

## Shared Decision Making Project at CDD



The Center for Disabilities and Development Unit Council is a group that works to plan and carry out CDD's programs. The group includes staff members from nursing, support services, registration, audiology, rehab therapies, medicine, behavioral services, psychology, and management. We care about what happens here at CDD, and are always looking for ways to make our processes better.

In the summer of 2017, we looked at our patient surveys and saw that we had room for growth. Providers at CDD always work to give the best care, care that is family-centered, evidence-based, and high quality. Still, the

survey results showed that we needed to do a better job to include patients and families in making decisions. Parents told us that they viewed themselves as the expert on their child, and wished to be more involved in planning for their child.

We know that some parents may want more information or involvement than others, but we have found that most do want to be involved. Studies show that patient-centered participation leads to higher satisfaction, engagement, and compliance with recommended treatments. Using shared decision making also helps to build a better patient-provider relationship, so everyone wins!

Unit Council looked at research to find a method we could add to our care routine. We chose 'Shared Decision Making: A Model for Clinical Practice' as the best option. This model has 3 steps; Choice Talk, Option Talk, and Decision Talk.

**Choice Talk** is not just talking about choices, but it also includes talking about how each choice is different. The provider will make clear the importance of choice, help with any doubt about the results of the choices, and give support in moving forward with talking about the options.

**Option Talk** is talking about what the parent/patient may already know or has heard on the matter. The next step is listing the options. They will talk about the differences of each, the pros and cons, and take the time to make sure the choices are understood.

**Decision Talk** is focusing on preferences, finding out if the family is ready to decide, and going over the choices.

CDD asked for a group of our providers who were willing to try out the model with their patients. Surveys were given out to see how parents felt about this model. The results were positive, so we asked more providers to join in with their

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patients. We shared the benefits of using shared decision making in our weekly newsletter to staff. A parent came to a clinic meeting and shared her story about how being involved in her child's care was of great value. We made an informational sheet to help our providers remember each step of the model. After that, we presented the information at a clinic meeting to all our providers.

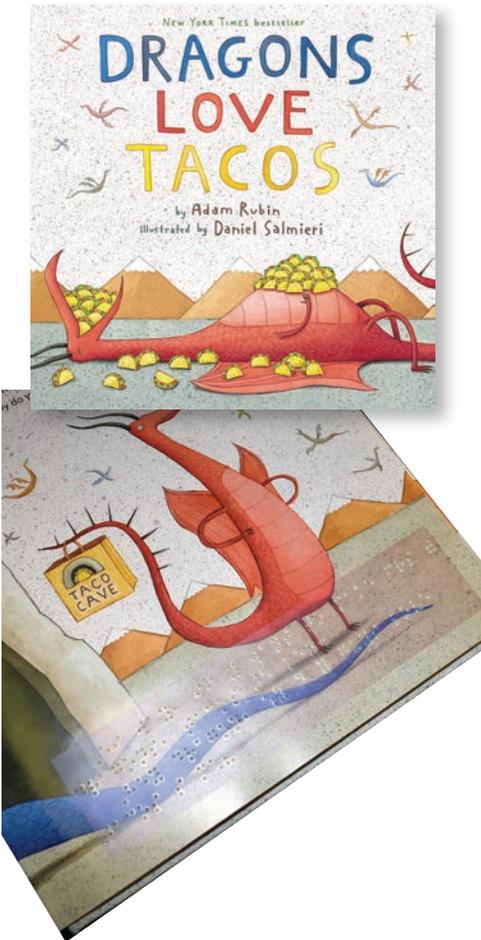
We have been happy by how well our results in shared decision-making have improved. We went from a starting score of 68.7% and ended up higher than our goal of 74.8%.

This is not a project that will go away with time, it is too vital for our patients, families and providers. Our goal is to keep shared decision making as part of our everyday practice at CDD. Next time you are here for a visit, be sure and ask your provider about the Shared Decision Making model.

Unit council meets once a month, and will continue to help with communication and information sharing between our staff members. Our goal is to improve safety, quality of care, work environment, and to increase patient, family and staff satisfaction. Consistently using shared decision making is just one way we have accomplished our goals to make CDD a place where you feel involved, welcomed, and remain confident in the care we provide.

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## New Print/Braille Children's Books in the Disability Resource Library



**Dear Deer: a Book of Homophones** Gene Barretta., Henry Holt, 2007.

**Ada Twist, Scientist** Andrea Beaty, Abrams Books for Young Readers, 2016.

**Dad and the Dinosaur** Gennifer Choldenko, G. P. Putnam's Sons, 2017.

**She Persisted: 13 American Women Who Changed The World**  
Chelsea Clinton, Philomel Books, 2017.

**Sadie Can Count: A Multi-Sensory Book**  
Ann Cunningham. Sensational Book, 2005.

**The Day The Crayons Quit** Drew Daywalt, Philomel Books, 2013.

**Frozen: Read-Along Story Book and CD** Calliope Glass, Disney Press, 2013.

**Looking Out for Sarah** Glenna Lang, Charlesbridge, 2003.

**Last Stop on Market Street** Matt de la Peña, G. P. Putnam's Son, 2015.

**One Hundred Hungry Ants** Elinor J. Pinczes, Houghton Mifflin, 1993.

**Dragons Love Tacos** Adam Rubin, Dial Books for Young Readers, 2012.

**Interrupting Chicken** David Ezra Stein, Candlewick Press, 2016.

**That's Not My Monkey ...** Fiona Watt, Usborne Publishing, 2008.

Call or visit the library to check out these materials at the Center for Disabilities and Development.

800-272-7713 • email: [disability-library@uiowa.edu](mailto:disability-library@uiowa.edu)  
[uichildrens.org/cdd/drl/](http://uichildrens.org/cdd/drl/)



## Coming Soon: Pet Therapy at CDD!

We are excited to share the news that a generous donor is helping us create an animal therapy program. The Naomi and Forrest Downing Animal Assistance Fund has been established to help our patients and their families enjoy the benefits of spending time with therapy dogs. A group is coming up with ideas and a plan to bring dogs to CDD a couple of times each month. We are looking at different ways patients can interact with the dogs. Some ideas are having a dog in the Disability Resource Library to spend time with and read to, as well as getting their picture taken with our visiting dog. Our program will also teach children how to interact with an animal appropriately and safely.

Research shows that therapy dogs can help reduce stress as well as give support to children with social and emotional learning needs. With this generous gift, we can start the process of creating our own “CDD Wag.” Watch for more information as the planning continues.



## Provider Highlight

**Marcio Leyser, MD**

Developmental and Behavioral Pediatrician

### How many years have you been a doctor?

20

### Why did you choose to become a doctor?

To help children and their families with complex neurodevelopmental conditions to live their lives in the best way they possibly can.

### What are your areas of practice?

Autism spectrum disorders, ADHD, cerebral palsy, spina bifida

### What is a Developmental and Behavioral Pediatrician?

A doctor trained in Pediatrics who gets additional training in order to better diagnose conditions that affect children’s motor, cognitive (thought process), language, social and adaptive (self-help skills) developments.

### Who benefits from seeing a Developmental and Behavior Pediatrician?

Children whose development levels are below what is commonly seen at their age or are happening differently than expected for their age.

### How do these services help people live independent lives?

By teaching them to cope with their difficulties while giving them strategies that will help them overcome their challenges and barriers. Our services also help them to find the resources they need for independent living according to their capabilities.

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

Our program is dedicated to delivering excellent care to people with special needs. We do this by using an individual-centered, family-centered, team-based, and evidence-based approach.

### Why did you choose CDD?

The CDD is a fascinating setting that, as part of the University of Iowa Stead Family Children’s Hospital, delivers high quality care for people with disabilities through its highly skilled, interdisciplinary, and dedicated team members, centered on the individual and his/her family, and based on the new scientific trends.

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

I will do my best trying to reach that extra mile for you and your beloved one.

# Attachment, Neurodevelopment & Psychopathology

Patricia McKinsey Crittenden, PhD



University of Iowa  
Stead Family  
Children's Hospital

Center for Disabilities  
and Development

September 19 - 21, 2018



**COURSE OVERVIEW** This 3-day course covers the development, prevention, and treatment of psychological disorder. It weaves together theory, human development, assessment, case examples, and treatment applications to reframe maladaptive behavior in terms of strategies for self-protection. The course covers development from infancy to adulthood, emphasizing the process of adaptation and developmental pathways that carry risk for psychopathology. The model used, the Dynamic-Maturational Model (DMM) of Attachment and Adaptation, is relevant to individuals who are at-risk, have been exposed to danger, display disturbed or maladaptive behavior, or are diagnosed as having a psychiatric disorder. A particular emphasis is cultural influences on attachment.

**Who should attend?** The course is aimed at professionals who work with troubled families or individuals, including: therapists, developmental pediatricians, psychiatrists, psychologists, lawyers, social workers, teachers and nurses.



## Patricia Crittenden

has many years of experience as an academic and practitioner in the fields of child abuse, attachment theory, and family therapy. After her training with Mary Ainsworth, she served on the Faculties of Psychology at the Universities of

Virginia and Miami. She has held visiting positions at the Universities of Helsinki and Bologna, as well as the Clark Institute of Psychiatry (Canada), San Diego State University (USA), and Edith Cowan University (Australia). As the founder of the Family Relations Institute (FRI), she is well known for having developed the Dynamic-Maturational Model (DMM) of Attachment and Adaptation and is one of the founders of the International Association for the Study of Attachment (IASA). In 2004, she received a Career Achievement Award from the European Family Therapy Association. In addition, she has published more than 100 scientific papers and several books.



## Center for Disabilities and Development (CDD)

is dedicated to improving the health and independence of people with developmental disabilities and creating a life with opportunities for everyone. Our patients often have complex physical, social and emotional needs, which is why we use an interdisciplinary team approach, bringing together the appropriate experts to help families find answers. At the heart of each team are the patient and family.

The **Attachment and Neurodevelopment Laboratory**, led by Dr. Lane Strathearn MBBS PhD, is located in CDD, and is funded by the National Institutes of Health. Ground breaking research has been performed in this lab using Crittenden's Dynamic-Maturational Model of Attachment and Adaptation.



## Comfort Room at CDD

The Center for Disabilities and Development (CDD) at University of Iowa Stead Family Children’s Hospital continues to focus on unique ways to enhance patient care.

The comfort room is a sensory experience for your child and family to use when you visit CDD. Using technology designed to reduce anxiety and stress, we have created a safe, fun, and educational environment.

The comfort room has interactive features designed to help reduce your child’s feelings of worry and fear. These include:

- LED, color-changing bubble tube on a soft padded base lets you sit close to the tube and feel its vibrations
- Floor pad with changeable music is a safe and calm place to sit or lie down
- Beanbag chair with LED fiber optic strands that change color
- “Firework bonanza” or “under the sea” video projected on the wall
- Carpet with a menu of interactive images. Step on the carpet and parts of the picture move, asteroids blast from space, fish swim through a pond with ripples, bubbles move and change color, and many more
- Wall-mounted motion sensor with music
- Mirror ball with changeable colored lenses

Along with creating a safe, calming space, the features of these devices can also be used to help with:

- Switching skills
- Understanding cause and effect
- Color recognition and color matching
- Improving motor skills



## 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.



**Have you been looking for us on Facebook?** Look no further! The Center for Disabilities and Development will be sharing stories, photos and information on child and adult development. Make sure to “Like” University of Iowa Stead Family Children’s Hospital Facebook page.

Would you like to share your story? Please email: **heather-roman@uiowa.edu**

## Universal Design and Assistive Technology



### What Is Universal Design?

Universal design is a big idea that fits people of all sizes, ages, abilities and disabilities. It's the idea that makes a home ready for all people to access and use. It assures all can live safely and easily in the same home. Universal design can cost a lot of money. Designing and building a new home is expensive. Making

big changes to an existing home can be costly too. But making small changes or adding assistive technology can help solve problems and create accessible housing for all.

### Start at the Front Door

Making it easy for people to get into a home on their own is the first step. Adding a threshold ramp or a berm made from soil for a no-step entrance can help. A small portable ramp will cost less than building a full ramp. A good grip on the door is next. Adding a door adapter to a door knob gives people a better grasp when opening or closing the door. Or they can push the lever with an arm or elbow.



### What's Up in the Kitchen

In an accessible kitchen, people can reach items in cupboards and on countertops. Lower cupboards with pull-out shelves keep dishes and other items in reach. Clearing space on countertops makes room for accessible appliances. Large buttons on new appliances are easy to read and use. Adding tactile markers or bright stickers with larger letters to old appliances is a less expensive option. An under the cabinet jar opener works for any size of twist open lid.



### Getting a Grip in the Bathroom

An accessible bathroom gives all people the space and safety they need there every day. Putting in a barrier-free shower allows users to walk in and sit down in a shower chair to avoid falls. It also allows a person who uses a wheelchair to roll in. If renovations aren't possible, adding grab bars and a shower chair to an existing bathtub can help. Some grab bars grip walls with suction cups. These can be moved easily to meet the needs of many users.

Shower chairs and grab bars can be purchased in stores or online. They may also be available through loan programs, such as the Easter Seals Iowa Assistive Technology Program or loan closets around the state.



### Getting Help from Easter Seals Iowa Assistive Technology Program

Assistive Technology (AT) can help make a home—existing, new, or newly renovated—more accessible. At the Demonstration Center in Des Moines, staff at the Easter Seals Iowa Assistive Technology Program show people how AT items can help them stay independent and safe at home. Their Lending Library loans items free for 30 days. Their Durable Medical Equipment Program has recycled and refurbished items for sale. Borrowing an AT item is a good way to find the best one to buy.

### Contact Information

Phone: 1-866-866-8782; TTY: 515-289-4069

Email: [atinfo@eastersealsia.org](mailto:atinfo@eastersealsia.org)

Inventory website: <https://eastersealsia.at4all.com/>



Whether you're looking to rent or buy a house or apartment, here are a list of resources that can help you with your search:

- **IowaHousingSearch.org**  
[IowaHousingSearch.org](http://IowaHousingSearch.org) is a rental housing locator funded by Iowa Finance Authority. The locator can identify properties that have accessible features, and those that accept public housing assistance.
- **Local ads**  
Look at listings in your local newspaper's classified section or community bulletin boards. Check out places where people get together like local community centers, coffee shops, and gas stations among many others. These are common locations for private landlords to advertise available properties.
- **Local property management companies**  
Find property management companies in your area through the phone book or use the words "property management near me" in a google search. Ask property managers about accessible apartments or houses available for rent. Ask if an accessible unit will be open soon.

## Finding Accessible Housing

- **Property Listing websites**  
There are now many websites that list rental housing. Several landlord/tenant-focused websites recommend these websites in their top five most reputable.
  - [Trulia](http://Trulia)
  - [Zillow](http://Zillow)
  - [Forrent.com](http://Forrent.com)
  - [Craigslist](http://Craigslist)
  - [Apartments.com](http://Apartments.com)
- **Real estate agents**  
Local real estate agents can help find accessible homes for sale. If there are no accessible homes for sale, the real estate agent might be able to help find a home to remodel to make it accessible. They may also help find property for sale to build a new accessible home.
- **For sale by owner**  
Some owners choose to sell their homes without the help of a real estate agent. These homes are listed for sale in local newspapers. They are also listed on community and "for sale by owner" websites. These sellers may have a "for sale" sign in their front yard. To find local "for sale by owner" houses online, use keywords "for sale by owner" or "for sale by owner Iowa."
- **Local disability organizations**  
Some experts suggest getting in touch with local disability organizations to find listings. You may meet other people with

disabilities who can offer tips on buying an accessible home. Landlords may try to get the word out about available accessible housing through these organizations.

### What to Say:

Make a list of all you need to get full use of your new home. This list will show the realtor, contractor, landlord or property manager what will make the home accessible for you. Their sense of accessible may not be the same as yours.

**Give details.** For example, if you need widened doorways, say how wide. List both common and accessibility features:

- **Common features:** the number of bedrooms and bathrooms, the style of the home, closeness to bus stops.
- **Accessibility features:** accessible parking/garage areas, no-step entryways, widened doorways, lowered kitchen and bathroom sinks.

For more ideas on home accessibility check out the [Universal Home Design booklet](#) from the Iowa Program for Assistive Technology.

### Compass Can Help

Check out Iowa Compass' tip sheet on [our website](#) or give us a call at 800-779-2001 for more details. Iowa Compass has information about financial assistance programs, as well as laws that ensure people with disabilities have access to housing.

# CenterLines

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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](http://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 and adult development, issues affecting

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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.