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Disability

Developed by Emily Kacer and Dr. Mohammad Zubairi for PedsCases.com.
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Introduction:

Hi everyone! My name is Emily Kacer and I am a second year medical student studying at McMaster University. In this social pediatrics episode of PedsCases, we will explore the topic of disability. I am incredibly grateful for the support of Dr. Mohammad Zubairi in creating this episode. As a developmental pediatrician and Associate Professor at McMaster University who serves as the Medical Director for McMaster Children's Hospital Autism Program, Dr. Zubairi's extensive work and expertise in the field of childhood disability was instrumental in developing this podcast.

Learning Objectives

The learning objectives of this podcast are as follows:

1. Define disability and provide an overview of common conditions associated with childhood disability.
2. Develop a clinical approach for history taking and the physical exam for a child living with a disability.
3. Introduce the F-words framework and how this conceptual lens can be applied in practice to benefit patients and their families.
4. Introduce and discuss some of the challenges faced by children with a disability and their family during transitions to adult care.

As the topic of disability is incredibly complex and multifaceted, we hope that today's episode will provide you with a broad overview of this concept and inspire further reading around disability. We've included some excellent resources within the references for this episode. We also recognize that you may have your own lived experience with disability or know someone living with a disability which will bring your own reflections to this podcast.

Today's Case

Let's start this podcast off with our clinical case. You are a third-year clerk doing a community placement in a general pediatrician's office. Your next patient on the schedule is a follow-up health surveillance visit with Rosie, a 13-year-old girl that lives with cerebral palsy. Rosie was born via C-section at 32 weeks gestational age with a birthweight of 1600 grams. After her stay in the NICU, the neonatal follow-up team observed that some of Rosie's developmental reflexes were absent and that she had difficulty with head control. During Rosie's well-baby visits, your supervisor noted increased muscular tone and marked spasticity in Rosie's extremities ¹. Her parents had also expressed concerns about possible seizures that they witnessed at home.

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Upon further workup and referral to a pediatric neurologist, Rosie was diagnosed with cerebral palsy ².

When reviewing her chart, you learn that Rosie also lives with an intellectual disability and has dysarthria which makes it challenging for others to understand her speech. Rosie uses a wheelchair for mobility and requires assistance from her parents for activities of daily living, such as feeding and dressing herself. Rosie is also followed longitudinally by her pediatric neurologist and receives regular therapy from a speech language pathologist and an occupational therapist ^{1,2}.

Rosie's usual medications include Levetiracetam as prescribed by her neurologist for seizure control and a multi-vitamin. Her scheduled immunizations are up to date and she does not have any known allergies.

Before entering the room, you begin to formulate your agenda for the visit. What questions should you include in your history for a follow-up health assessment? How can you ensure that both Rosie and her caregivers are involved within the conversation? What are your implicit assumptions and biases about providing care for Rosie with her disability?

Defining disability and associated conditions

Disability is an overarching categorical term that encompasses a diverse array of health conditions. In North America, 1 in 10 children live with a disability ³. As defined by the United Nations Convention on the Rights of Persons with Disabilities, a disability can be understood as any chronic "physical, mental, intellectual, or sensory impairment" which can impact someone's ability to participate in society due to environmental barriers ⁴. Looking at the first part of this definition, functional impairment has multiple causes and children may be either born with their disability or acquire it throughout their lifetime. For instance, a traumatic brain injury due to a motor vehicle accident may lead to both physical and mental impairments for a child who did not have any previous experience of disability.

Disabilities can also be either visible or invisible. Visible disabilities can be identified by observers who do not have a relationship with the child, whereas invisible disabilities are not readily apparent to external observers but still impact a child's functioning. For example, a visible disability may include the usage of medical assistive devices such as a tracheostomy tube, whereas an invisible disability may be a learning disability like dyslexia.

Children living with a disability face many barriers that can limit their participation within the world around them including physical, social, and communication barriers. For instance, physical barriers may be present by a lack of accessible equipment at the playground which can exclude children from playing with their peers. Social barriers, such as stigma and discrimination, can be evident through a lack of acceptance in both interpersonal and institutional interactions. Finally, communication barriers may include a lack of skill in sign language or routine use of communication devices for interactions with someone that has a hearing impairment ⁵. It is necessary to identify and address these barriers to facilitate children's independence, involvement in daily activities, and achievement of their maximal potential.

While we will now discuss some common conditions associated with childhood disability, it is important to recognize that this list is not comprehensive. Pediatric presentations of primarily physical disabilities can include speech language disorders, such as apraxia or dysarthria, and gross motor disorders such as cerebral palsy or spinal muscular atrophy. Childhood

developmental delays can also significantly impact a child's participation in their world. For instance, children with a global developmental delay, defined as a significant delay in two or more domains of development, may require support from their family and intervention from healthcare providers for their activities of daily living ⁶.

Cognitive disabilities include both intellectual and learning disorders. Intellectual disability can be characterized by deficits in both intellectual and adaptive functioning that occur during childhood ⁶. Intellectual functioning includes both reasoning and problem-solving abilities and can be assessed using standardized testing such as the Weschler Intelligence Scale. Adaptive functioning encompasses social, practical, and conceptual domains and can be evaluated using the Vineland Adaptive Behavior Scales ^{6,7}. Since children with intellectual disabilities are unique in their challenges with learning, each child can benefit from personalized interventions. While more severe intellectual impairments may present early in childhood, a mild intellectual disability may not be identified until a child begins school ⁶. Specific learning disabilities represent a difference between one's intellectual functioning and their academic achievement. Learning disabilities can occur in the domains of math, written expression, and reading with dyslexia as a common example ⁸. Often, these differences in learning become evident as educational expectations increase with progression through school years.

Finally, there are common neurodevelopmental disorders which include autism spectrum disorder or ASD and attention deficit / hyperactivity disorder or ADHD. ASD and ADHD are also increasingly recognized as examples of neurodiversity, which is grounded on the concept that there is no one right way to engage with the world. Through a neurodiversity lens, neurological and developmental differences are not seen as disorders or deficits ⁹. Children with autism spectrum disorder have alterations in their social functioning whereas children with ADHD have challenges with inattention or struggle with impulsivity/hyperactivity or a combination of both. To ensure that these neurodiverse children can fully participate and flourish in their environment, additional programs and services may be beneficial.

Importantly, a child's experience with disability is shaped by social factors including their family, culture, and societal attitudes ¹⁰. A specific diagnosis of disability is non-deterministic as it cannot predict a child's abilities and potential achievement within their environment. Every child is unique in their development and clinicians must take an individualized approach when assessing the level of support that may benefit a child ¹¹.

Clinical approach to a child living with disability

In the journal *Pediatrics*, a 2023 publication by Ames and colleagues from the University of Utah Pediatrics department revealed that children living with a disability continue to experience discrimination in their interactions with healthcare providers ¹². When interviewing caregivers of children with a medical complexity, they identified key areas for physicians to take action when caring for these children and their families. Common themes included barriers to care access, suboptimal care delivery, and experiences of dehumanization that were associated with insufficient provider knowledge, disinterest in care provision, and inaccurate assumptions about the child. The authors also outlined the disability paradox whereby physicians often predict that a child's quality of life is much worse than is reported by the parents ¹². As evidenced by these findings, it is important to lead with curiosity and compassion when providing care for a child with a disability. Clinicians must address their own implicit biases about disability and recognize that these children lead full and meaningful lives outside of the clinic. Each appointment is truly

just a snapshot in time and thus cannot possibly provide us with a complete understanding of the child.

Starting with our history, it is crucial to explore a child's strengths in addition to their challenges. Every child has unique qualities and interests regardless of their disability. Ask caregivers to brag about their child and share with you what makes them special. If the child is older, you can ask them what they enjoy and what makes them feel proud about themselves. At the start of the visit, it can also be beneficial to ask about other physicians and allied professionals involved in the child's care to facilitate interprofessional collaboration and provide a more holistic picture of their current management.

After eliciting the presenting concerns, it can be helpful to explore the child's development and behaviour. When did the caregiver first have concerns? Was there any regression in the child's developmental milestones? Relative to the child's chronological age, we can then assess their current developmental age in each of the major domains of gross motor, fine motor, language, and social development. Using gross motor development as an example, the 50th percentile of children with a chronological age of 5 will have achieved the motor tasks of skipping, balancing on one foot for 10 seconds, and learning how to ride a bicycle. In the context of a neuromuscular disorder, these tasks may not be achieved by this age. Instead, a 5-year-old child with a diagnosis impacting their gross motor function, may meet the 12-month-old milestone whereby they can walk a few steps and have a wide based gait ¹³.

In addition to developmental milestones, we can also ask about the child's activities of daily living and if any support is required to complete these tasks which include toileting, hygiene, and eating. We may ask about the child's usage of technology for assistance in their environment, such as a device that supports communication, and for recreational purposes. We often inquire about sleep behaviours and nutrition within our review of development as these factors are fundamental in health outcomes.

It is crucial to ask about a child's experience with school and any present accommodations that are captured in an individualized education plan. Does the child enjoy attending school? Does the child have friends that they enjoy spending time with? Do they have any difficulties with learning? Has the child demonstrated any problematic behaviours at school? Has their teacher raised any concerns about their academic performance ⁸?

Next, we can move into the child's past medical history including gestation through questions about ultrasounds, prenatal screening, maternal health, medications, and substance use. We will ask about the child's delivery and neonatal interventions such as resuscitation or phototherapy. How many weeks were they at delivery? What was their birth weight? Was there a stay in the NICU? We want to inquire about any current medications that the child may be taking including prescriptions and over-the-counter medications. Do they have any allergies? Are their immunizations up to date? We would also elicit information about other medical diagnoses, prior hospitalizations, and surgeries. A head-to-toe review of systems approach can be helpful to ensure that we do not miss any major medical issues including auditory or visual difficulties that may otherwise be overlooked.

In our social history, we always ask about a child's family to better understand them and their developmental context. Who lives at home with them? Do they have siblings? If so, did their siblings have any developmental challenges? Is there any history of consanguinity? Are there any family members with genetic conditions or similar clinical presentations to the child ⁶?

Before moving onto our physical assessment, we always want to ask about any collateral sources of information. For instance, has the family brought any documents from school or other allied health members, such as psychologists, or physical therapists, that work with the child? Do they have results from any formal tests or evaluations? When formulating our understanding of the child, it can be incredibly beneficial to consider additional perspectives.

While the physical exam can vary depending on the presenting concern, we generally will always want to obtain height, weight, and head circumference to plot on the appropriate growth chart and assess for any failure to thrive. If a child uses a wheelchair or other mobility devices, we can use an accessible scale to accommodate the device or we may ask the caregiver to assist in this measurement by holding their child. After documenting their growth, we observe the child and evaluate for any dysmorphic features or congenital abnormalities⁶. Often, we perform a neurological examination to evaluate both motor and sensory function. During a developmental assessment, playing and directly interacting with the child is a key component of the examination. Throughout our play, we can observe their social interactions, engagement with the environment, language usage, and other behaviours. This is crucial when considering a diagnosis of autism spectrum disorder for which we want to assess for sensory interests or aversions, sharing of toys, and social overtures to inform our clinical picture. When formulating any diagnosis, it is also helpful to identify possible genetic or medical precipitants as secondary etiologies¹⁴.

Communicating a diagnosis associated with disability to caregivers can be challenging and listeners of this podcast may find it helpful to observe how different preceptors approach this conversation. Delivering this life-changing news involves sharing what was observed during the appointment and how this relates to the information provided by the caregiver. Upon explaining our clinical impression, we highlight the strengths of the child and areas where they may require additional support. After delivering the diagnosis, we may ask whether this information is surprising to caregivers or whether they had expected this news. Additionally, we want to inquire about the caregivers' understanding of disability and their expectations for management¹⁰. For instance, a parent of a child with a learning disability may believe that their child is simply not putting in enough effort at school and lacks motivation. With counselling, we can rectify this misunderstanding by explaining that these academic challenges are differences in learning which the average educational system does not address or adjust teaching strategies accordingly. We would also explain that a learning disability is not the fault of the child and that their learning can be supported by classroom accommodations such as assistive devices or an educational assistant⁸.

To inform next steps, we can use our understanding of the health system to connect caregivers with resources and community programs. There is an opportunity for physician advocacy to ensure that children receive services that can benefit their development⁸. Caregivers may ask for treatments that will fix or cure the disability because they view disability as an illness^{15, 16}. The field of childhood disability is shifting from a diagnosis centred framework to favour functional explanations. This is best evidenced by the F-words developed in 2012 by Rosenbaum and Gorter of the CanChild Centre for Childhood Disability Research. This approach was inspired by the International Classification of Functioning, Disability, and Health from the World Health Organization¹⁶.

The F-words

The experience of disability is much more complex and heterogeneous than a particular diagnosis may suggest. The more we learn about childhood development and the impact of

individual factors, including environmental, personal and social influences, the more we can appreciate that each child has a unique developmental trajectory ¹¹. With this in mind, we will discuss the F-words, a holistic strengths-based approach that healthcare providers across the world are using in their care of children living with a disability.

The F-words framework shifts away from the traditional biomedical understanding of disability to focus on inclusion and accessibility for children. Let's start off with the first F-word, Function, which describes the activities and actions of a child. This word emphasizes that there are many different ways to accomplish a task and that no way is better than another. For instance, a child may use nonverbal communication and a communication board rather than spoken language, but they are still able to convey their thoughts and feelings.

The second F-word is Family. Taking a family-centred approach is crucial when caring for a child that lives with a disability and has been associated with more positive care experiences. As the family is the expert on the child, they are a key component of the care team.

The third F-word is Fitness which includes both physical and mental health. Promoting physical activity through recreation is crucial during childhood and can help establish good habits early in life for health promotion. Reducing pain and discomfort with activity is vital and may involve adaptations such as moving in water or using assistive devices.

The fourth F-word is Fun. All children want to have fun in life, including those that live with a disability. Adapting activities for children to participate provides enjoyment and helps a child to grow their confidence and independence.

The fifth F-word is Friends. As we discussed earlier, social development is one of the key domains of childhood development. We want to encourage children to establish friendships and find opportunities to interact with their peers.

The final F-word is Future which highlights a child's continued development and goals for the future. It is important to explore possibilities for the future and set goals that are both meaningful to the child and their family. We want these goals to be collaborative and updated regularly to support the child's intrinsic motivation in achieving their hopes and dreams.

The six F-words, Function, Family, Fitness, Fun, Friends, and Future, are interconnected such that a change in one area can have a ripple effect in the other five domains. This approach can help inform care delivery and shape the life experiences of children and their families. There are numerous resources available for families, clinicians, and medical students on the CanChild website which we encourage you to explore ¹⁶.

Transitions in care and associated challenges

For children living with a disability, their medical care may be delivered by a combination of their family physician, developmental pediatrician, physiatrist, child and adolescent psychiatrist, and/or other pediatric subspecialists. Upon turning 18, these services will transition to the adult sector. In addition to changes in their physician team, many emerging adults will also see changes in their social and rehabilitative programming from their school and the community. Unfortunately, this transition is not always seamless and can be challenging for patients and their families to navigate as the pediatric and adult care systems are not fully integrated. A noticeable absence is the adult counterpart of developmental and behavioral pediatrics.

Throughout the adolescent years, we can help children and their families prepare for this adjustment by developing a personalized transition plan for their healthcare delivery and activities of independent living ⁷. This process should be viewed as gradual rather than a single event upon turning 18 ¹⁷. Throughout this journey, the youth should be in the driver's seat with their family and care providers supporting them along the way ¹⁸. It is crucial for the youth to have an increasing role in their care as they reach their adolescent years. As they develop, we can encourage families to give their child additional responsibilities in the home to help foster independence and confidence in their abilities. We can start developing transition plans with collaborative goals for the future including career planning, educational goals, living arrangements, and self-care ^{17,18}. As system navigators, we may share information about government funding opportunities and community organizations for adult clients.

Throughout this transition, we must respect the goals and decisions of the youth to promote self-determination and resilience. The level of support required by youth during this time must be flexible and establish interdependence within their new networks and communities rather than isolating the youth as they age out of pediatric care. Pediatricians can facilitate this process by scheduling staggered dates for transfer of care to reduce the amount of change happening simultaneously ¹⁸.

Case review

Now, let's apply what we've learned in Rosie's case. You begin the appointment by introducing yourself to both Rosie and her parents. Since this is a follow-up appointment and you've already reviewed her perinatal and developmental history, you ask how things have been going at home. Rosie's father, Frank, outlines that Rosie has been working on her self-care skills with her occupational therapist and Rosie proudly demonstrates her assistive device that she uses to hold her water bottle. In addition to her occupational therapy progress, you inquire about Rosie's speech language pathology services. The family is pleased to share that Rosie's speech clarity has been making strides with one syllable words.

You review if Rosie's neurologist has made any recent changes to her management plan and her mother, Angela, reports that Rosie's seizures remain well controlled with Levetiracetam and there have not been any other changes to Rosie's medical history since her last visit. As Rosie will be starting high school in the fall, Angela asks if you can provide a letter for the school about Rosie's cerebral palsy, intellectual disability, seizures, and dysarthria to ensure continued access to her educational support which includes an educational assistant and accommodations in the classroom. You make a note of this to ask your supervisor about writing an official letter. When you ask Rosie if she enjoys school, she nods her head excitedly.

Since the F-words have previously been discussed with this family, you review Rosie's previous goals and progress. Self-care continues to be a major area of motivation for Rosie and you work alongside the family to update their current goals around independent feeding. You measure Rosie's standing height, with assistance from her mother, and then use the wheelchair accessible scale for her weight. Plotting these values on her growth curves reveals that Rosie is growing appropriately. You take her vitals which are within normal limits and perform brief screening cardiovascular, respiratory, and neurological exams. All findings are comparable to the prior visit.

You close the visit by discussing Rosie's transition to high school and how adolescence is a time of many transitions, including puberty, which can be both exciting and scary. You propose that in future visits, as a means of establishing autonomy, Rosie could take on a more active role in the

interview which the family is open to trying. With the SSHADESS framework in mind, you also share that it is common for adolescents to be interviewed alone during their visit to further support independence. For the next visit, you ask Rosie if she would be interested in speaking with her pediatrician, without her parents present, and Rosie says “yes” with a smile. Before reviewing with your supervisor, you provide resources on transition planning for Rosie and her parents to read before their next visit.

Summary

Revisiting our learning objectives, let’s summarize the key takeaways:

- As we saw, disability is a broad term that can apply to any chronic condition that leads to a functional impairment ¹⁵. Some common examples of childhood disability include cerebral palsy, global developmental delay, learning disability, and autism spectrum disorder.
- During clinical assessments, we want to create a safe environment for children, youth, and their families by promoting inclusivity and accessibility through care. In our interview, it is crucial to be curious and take a strengths-based approach when exploring a child’s developmental history, school experience, past medical history, family history, and current concerns. The physical exam for a child living with a disability will vary depending on the clinical picture but should cover all the same components as we would for any child with accommodations as necessary.
- The F-words approach highlights the importance of Function, Family, Fitness, Fun, Friends, and Future in the life of a child with a disability. In clinical practice, this framework can be used for collaborative goal setting and to reframe families’ understanding of childhood disability ¹⁶.
- The transition from pediatric to adult healthcare services can be challenging for children and their families. Clinicians can assist throughout this journey by acting as system navigators, discussing transition planning during adolescence, and promoting a child’s involvement in their care.

Thank you so much for tuning in to this episode of PedsCases on Disability. We hope that you enjoyed listening and learning with us today.

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