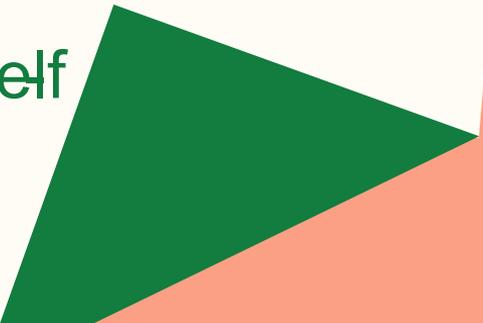


Women's Health Guide for Women with IDD

Supporting Health, Dignity, and Self
Advocacy



Meet Today's Team



Whit Downing, VP of Policy
and Programming, Self -
Advocate



Allyson McCain, Deputy
Director and Health Equity
and Outcomes Director



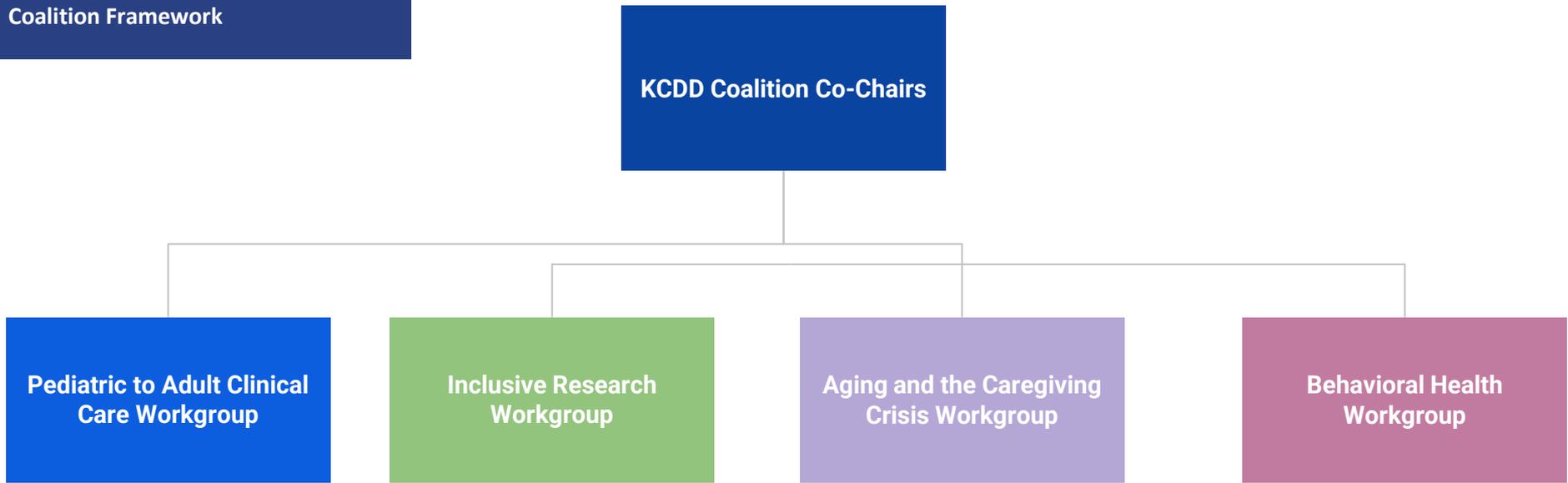
Lola Kernell, Advocacy
Coordinator, Self -
Advocate

Our Mission: Empower individuals with intellectual and developmental disabilities (I/DD), families and caregivers to lead systems change, build capacity, and advocate for inclusive, integrated, accessible communities where everyone belongs and thrives throughout Kansas.

Our Vision: We envision a state where all people with intellectual and developmental disabilities live, learn, work, play, belong, and thrive in the community they choose.

Our Purpose: The purpose of KCDD is to support people of all ages with developmental disabilities so they have the opportunity to make choices regarding both their participation in society and their quality of life.





FRAMEWORK

1. Create working groups focused on each of the stated goals.
2. Within each group, undertake an assessment of progress, gaps, and opportunities for advancing health equity for people with IDD in Kansas.
3. Develop an outreach, education, advocacy and public policy strategy that seeks to address the recommended outcomes in a meaningful way.

Coalition Members

Advent Health
Aetna Better Health
Alliance Rehab and Medical Equipment
Amgen
Assured Trust Company
Autism Society - The Heartland
Bert Nash Center
CareSource
Catholic Charities KC-SJ
Children's Mercy Hospital Kansas City
Community Health Council of Wyandotte
Developmental Services of Northwest Kansas, Inc. (DSNWK)
Down Syndrome Innovations
The Golden Scoop
Institute for Advancing Medical Innovation
Johnson County Developmental Supports
Kansas Center for Autism Research and Training
Kansas City Hospice & Palliative Care
Kansas Department for Children and Families
Kansas Family Support Center
Kansas LEND, University of Kansas Medical Center
Kansas State Physician Assistance Program
KU Center on Developmental Disabilities

KUMC Girls Night Out Program
L'Arche Heartland
Onward Kansans
Optum Care
Oral Health Kansas, Inc.
Raise Health Innovations
Rush University Dept of Community,
Systems and Mental Health Nursing
and PATHPWIDD
Sedgwick County Department of Aging
and Disabilities
Sedgwick County Developmental
Disability Organization
Special Needs Assured
Special Olympics Kansas
Sunflower health plan
UnitedHealthcare Community Plan of
Kansas
University of Kansas Medical Center
(UKMC)
University of Kansas School of Nursing
We Care and Connect
Whole Story Planning

Our Lived Experience Matters

Personal



Professional

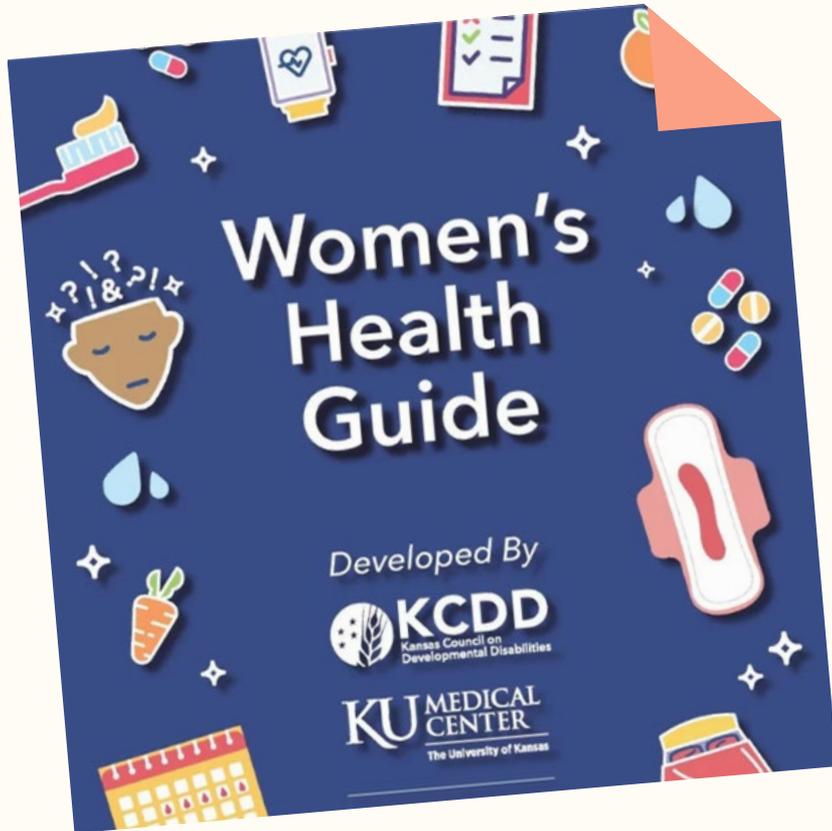


What is the Women's Health Guide?

We made this guide with help from women with IDD, doctors, and health experts from across Kansas.

It has easy-to-understand tips about eating healthy, taking care of your body, visiting the doctor, staying well, and more.

The information comes from real experiences and advice from people who care about good, fair healthcare for everyone.



Why This Guide Was Created



Information often isn't accessible



Women with IDD are left out of health education



Too many decisions made about us, not with us



So, Why This Webinar?



Women with IDD face health disparities



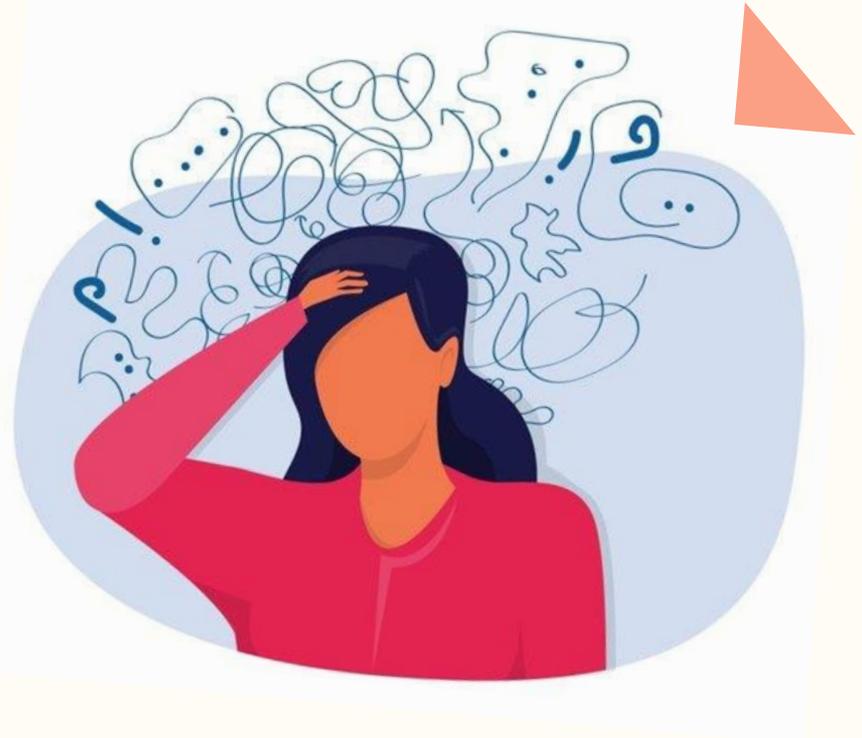
Healthcare can be confusing, overwhelming, or inaccessible



Everyone has a role to play



What's one challenge
you've seen women
with IDD face in
healthcare?



The Guide Has SIX Sections...



Women's Health Guide

- Women's Healthcare Overview and Standards of Care
- What to Expect During a Doctor's Appointment
- Staying Healthy, Eating Right, and Wellness
- Reproductive Health and Preventable Cancer Screenings
- Requesting Accommodations During Exams & Doctor's Visits for Self-Advocates & Caregivers
- Annual Checklist

Women's Healthcare Basics



What is Healthcare?

Healthcare is the help you get to stay healthy, feel good, and take care of your body and mind.

It includes things like going to the doctor, taking medicine, getting shots, having your eyes or teeth checked, and learning how to eat healthy food or exercise.

Healthcare helps you feel better when you are sick and stay well when you are not sick.

Women with intellectual and developmental disabilities have the same health needs as all women.

But sometimes, they don't get the care they need.



What to Expect at the Doctor



➤ Before, During, and After Appointments

Not knowing what will happen can be terrifying. This part breaks visits into steps and explains medical words that doctors often forget to explain.





KCDD

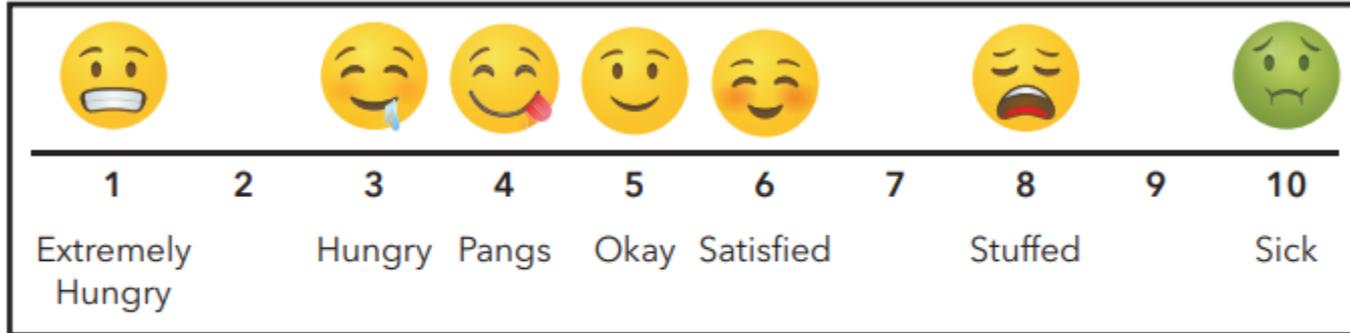
Kansas Council on
Developmental Disabilities

What about going to
the doctor could make
women with IDD feel
nervous or scared?



Staying Healthy, Eating Right, and Wellness

→ This section is FULL of visuals!



Make sure to listen to what your body is telling you. If your stomach is growling or feels empty, you may be hungry and need to eat. If you feel full your body is telling you it has had enough food for now.

Visuals Cont'd



What are realistic wellness goals for you or for someone you know with IDD?



Reproductive Health and Preventable Cancer Screenings

This section can feel uncomfortable, but it's necessary. Women with IDD deserve accurate, respectful information about their bodies. Avoiding these topics doesn't protect us... it leaves us vulnerable.





KCDD
Kansas Council on
Developmental Disabilities

72%

Women with IDD have been found to be about 72% less likely than women without disabilities to receive cervical cancer screening.

Social Story: How to Change Your Pad

1



Sit on the toilet

6



Pee or poop if you need to

2



Take dirty pad out of underwear

7



Wipe

3



Throw away dirty pad

8



Pull clothes up

4



Open new pad

9



Wash your hands

5



Stick the pad onto clean underwear

10



Ask for help if you need it

DISCHARGE COLORS and what they might mean



Clear / watery
This is normal. It can change during your cycle.



White
Usually healthy, but if it looks thick and clumpy, it might mean infection.



Gray
This could mean a bacterial infection and might have a strong smell.



Red
Usually blood from your period. It can also mean spotting or, sometimes, a miscarriage.



Brown
Old blood from your period or spotting. In pregnancy, it might mean labor is coming soon.



Pink
Fresh blood or spotting. It can also happen if the cervix or vagina gets irritated.



Green
Might mean an infection, like an STI or UTI. You may notice a different smell.



Yellow
Can be blood mixed with mucus. If it looks greenish, it could mean an infection like PID or an STI.

Requesting Accommodations

This section is about power. It teaches women they are allowed to ask for what they need, and that accommodations are a right, not a favor.

- Asking for Support
- Sensory Accommodations
- Bringing Support People



How the Guide can be Used for:

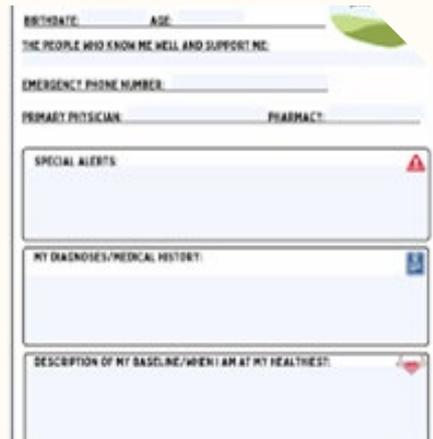
Pre-Appointment Prep

02. What to Expect During Doctor Exams

REVIEW CHAPTER 2 OF THE
GUIDE



ROLEPLAY QUESTIONS DR.S
MAY ASK



BIRTHDATE: _____ AGE: _____

THE PEOPLE WHO KNOW ME WELL AND SUPPORT ME: _____

EMERGENCY PHONE NUMBER: _____

PRIMARY PHYSICIAN: _____ PHARMACY: _____

SPECIAL ALERTS: _____

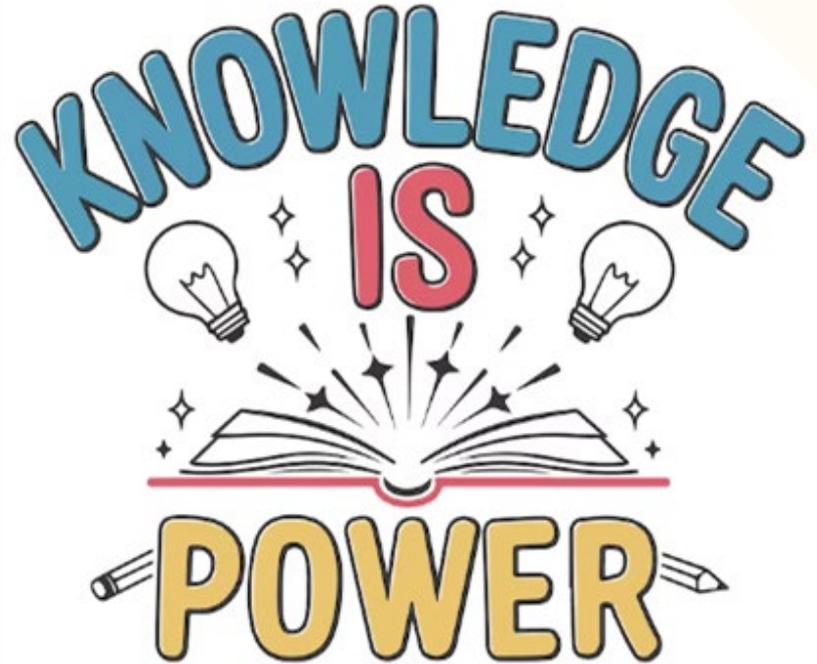
MY DIAGNOSES/MEDICAL HISTORY: _____

DESCRIPTION OF MY BASELINE/WHEN I AM AT MY HEALTHIEST: _____

FILL OUT 'MY HEALTH
JOURNAL' FOUND IN THE
BACK OF THE GUIDE

How the Guide can be Used as a Teaching Tool

- Review Chapter 3: Staying Healthy, Eating Right, Wellness
- Review Chapter 4: Reproductive Health
- Go over the chapter on preventive cancer screenings
- Review the Annual Checklist



How the Guide Can be Used for: Advocacy Support

Chapter 6: Requesting Accommodations During Exams

- Teach them to lead their own care
- Discuss finding resources and support

Small Group Activities with the Guide:

- Role-play different scenarios talked about in the Guide
- Help clients come up with questions for their doctor

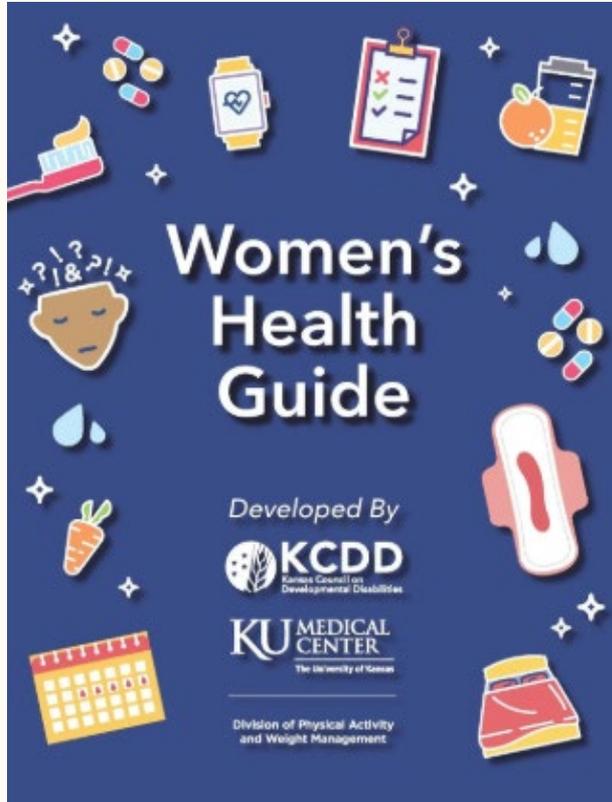


This guide can be used in pieces. You don't have to go cover-to-cover. Use the section that matches the need in front of you.

Key Takeaways



- **Lived experience matters**
- **Plain language is powerful**
- **Healthcare should be respectful**



This guide is about dignity. Women with IDD deserve care that is kind, clear, and respectful... just like anyone else.

How the guide and it's creation has impacted Whit and Lola!



“Whit, I don’t know what your experience with healthcare and doctors has been like until now; I am here to listen and give you the best care.”- **Dr. Laura Gaffney, SPAN Clinic, Advent Health**

**“You can’t go
back and change
the beginning,
but you can start
where you are
and change the
ending.”**

- C.S. LEWIS

Questions

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Answers

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Contact



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