



Growing Up Together:

Care for Adults with Developmental Disabilities

Pixie Plummer, MD

“What are we going to do when Brian turns 22?”*

Twenty-five years ago, I was working as a nursing assistant on the inpatient unit treating patients with developmental disabilities and challenging behaviors. One patient had made great progress with support and guidance from his multidisciplinary team at UIHC's Center for Developmental Disabilities (at that time called the University Hospital School). But I remember hearing someone ask that question with anxiety and concern knowing that our specialty has historically been rooted in Pediatrics and care for children.

Children and youth with congenital and acquired disabilities are growing up well into adulthood, in part due to the increasing effectiveness of health care in recent decades. While in medical school in the 1990's, I noticed that patients with developmental

disabilities were often struggling to find a medical home in the world of adult health care for primary care and often multiple specialists.

With the support and advice of CDD Developmental Specialists, I completed a combined residency in Internal Medicine-Pediatrics at Baystate Medical Center in Springfield, Massachusetts and then fellowship training at Boston Childrens Hospital in Neurodevelopmental Disabilities. This training involves caring for patients of all ages with a broad range of developmental diagnoses including intellectual disability, autism, cerebral palsy, spina bifida, and traumatic brain injury. For many patients their neurodevelopmental care includes advice and supports around school and community services, but also evaluation and management of ongoing complex special healthcare needs. Sometimes there are specific medical conditions

we know to watch out for, but also, common medical problems may present for our patients in unique ways. Needs and medical issues clearly change over time and aging brings new challenges to address.

As a neurodevelopmental specialist I am experienced in caring for patients who use a variety of medical technologies such as G tubes, tracheostomies, ventilators, and other equipment for important life functions at home, school or work. It is often critical that your provider partners with you in a way that is creative to meet your unique health needs. Including your family and caregivers with their knowledge and insight is vital.

As we all know this transition from youth to young adulthood involves many aspects of life, not just related to healthcare. School, family supports,

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insurance and benefits structure, as well as social networks and recreation opportunities, are all shifting during this time. The challenges continue to come our way moving into our 30's, 40's and beyond.

Now, more than 20 years after overhearing that question wondering what we can do for Brian as he is turning 22, I am very excited to be joining the team at the CDD and to provide care for adult patients. I am happy to provide ongoing consultation in a way that helps patients and primary care providers.

(* name has been changed)



Dr. Pixie Plummer, a Neurodevelopmental Disabilities specialist has joined CDD to expand our care for youth and adults with developmental

disabilities. She is an Iowa native and 1999 graduate of the University of Iowa College of Medicine who always dreamed of helping support patients of all ages with disabilities in our state.

I joined University of Iowa Stead Family Children's Hospital to be part of a unique and innovative team that supports patients with disabilities across the lifespan.

– Pixie Plummer, MD



REVIEWED BY Lucy Roth

My name is Lucy Roth and I'm in fourth grade. My physical therapist, Katie Laubscher at CDD

had told me about a book called *Meena Meets Her Match* that she thought I might like to read. One weekend the author, Karla Manternach, was at Barnes & Noble talking about her book, and I got to meet her and get the book. I'm so glad I did because I loved reading it!

The main character, Meena, is a creative and outgoing third-grader. Colors are very important to her — she loves all the colors of the rainbow! She has an eye for colorful trash that she finds in the recycling bins. She loves digging around in the trash because she finds all the colors there, like a pink feathered scarf and different colored candy wrappers. She uses the trash for her craft projects and for a Valentine's box she's making at school. A funny part of the book was when Meena, her little sister Rosie, and her cousin Eli built an igloo out of old milk cartons that Meena had found in the recycling.

Meena loves colors so much that she purposely eats foods that are every color of the rainbow. She feels like colors make up her personality, and that the colors all drain out of her when she's unhappy. When she's sad, she feels gray. She's going through a hard, gray time in the story because her best friend Sofia has stopped playing with her at recess and being her friend, and Meena doesn't understand why.

This makes Meena feel competitive. She wants her stuff to be better than Sofia's — like how she styles her hair on Crazy Hair Day and how creative she is with making her Valentine's box. She wants her Valentine's box to be the best and most colorful in the whole class! Meena thinks Sofia stays in for Catch Up Club during recess just because she wants to be better at things like cursive writing than Meena, but it turns out that Sofia is having some troubles of her own.

One day at school Meena feels dizzy, and she starts scribbling on her paper and can't hear her teacher. Then at home she suddenly has a seizure at breakfast. She has to go to the hospital and have some tests done. Meena brings her rainbow-striped, stuffed zebra Raymond into the MRI with



I think some lessons that *Meena Meets Her Match* teaches are:

- 1) Even though someone isn't being your friend anymore, you can still move on and find other friends. You don't always have to try to get them to be friends again – sometimes they need time because they're going through something you don't know about. Sometimes you have to just move on until the friend tells you what's going on.
- 2) It's okay to be scared when something is happening to you, and it's going to be okay.
- 3) Whatever condition you have, it's okay, because you're a unique person because of everything you've survived or been through.

her. That's how Meena and her parents find out that she has epilepsy. Reading about her going to the hospital was emotional for me because I've been through a lot and it reminded me of all the times when I had to go to the hospital.

Back at home, Meena's parents want to be very cautious and not let her be alone, in case she has another seizure. She uses a monitor just like I do, except that her parents can see her on the monitor instead of just hear her like the one at my house. Her parents want her teacher, Mrs. D, to be very careful with her at school too, so Mrs. D wants Meena to have a partner in class. But Meena doesn't want a partner – she wants to be independent.

This is a story that a lot of kids like me can relate to because Meena has been through a lot with her epilepsy. It's also a story about competition versus friendship. There were some complicated words during the hospital scenes, but otherwise this book was easy to read and I really enjoyed it. Some parts were emotional for me to read, but I loved this book because it really matched my personality – Meena is creative just like me and she's been through a lot like me. We both love bright colors and crafting and we both have a lot of friends. We could be sisters! I think you'll like this book too.

Meena's Story

Meena's life is full of color. She wears vibrant clothes, eats every shade of the rainbow, and plucks eye-catching trash from the neighborhood recycling bins. But when Meena's best friend, Sofia, stops playing with her at recess and she experiences an unexpected and scary incident at breakfast, nothing can fight off the gray. That's when Meena comes up with a plan to create the BEST and most COLORFUL Valentine's Day Box in the class. With the help of her cousin, Eli, and her stuffed zebra, Raymond, Meena discovers that the best way to break through the blah is to let her true colors shine.

Karla's Story At Meena's age, Karla was a smudgy kid in tube socks. She once stopped an entire parade by running in front of a fire truck for candy. She liked every subject in school, even Government, but she always loved writing best of all. When she was ten, she wrote her most ambitious piece yet: a ten-page story called *The Berry Hunt That Went ALIEN*. Today, she texts with only one finger...but with perfect punctuation. Karla is also a freelance writer for nonprofit and religious organizations. She lives with her family in small-town Wisconsin.

<https://www.karlamanternach.com>

CDD Welcomes New Disability Resource Librarian



On February 27, CDD's Disability Resource Library (DRL) welcomed Mitch DeFauw as its new specialty librarian. A native Quad Citian, Mitch received his BA in English and creative writing from Luther College in Decorah and his MA in Library and Information Sciences from the University of Iowa.

After graduating, Mitch worked as the assistant youth and teen services librarian at the North Liberty Public Library.

Mitch's personal and professional experiences around children and adults with disabilities make this new position very important to him. "I want to give all of

our patrons ease of mind when they access our library services," he says.

Mitch expressed his future goals for the DRL, "I want it to stop being Iowa's best-kept secret. We are the largest resource for information on disabilities in the state of Iowa, and need to let people know we're here." Other priorities include making the library as accessible as possible, adding stories which include children with disabilities which would be of interest to any child, hosting fun events in conjunction with CDD's Thursday night clinic, and expanding the collection to include titles in multiple languages. "I believe a library's collection showcases its values, and I want patrons across the state to know that we value individuals representing all identities," says Mitch.



DRL Receives Generous Gift from Volunteers

Ellen and Alysia Haman are a dedicated mother and daughter volunteer team. Since 2001, they have each volunteered close to 6,000 hours. While they have contributed the majority of their time to the Center for Disabilities and Development, UIHC Patients' Library, and Spiritual Services, it isn't a rare occurrence to see them all around the hospital! Both have a very special connection to CDD and were honored to help fund a book cart for the CDD Disability Library through Volunteer Services. The books are available for free to new patients. For more information, contact Mitch Defauw, mitchell-defauw@uiowa.edu.

Ellen and Alysia Haman with Mary Hubbard, retired Disability Resource Librarian. Above, the cart of books funded by their many hours of volunteering.



Provider Highlight

Angie Smith

Developmental Psychologist

FUN FACTS:

I have completed an Ironman competition. I also love traveling with my kiddos and have taken them to the 48 continental states, and to 9 countries.

How many years have you been practicing?

I have been at CDD 18 years this July, and my first year here I was a LEND post-doc trainee.

Why did you choose your field?

When I was younger, I babysat someone with Autism and always had a special place in my heart for individuals with disabilities. When I was in high school I met Bill Sackter and the movie about his life also really touched me. I also knew I wanted to work with children but wanted a job different than my parents who were teachers.

What areas interest you in your field?

I enjoy trying to provide valuable information which can help a family better understand why their child is not developing typically. Each child can be a unique mystery and my clinical impression can provide insight into solving the mystery.

What is a Developmental Psychologist?

There are psychologists with a variety of job descriptions. Some psychologists do research, others see patients in therapy, others help athletes with peak performance, and some work in businesses to help improve industry. As a developmental psychologist, I assess an individual's developmental level. While their chronological age might be ten, their

skills might be more similar to a 4-year olds. It is helpful for people who are working with individuals with developmental delays to have appropriate expectations. This understanding can help them from creating unintended behavioral or emotional problems. I believe this is valuable information for patient's, their families, and care providers to help them better understand each child's unique set of strengths and weaknesses. I tell families the data I can provide will add a piece to the puzzle in better understanding each patient's unique presentation.

Who benefits from seeing a Developmental Psychologist?

Seeing a psychologist can help people understand their strengths and weaknesses. Some children with a reading disability might feel they are not good at school and feel inferior to their peers, but may actually be quite smart. Some children with significant behavior problems may be embarrassed by their learning problems so they are acting out in order to cover-up the fact they are confused in the classroom. It is also good for people to know their strengths and weaknesses so they can use their strengths to bypass around their weaker areas.

How do these services help people live independent lives?

The information provided through our clinical appointment can let

others who are working with a patient know how much support they need in order to continue to progress at their own unique rate.

What does your department offer to patients that other programs don't?

At CDD we are able to provide multiple clinical impressions within our one department. Working one-on-one with a patient also offers unique information, such as how they were able to attend to a task, which provides valuable information beyond just numbers or performance levels. The activities we do with the patient provide information about each child's unique cognitive strengths and weaknesses. These provide valuable information regarding developmentally appropriate expectations.

Why did you choose CDD?

I really like working with the patients and their families. The staff that want to work with individuals with disabilities are also great people I love to call my colleagues.

What you would say to a patient and family coming to the CDD for the first time to see you?

Today we are going to play some games to get a better idea of your strengths and weaknesses so that we can add a new piece to the complex puzzle of your child.

Security at Iowa Compass

As Iowa’s disability-related information and referral service, Iowa Compass reaches out to a broad audience. Because we use information technology (IT) to reach our audience, we pay close attention to the need for digital security. Iowa Compass is based at the University of Iowa Hospitals and Clinics (UIHC). This allows us to share IT security provided by UIHC and the University of Iowa. We follow best practices for online safety to make sure the Iowa Compass website is secure.

Keeping Iowa Compass secure means that we all must learn how scams work. There are many kinds of scams that take place online and by phone. There are more and more “bad actors” who scheme to steal information from people and businesses.

Phishing and Spoofing

Phishing and spoofing are common IT scams. Phishing scams use email, phone and text messages. A phishing scheme may use “spoofed” or fake emails to bait people into giving scammers private information. Most often their goal is to get people to share bank and credit card numbers, or even their social security numbers.

Spoofing happens when a person or program pretends to be someone else electronically. They use the real email address or phone number of a trusted source to hide their own. They send a message that may contain malware or a virus. This helps them get around security to steal data or financial information.

Beating the Scams Together

Recently some spoofing emails have involved Iowa Compass. These emails have used our name and our email address. Some have asked for payment to be in the Compass database. Some have sent links or attachments to phony invoices or receipts in the emails.

It is important to remember Iowa Compass does not charge for its services:

- We do not charge to be in our database.
- We do not charge for our information and referral services.

If you get an email from Iowa Compass that you think might be a scam, call us at 1-800-779-2001. We report all suspicious emails to the University of Iowa and to Homeland Security.

What to Do with Suspicious Emails

If you get an email you suspect might be a scam, the following steps can help keep you, your computer, and your information safe:

- Do not click on links or open any attachments.
- Move the suspicious email to your “Junk” folder.
- Alert your organization’s IT support team, if you have one.
- If you don’t have IT support, get in touch with your email domain provider for help.

Email Domain Providers

Below are links to common email domain providers in Iowa.

Use these links to find instructions to report spam:

- [AOL](#)
- [Yahoo](#)

Use these links to report spam by email:

- Outlook
- [Hotmail](#)
- [Mediacom](#)
- [Century Link](#)

Use this link to reach Gmail’s Program Policies violation form:

- [Gmail](#)

Being aware and learning more are the best ways to avoid falling victim to scams. Two great sources to find out more about IT security are:

- The University of Iowa Information Technology Services: <https://its.uiowa.edu/phishing>
- The U.S. Department of Homeland Security: <https://www.us-cert.gov/report-phishing>

Do It Yourself Assistive Technology

New needs inspire people to come up with new ideas for assistive technology. Ideas for items that don't cost a lot and are easy to use make good choices. Do It Yourself (DIY) assistive technology is often a low-cost choice. It can also offer people the best fit for their needs.

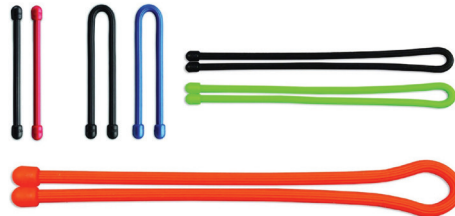
Dr. Therese Willkomm is the director of the New Hampshire Statewide Assistive Technology Program. She is known as the “MacGyver” of assistive technology. Dr. Willkomm has come up with many ideas for DIY assistive technology (AT). One of her ideas is the Mini Eileen.



What Is a Mini Eileen?

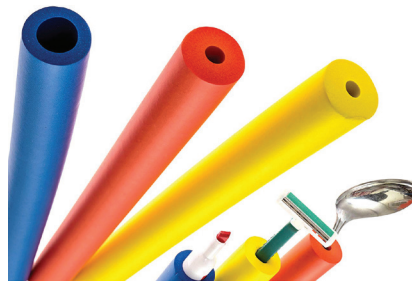
The Mini Eileen is a hands-free option to hold a smart phone or small tablet. It holds the device vertically or horizontally. First, Dr. Willkomm invented the Traveling Eileen to hold her iPad. But the design was too big for her new iPad Mini. So she invented the Mini Eileen. It is also known as the Mini-Lean.

The Mini Eileen is made of corrugated plastic, double-sided tape, Velcro, and adhesive squares. These squares stop the Mini Eileen from slipping. It can cost as little as \$4.00 to make one. Learn how to do it yourself: <https://iod.unh.edu/sites/default/files/media/AssistiveTechnology/theminieileen.pdf>



Gear Ties

A gear tie is a thick, bendable wire with a strong rubber covering. Gear ties have many uses. Wrap a tie around a spoon handle for an alternate grip. Wrap one end of a tie around a person's hand and the other a stylus to secure a grip. In place of holding a cup, wrap one end of a tie around a person's wrist and the other around the cup.



Foam Tubing

Foam tubing can also be used to get a better grip. Foam tubing comes in different textures, sizes and colors. Put a pencil in foam tubing to help a person write. Add a piece of tubing to each end of a jump rope to make a larger grip to hold while jumping.

For more information about these DIY Assistive Technology products, contact the Easterseals Iowa Assistive Technology Program at 866-866-8782, or by email at atinfo@eastersealsia.org.



We have many ways you can stay connected

Would you like to get *CenterLines-News* you can use from the Center for Disabilities and Development by email? If so, email us at:

CenterLines@uiowa.edu

Please give your name and all email addresses where you wish to have the newsletter sent. We will still mail copies to those who want them.

If you would like to share your story, please email: **heather-roman@uiowa.edu**

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CenterLines is published quarterly. We encourage subscribers to also read our partner newsletter *Possibilities in Education and Training*. You can find that newsletter and others at disabilitytraining.org.

CenterLines, the newsletter of the Center for Disabilities and Development at University of Iowa Stead Family Children's Hospital, is published four times a year. It provides families with current information on child

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and adult development, issues affecting people with disabilities, and resources available to them and their families. The newsletter is available in print, in Spanish, and also by email.

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The role of the information in this newsletter is not to provide diagnosis or treatment of any illness or condition. We strongly encourage you to discuss the information you find here with your health care and other service providers.