that about him. However, there is often difficulty in balancing scheduling, and it requires a lot of flexibility. You also have to be the advocate for your own child.	Parent is child's advocate
12. "The disability does not go away." They live with them their entire life. Also, obtaining services changes constantly, so physicians need to be aware of the challenges that come with that.	Be aware of challenges in medical care for child
13. Ask questions and be thorough in examinations in case something is missed.	Ask questions
14. Physicians should be aware of what every single test, procedure and order they make really means in a patient's life. How intrusive or inconvenient a test is can really affect a parent's ability to have the test performed. A particular test [the mom] mentioned was the EEGs that [her son] was sent to have performed when he was initially being diagnosed; did her physician understand that this test had to be performed miles away from home which required an enormous amount of effort just to get [her son] to the clinic? Did they understand that [her son] would be unwilling to leave the electrodes on his head during the exam so he needed to be restrained? Did they appreciate how hard it must be to see your child restrained and uncomfortable from the examination?	Be informed about treating children with disabilities
15. Parents need doctors that are sincere, polite, and considerate towards patients and their families.	Be empathetic

students. This gap in training (Coret *et al.* 2018) is one possible explanation as to why many families of patients with DDs find themselves switching between doctors to find someone with at least basic disability training. More interactions with such patients during medical school may translate into increased perceived comfort, confidence, and competence among healthcare providers regarding this underserved population (Boyd *et al.* 2019). However, more studies are necessary to assess whether interactions with these patients during medical school may translate into skills necessary to gain the trust of this underserved population and provide them with high quality healthcare.

To facilitate the development of these skills, a service-learning model like ARIE can be incorporated in other medical schools. When examining the survey conducted among students in the ARIE program, students reported more comfort and confidence in

working with patients with DDs and their families after completing the program, as seen in Table 2. However, the rest of the student survey responses were not statistically significant when comparing pre- and post- program data. These remaining questions focus more on student perceptions of those with disabilities.

A survey of United Kingdom medical school curriculums found that most intellectual disability content was taught during the first half of medical school in didactics, but personal experience working with patients experiencing intellectual disability was lacking (Lennox and Diggens 1999). Creating opportunities for medical students to interact with this population can bolster their training as medical professionals and maximize the efficiency of their encounters with these patients. For example, a 2016 study showed that when third-year medical students at The Ohio State University

participated in a training for ASD, they reported positive changes in their confidence and understanding of difficulties that people experiencing ASD encounter. The training included an online lecture alongside a panel discussion with health care professionals, people with ASD, and family members of those with ASD (Havercamp *et al.* 2016). Furthermore, students felt they were better prepared to treat these patients in future practices. However, it is important to note that self-reported changes in confidence are subjective and do not necessarily translate to greater improvements in care for patients with DDs. A systematic review conducted in 2019 identified articles discussing interventions that sought to teach medical students about patients with disabilities. The authors found that not much is known regarding the impact of disability interventions on knowledge and skills of medical students. Further investigations using longitudinal evaluations are necessary to assess if interventions in medical education on disability affect patient care (Ioerger *et al.* 2019).

Another study found that medical students' disability knowledge, attitudes, and comfort level increased over a 6-week training period focused on exposure to patients with DDs. This program at the University of South Florida Health, Morsani College of Medicine (USF) occurred during the primary care clerkship. It included lecture, community site-visits, panel discussions with advocates experiencing different disabilities representing various community agencies, service learning projects in which students learn how to engage their target population by presenting a health topic to a group with intellectual disabilities, and home visits with persons with disabilities (Woodard *et al.* 2012). Similarly, the immersive experiences ARIE offers students can increase confidence by actively encouraging and facilitating conversation between students and patients to better understand the latter's needs as well as skills needed for treating patients with DDs such as empathy, understanding, and intellectual curiosity when navigating DDs that are often not taught otherwise in medical education. The Family Interview Questions (Appendix B) include an item explicitly asking the families what they would like future medical practitioners to know about parenting a child with special needs. Parents' responses commonly centered around valuing empathy, open communication, and willingness of physicians to offer appropriate support to these families (Table 4). ARIE gives students opportunities to foster these skills.

We hope to include more students in this program each year to help more future physicians improve their interactions with and treatment of patients experiencing DDs. Additional plans in expanding this program include releasing an annual newsletter to families in the program to update them on the status of the program and the progress of medical students involved in it. We also hope to include insight from current physician

residents that were previously part of the program, allowing families to see their longitudinal impact in medical education. The current program is only open to first- and second- year medical students, but we are aiming to have the third- and fourth-year students visit families that they met as first- and second- year students. Perhaps a continuation of contact with these families will further encourage an increase in comfort and confidence among future physicians caring for this patient population. Furthermore, to allow the whole student body to have exposure to families experiencing DDs, we continue to look for opportunities to incorporate the program into the preclinical curriculum. Through direct communication with these families and clinical experiences with people with disabilities as standardized patients, students can become more accustomed to interacting with and treating a broad range of patients with disabilities.

Limitations to expanding the program include finding additional financial support, creating larger student and family cohorts, and solving logistical challenges in scheduling between students and families in the program (Woodard *et al.* 2012). By offering opportunities for medical students to build relationships with this patient population, we expect progress in their confidence and abilities to care for these patients as well as improved attitudes of families towards healthcare professionals.

Limitations

First, when assessing demographic data, it is important to note that since the information was collected through a *family* survey, some respondents shared this data in reference to the parents while others shared data in reference to their child. This was not consistent across participants leading to incomplete demographic data (date of birth, gender, marital status, languages spoken, race, and employment status). In subsequent home visits, this survey should be clear to ensure that responses are measuring the same variables for children and parents across all families.

Loss of responses in the post-visit surveys or completion of the post-visit surveys at the end of the year celebration contributed to our small sample size of participating families. Only 8 families completed the program and both the pre- and post-visit surveys. Since our current study is limited by our sample size, we aim to include more families in future cohorts to gain a greater sample size for our continued analysis of families' attitudes towards their physicians. Another consideration is the program was conducted over three months with three occasions of in-person contact between families and medical students. This could play a part in families' attitudes in this study. All these factors may contribute to the lack of significant change in pre- and post-visit surveys for families. Another limitation is the Likert

scale used for the student surveys. While our studies used a 5-point Likert scale in the students' surveys, the original survey questions used a 4-point Likert scale (Symons *et al.* 2012). Furthermore, our survey instruments rely on self-reported attitudes. Respondents may not necessarily record their beliefs about people with disabilities accurately (Robey, Beckley, and Kirschner 2006). Also, as students self-selected to be part of this program, their attitudes or perceived level of comfort and confidence working with this patient population may have already been high before beginning the program. With respect to the student surveys, we also encountered loss of responses for the post-program surveys; additionally, some students only filled out the post-program survey and not the pre-program survey. We did see that individual students felt the program had a positive impact on their perceptions about caring for people experiencing disabilities with a small sample size and no power.

Future directions

We will adjust our follow-up methods with families in future cohorts to ensure more responses are considered in our studies. We may consider conducting post-visit surveys over the phone before the end of the program. It is interesting to note that families' perceptions of trust in physicians did not differ significantly between home visits with medical students. We must consider that positive experiences with medical students during these home visits may not change past negative experiences with practicing healthcare professionals, nor do they necessarily change perceptions towards those currently practicing medicine. Perhaps a program with increased number of home visits spanning over a longer period could affect families' perceptions more than the current program design. Obtaining more demographic data in future studies from families and obtaining such data from medical students will enhance our understanding of our study population.

To increase our student survey responses, we need better follow-up to ensure completion of both pre- and post-program surveys. That, combined with more qualitative or mixed methods approaches, may help us to better assess the program's impact on students. Since students could use this experience to fulfill their service-learning requirement for the medical school curriculum, a future consideration could require that all participating students must complete all surveys to obtain full credit for the program. This could increase survey response rates. Future studies will compare the attitudes of students participating in the ARIE program to students who do not participate. It may be more prudent to focus on medical students' attitudes towards caring for this patient population rather than families' perceptions of physicians, similar to studies mentioned previously.

We can also collect feedback from program participants, both families and students, regarding their satisfaction with specific parts of the program to assess what changes should be made for future cohorts. This can also provide suggestions for other institutions to implement a similar program if they wish. More studies should also be conducted in the future to see if such training programs in medical schools can lead to improvements in healthcare for patients with DDs.

Conclusion

This study illustrates that families of children with DDs do not strongly trust physicians. Families have experienced lack of physician empathy and knowledge when caring for their children with DDs. Implementing a service-learning model like ARIE with training on communication techniques and home visits in medical schools can equip future physicians with comfort and confidence when interacting with this patient population. Learning healthcare experiences from families during home visits and communication techniques from experts can impact students' attitudes towards treating patients with DDs. These aspects may help foster the empathy and knowledge concerning patients with DDs that families desire in future physicians.

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Appendix A. Pre-visit family satisfaction 2018

Please select whether you agree or disagree with the statements:

	Strongly disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)
Doctors in general care about their patients' health just as much or more as their patients do. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sometimes doctors care more about what is convenient for them than about their patients' medical needs. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors are extremely thorough and careful. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You completely trust doctors' decisions about which medical treatments are best. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors are totally honest in telling their patients about all of the different treatment options available for their condition. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors think only about what is best for their patients. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sometimes doctors do not pay full attention to what patients are trying to tell them. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors always use their very best skill and effort on behalf of their patients. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You have no worries about putting your life in the hands of doctors. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A doctor would never mislead you about anything. (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All in all, you trust doctors completely. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix B. ARIE family interview questions 2018

1. Group Assignment (letter) and Family Number
2. Please tell us a little bit about (child's name).
3. Has (child's name) been diagnosed by a physician?
4. If yes, please tell us a little bit about the diagnosis.
5. How long has he/she been diagnosed?
6. Has the condition evolved or changed in any way? How so?
7. Is there a second, or additional diagnoses?
8. If (child's name) has not been diagnosed by a physician, has the doctor told you of any suspected conditions (child's name) may have, even if unconfirmed?
9. What are some challenges that come with caring for (child's name)? Ex. Communication, feeding, monitoring
10. Does (child's name) have siblings?
11. Does his/her condition influence how you care for the other children? How so?
12. Has your child's disability changed family relations/dynamics in any way? How so?
13. Does the cost of care influence financial decisions? How so?
14. Does your family receive financial support?
15. Has (child name)'s disability affected work lives? In what way?
16. Is transportation ever an issue?
17. Do you, as a caregiver, have a support system? If yes, what type of support?
18. Are there other family members or close friends that provide support for (child's name)?
19. Have you encountered any difficulties working with the medical field? Please share some of your experiences.
20. Do you feel like you are able to effectively communicate with your physician?
21. Does your physician spend enough time with you during appointments? What would be an optimum amount of time?
22. How can physicians make office visits with your child an easier or more family friendly experience?
23. Do you feel like you have proper access to information/resources for your child's condition? What type of information have you received, and from where?
24. Is (child's name) receiving treatment? Does he/she have all of his/her health services met?
25. Does your physician consider your opinions in the treatment process? Please explain.
26. What are some things you would like to see changed?
27. What are some things that you have been satisfied with?
28. What other things can health professionals do to help you child and provide support for your family?
29. As future medical practitioners what would you like us to know about parenting a child with special needs?

- 30. Are you part of any support groups?
- 31. Are you in contact with other families that have similar experiences? Would you like to be?
- 32. Do you use any resources specific to your child's condition?

- 33. Are there any topics that you would like more resources or information about?

Appendix C. Student survey 2018

Please select whether you agree or disagree with the statements:

	Strongly disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)
I feel confident working with patients who have a disability. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident communicating with a patient's family member(s). (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would be comfortable interacting with a person with an intellectual disability who was in the community on his or her own (i.e. without staff members or caretakers). (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am comfortable being around a person who has an intellectual disability. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most people with disabilities feel sorry for themselves. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most people with disabilities resent people without disabilities. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>