



**Sooner SUCCESS:
Helping families impacted by disability
and their providers navigate complex
systems.**

WHO WE SERVE

Serve families with children
birth to 21

- Developmental Disabilities
- Chronic/Special Health Care Needs
- Mental/Behavioral Health Needs
- Abuse/Neglect Issues

No Income guidelines

No “qualifying
criteria”

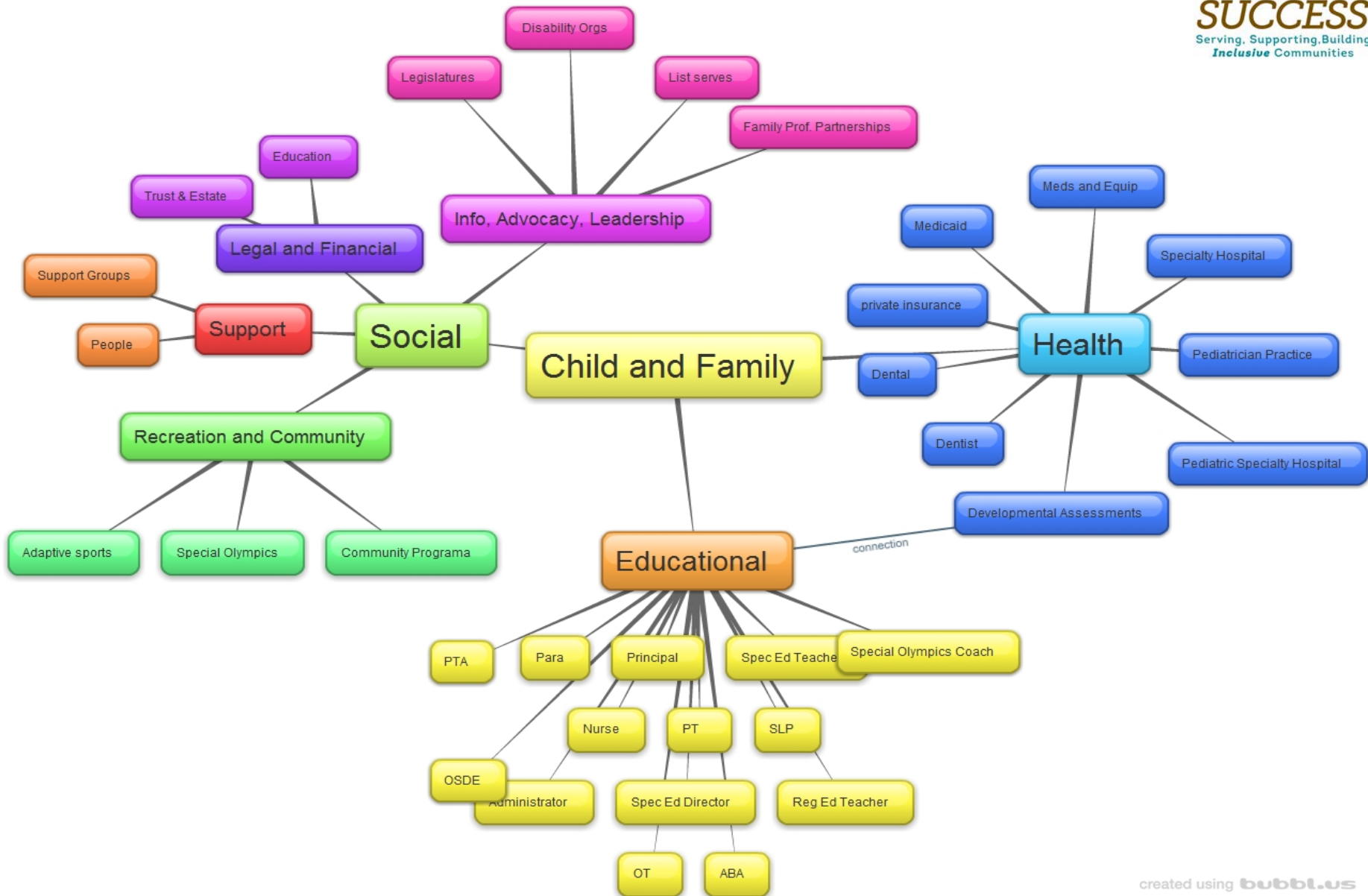
No application
process

No cost

Families impacted by disability:

- ***often need multiple services from multiple providers***
- ***are overwhelmed and are frequently the only “coordinator” of their child’s services***
- ***have difficulty locating needed services in their community***
- ***must travel to several agencies while struggling with unreliable transportation, child care, illness and other challenges***

CARE MAP



SOONER SUCCESS

How can we help you as a
professional and for the
families you serve?

HOW SOONER SUCCESS CAN HELP

- A single point of contact @ **405-271-2710**
- We will listen and offer **emotional support**.
- We connect families with **experienced providers**
- **We do research** for families and providers who don't have time to do it themselves
- We give **resource information to providers** so that they can more effectively help families

HOW WE HELP

- We bring **training and information** into communities
- We host and participate in **community events to encourage networking** among service providers.
- We **identify service gaps and develop capacity** within communities to help closed identified gaps.

“You have been a really big help to me. I just **don’t have the time** to do the leg work it takes to find the information about services for my daughter. As a single parent I must work and take care of her needs as well as the needs of other family members. I feel that I **have an assistant in this unique and difficult journey of navigating** the government and non-profit agencies that are designed to help improve the quality of life for my daughter. Thank you for all you do.”

-Parent Quote



SOONER SUCCESS



Where is Sooner SUCCESS
located in Oklahoma?

SOONER SUCCESS COUNTIES



REGION 1:

REGION 2:

Region 3:

Region 4:

- Blaine
- Canadian
- Kingfisher
- Garfield
- Major

- Tulsa
- Creek
- Rogers
- Delaware
- Mayes

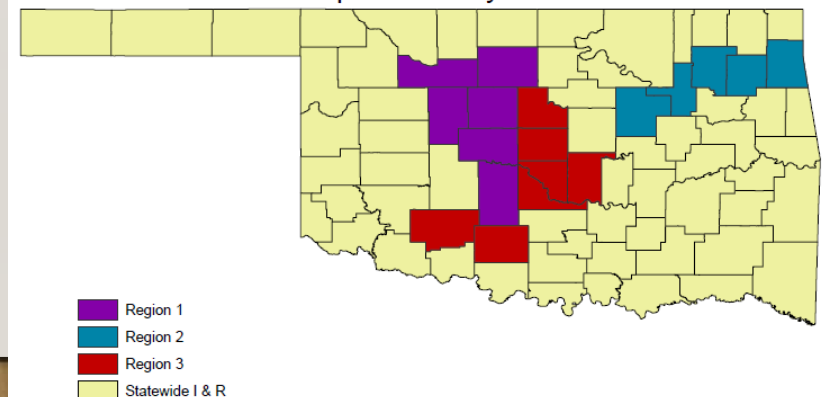
- Pottawatomie
- Oklahoma
- Logan
- Lincoln

- Cleveland
- McClain
- Comanche
- Stephens

405-271-2710

soonersuccess.ouhsc.edu

Statewide services provided by Sooner SUCCESS



FOR HISPANIC FAMILIES IMPACTED BY DISABILITY

- **Oklahoma County/Bilingual Coordinator**
- **Ana Salas-Ocampo**
- 405-534-8000
- ana-salasocampo@ouhsc.edu
- Support group for parents that meets monthly via zoom

Referral Process

- Direct referral to coordinator from family or service provider.
 - Service Providers can call us and relay information back to family.
-

Common requests

- Diagnosis is new, terms can be confusing; families need guidance through process.
- “Triage” families – family is overwhelmed and not sure what will help
- Community Programs and Parent Support Groups – not sure what’s out there
- Help to navigate eligibility and benefits (Soonercare, SSI, DDS)
- Respite – which program fits?
- Physician Referral – who understands?
- Individual Education Program (IEP) Assistance

RESPITE:



WHO IS A CAREGIVER?

For our purposes, a caregiver is an unpaid individual who provides ongoing care for someone with a chronic health condition or a disability.

- Parent of a child with special needs
- Grandparent or other relative raising a child
- Spouse/Partner
- Friend/Neighbor
- Adult Sibling
- Child caring for parent

Quotes from Caregivers



“Care for my child with special needs is 24/7. I just need a break every once in awhile.”

“I feel like a person on a bungee cord, constantly being yanked back. I have little to no life and feel edgy and anxious all the time now. I now have high blood pressure.”

“I am raising my grandchild and caring for my mother. Everyday brings a new challenge. Caregiving is the most important job I have ever had.”

WE CAN HELP!

- Lifespan Respite Grant Voucher Program can help Oklahoma's caregivers \$300 to be used within 3 months;
- Educational Vouchers: Caregivers attending an educational event/conference \$100 full day voucher or a one time \$50 half day voucher.
- Emergency Vouchers available. Examples, surgery or funeral. A one time \$250 voucher is available to eligible caregivers.

Eligibility for caregiver:

- Is 18 or older, full-time, unpaid
- Is a grandparent or other relative age 54 or younger raising a child
- No household income restriction
- Does not receive respite services or payments from other programs including, but not limited to foster care, Family Support Assistance Payment, OAA Title III-E, ODMHSAS Systems of Care funding, or a DHS Child Care Subsidy.

Need a Break?

Respite services can provide a much-needed, temporary break from the often exhausting challenges faced by family caregivers. Respite vouchers let caregivers hire another person (respite provider) to temporarily care for their loved ones.



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For more information:

Robyn Boswell

405-271-5700 x47801

respite@ouhsc.edu

Where can respite care happen?

Respite care can be provided in the caregiver's home, someone else's home, a center-based program or care center, such as an adult day services center or nursing facility, as long as agreed to by the caregiver and respite care provider.

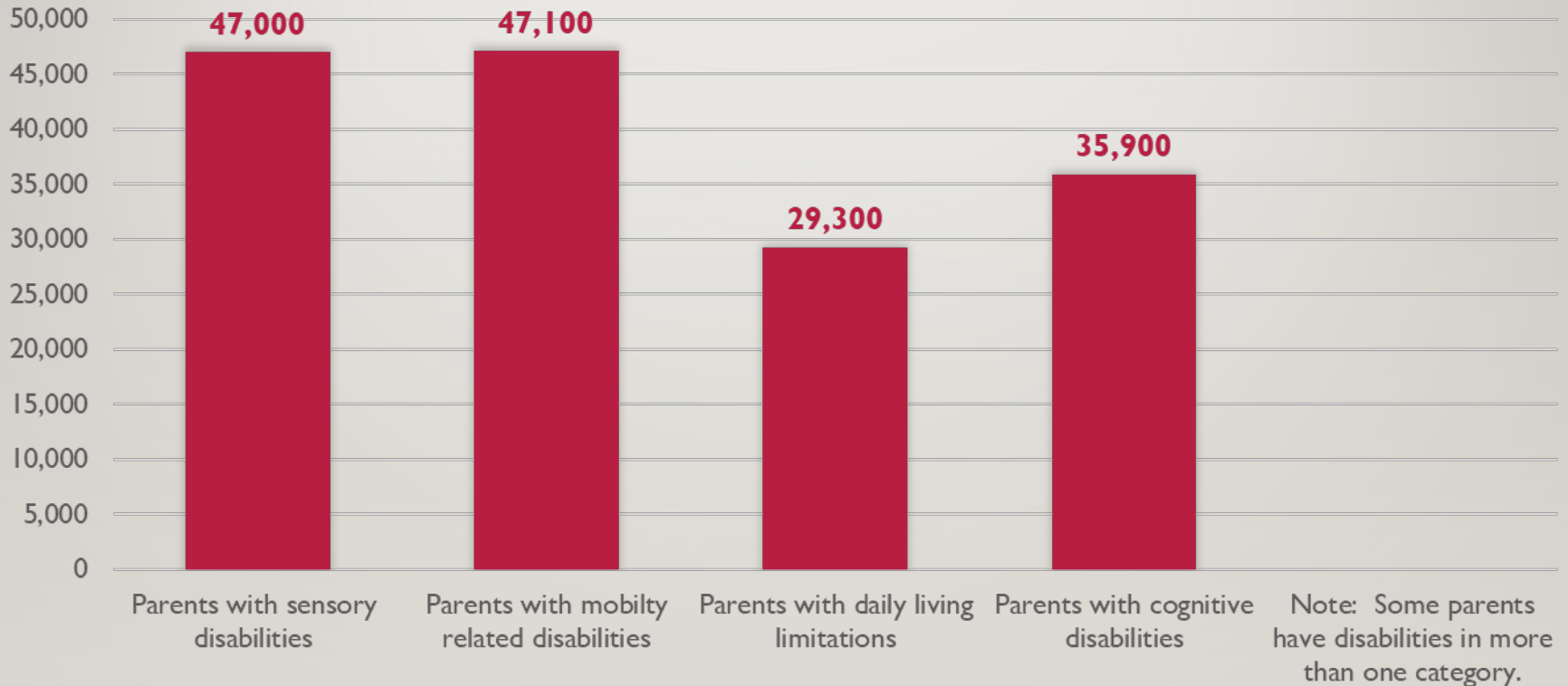
Covid-19 adjustments through September 30, 2020

- Increase the current voucher amount from \$300 to \$400
- Respite provider must be 18 or older, can live with caregiver and care receiver
- Lift household income restriction from \$90K to no household income

SUPPORTING OKLAHOMA PARENTS WITH DISABILITIES



How many parents in Oklahoma have a disability?



Source: Kaye, H. Steven. Current Demographics of Parents with Disabilities in the U.S. Berkeley, CA: Through the Looking Glass, 2012 (Oklahoma data is from 2008-2009)

BARRIERS TO HEALTHCARE CAN BE:

- physical
- architectural,
- communicative,
- attitudinal,
- social/economical

SURVEY RESULTS



ACCESS TO MEDICAL CARE FOR INDIVIDUALS WITH MOBILITY DISABILITIES

Guidance to make sure your facilities and practices comply with the Americans with Disabilities Act

https://www.ada.gov/mcdcare_ta.htm



IDENTIFICATION – EQUIPMENT



IDENTIFICATION: PHYSICAL APPEARANCE OR COMMONLY KNOWN DIAGNOSIS



IDENTIFICATION: NON-PHYSICAL APPEARANCE: LEARNING DISABILITY, TRAUMATIC BRAIN INJURY, MENTAL HEALTH



BEHAVIORAL **RED FLAGS** OF LEARNING DIFFICULTY

- Missed appointments
- Disorganization
- Poor judgement
- Sequencing difficulty
- Problems understanding time
- No follow through when they seem to understand
- Short/long term memory issues
- Performance fear
- Attention issues
- Not wanting to get down on the floor with their child or appear to play/be silly
- Difficulty generalizing information
- Rigidity
- Child has frequent or chronic health problems
- Competing with child for attention or toys

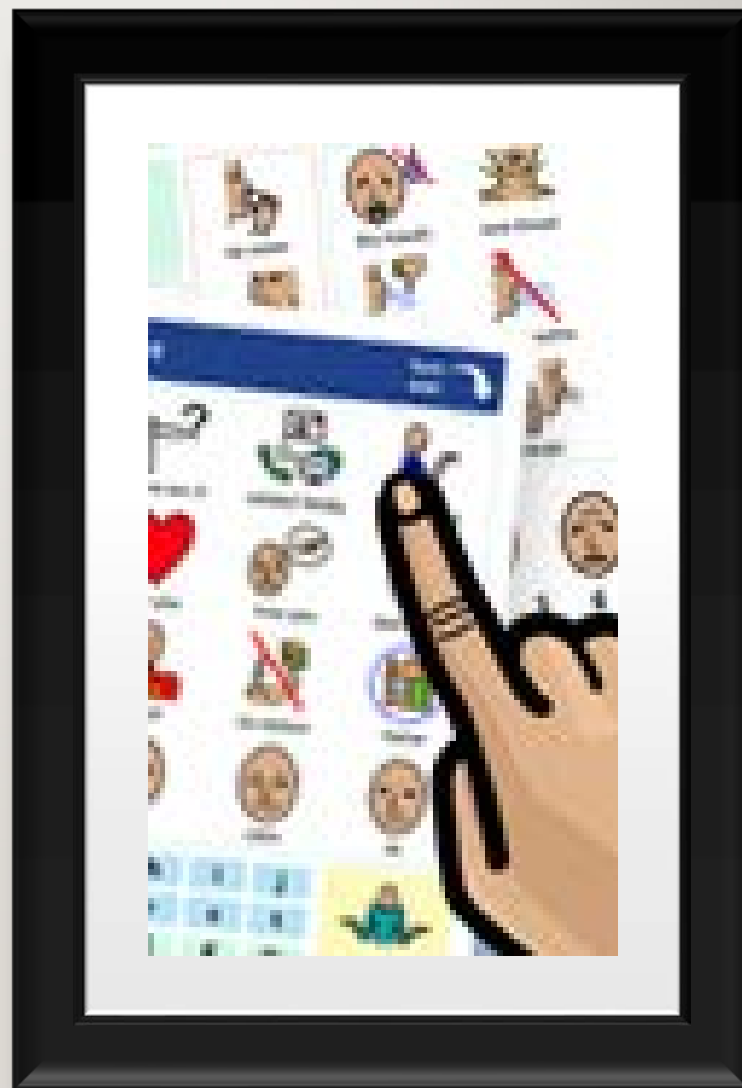
GENERAL COMMUNICATION TIPS

- Person first, not the disability
- Introduce yourself and offer a handshake. People with limited hand use or wear an artificial limb usually can shake hands. The person will often tell you if they are not able to shake hands for some reason.
- Always ask before providing assistance - wait until the offer is accepted.
- Speak directly to the person and not their attendant, interpreter, family member, etc.
- Do not pet service animals without checking with the owner first.
- Ask questions if you are unsure how to proceed or what to do next.

COMMUNICATION BOARDS FOR MEDICAL SITUATIONS

[HTTPS://WIGIT-HEALTH.COM/DOWNLOADS/FOR-PROFESSIONALS.HTM](https://wigit-health.com/downloads/for-professionals.htm)

- Communication boards to assist with:
- COVID appointments
- Routine medical encounters
- Accident & Emergency appointments
- Dental procedures
- Hospital procedures
- Eye issues
- Diabetes appointments



THE HOSPITAL COMMUNICATION BOOK

The book contains useful information about why people may have difficulties understanding or communicating. It has useful tips you can use to improve communication, and pages of pictures you can use to help you communicate with individuals who have disabilities

<http://www.surreyhealthaction.org/going-to-hospital-section/the-hospital-communication-book.html>



TIPS FOR NURSES

- **Effective communication may require adaptation** – interpreter, plain language, pictures/visuals
- **Even if you are treating the child, consider the parent's disability** – talking thermometer, cry signals; marked med cups
- **Your role may be resource and referral** – adaptive baby care equipment, home visitation services
- **Don't make assumptions** – Assumptions leave families at risk. Success is possible, support is usually necessary. Start there and ask questions.

ACCESSIBILITY - HEARING DISABILITIES

- Tap on the shoulder or wave your hand to get their attention
- **Ask** how they want to communicate – sign language, lip reading, writing notes, communication boards, etc.
- Face and speak directly to the person & use short, direct sentences.
- Rephrase rather than repeat sentences a person doesn't understand
- Hire certified American Sign Language interpreters if required—do not rely on family members as interpreters

BE PATIENT WITH YOURSELF AND THE PARENT

- Keep your face in the **light**.
- Speak **slower** if you tend to talk fast.
- Keep sentences **short** and simple.
- Give **specific** directions (time, place, med/instructions, addresses, phone numbers) in writing.
- **Eliminate interruptions** as much as possible, explain if necessary.
- Keep pen and paper handy.
- When in groups, **sit in a circle and speak I at a time**.

Area most likely to need support:

Communication



Find a sign language interpreters at:

<https://okrid.org/resources/>

If they need assistive devices, contact Deaf and Hard of Hearing Services thru DRS - <http://www.okdrs.gov/independence/deaf>

DeafDoc provides clear and concise health education in American Sign Language to promote the overall wellness of the Deaf & Hard of Hearing community.

<http://deafdoc.org/video-dictionary/medical-video-dictionary/>

Improving Communication access for individuals who are deaf and hard of hearing

<https://www.cms.gov/files/document/audio-sensory-disabilities-brochure-508c.pdf>

ACCESSIBILITY - INTELLECTUAL DISABILITIES

- Get their attention before speaking and focus on 1 thing at a time.
- Provide information in plain language (3rd or 4th grade level)
- Ask the individual to repeat the information they've received in their own words to be sure it was understood
- Never pretend to understand what a person says—ask them to repeat it slowly
- Be alert for the “smile & nod” response
- Reinforce words with visuals – pictures, videos, etc. and repetition

BE PATIENT - ALLOW PLENTY OF TIME TO RESPOND

- **Do things together** – make appointments, enroll, fill out paperwork
- Don't just give an assignment – walk through **all the steps**.
- Give specific directions (time, place, addresses, phone numbers) in writing – to them AND their **driver** if they use one.
- Don't ask yes/no questions, use **open ended** questions, have them give you an example.
- **Praise!** Tell them all the things they are doing right!!
- **Build rapport** so they will be honest about their barriers.



Getting Ready for School



Wake Up



Get Dressed



Understood.org

<https://raisingchildren.net.au/toddlers/parenting-in-pictures>



Area most likely to need support: **Communication, Organization, and educational pacing**

So, You are Going to Have a Baby: A Guide for Women with Developmental Disabilities”

https://www.ucucedd.org/wp-content/uploads/2018/10/A-Guide-for-Women-with-Developmental-Disabilities-to-Prepare-for-Pregnancy_UCCEDD.pdf

Providing Prenatal Care for Women with Developmental Disabilities

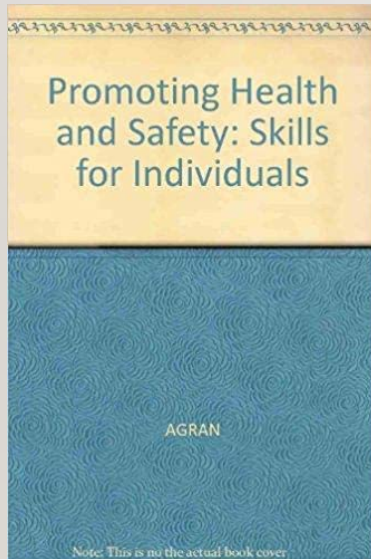
https://www.ucucedd.org/wp-content/uploads/2018/10/Providing-Prenatal-Care-for-Women-with-Developmental-Disabilities_UCCEDD.pdf

Communicating medication instructions through pictogram –The USP Pictogram Library provides standardized images to convey medication instructions, precautions, and/or warnings to patients and consumers. Pictograms are particularly helpful in passing on important information to patients with a lower level reading ability and patients who use English as a second language. Available free-of-charge to professionals and patient information providers to reinforce printed or oral instructions.

<https://www.usp.org/download-pictograms>

PREPARING FOR EMERGENCIES

PROMOTING HEALTH AND SAFETY: SKILLS FOR INDEPENDENT LIVING



<https://www.amazon.com/Promoting-Health-Safety-Skills-Independent/dp/1557661359>

FIRST AID AND DISASTER SAFETY FOR PEOPLE WITH SPECIAL NEEDS

- First Aid
- Fire Safety
- Natural Disaster Safety

<https://alertfind.com/first-aid-and-disaster-safety-for-people-with-special-needs/>

CLINICIAN RESOURCES

- Healthcare for adults with intellectual and developmental disabilities: a Toolkit for primary care providers

<https://inclusivehealth.specialolympics.org/resources/tools/idd-toolkit-for-primary-care-providers>

- Tools to Empower Clinicians and Women with Disabilities to Interact Effectively

This online toolkit is available for use by health educators, as well as clinicians and women with disabilities, to improve health care interactions.

<http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/WomensHealthDisability/Pages/CliniciansandWomenInteractions.aspx>

- Easy to Read Medline – Patient education materials

https://medlineplus.gov/all_easytoread.html

ACCESSIBILITY - PHYSICAL DISABILITIES

- A wheelchair = a person's personal space – ask before pushing or touching it
- Get on eye level with a person in a wheelchair to talk
- Keep walk ways and hall ways free of clutter and barriers

Adaptive Baby Care *for* Parents with Disabilities

ADAPTIVE BABY CARE (ABC) PROGRAM.

THIS INVENTORY IS NOW FOUND IN THE DEVICE REUTILIZATION PROGRAM INVENTORY.

ADAPTIVE BABY CARE INVENTORY LINK

[HTTPS://MYATPROGRAM.ORG/HOME/40](https://myatprogram.org/home/40)

PHONE: 405.523.4810 OR 833.431.9706

FAX: 405.523.4811

EMAIL: ATREUSE@OKSTATE.EDU

Equipment is for baby care tasks such as:

- Feeding
- Bathing
- Diapering
- Dressing
- Holding/Soothing
- Carrying
- Sleeping
- Health & Safety

Equipment can accommodate for challenges such as:

- Fatigue
- Hand weakness, pain, coordination, numbness
- Back Pain
- Shoulder weakness/decreased range of motion, pain
- Mobility
- Blind/low vision

- Rollator walker with a feeding seat attached.
- Useful for parents who have difficulty carrying their child
- Baby can be placed securely in the seat while parents use the walker for support as they walk.

- For newborn children, a rollator with a bouncy seat attached is available.

BABY CARE ROLLATOR – WITH FEEDING SEAT



DIGISCAN INFRARED TALKING THERMOMETER

- Helpful for parents with visual impairments
- Instantly speaks the temperature results
- Red indicator lights when a fever is detected
- May also be helpful for a parent with an intellectual disability



BABY CRY SIGNALER

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- Helpful for parents who are deaf or hearing impaired
 - Alerts parents to a baby's cry and can be adjusted to alert for quieter noises as well
 - Provides a signal that the parent can receive through visual or tactile senses



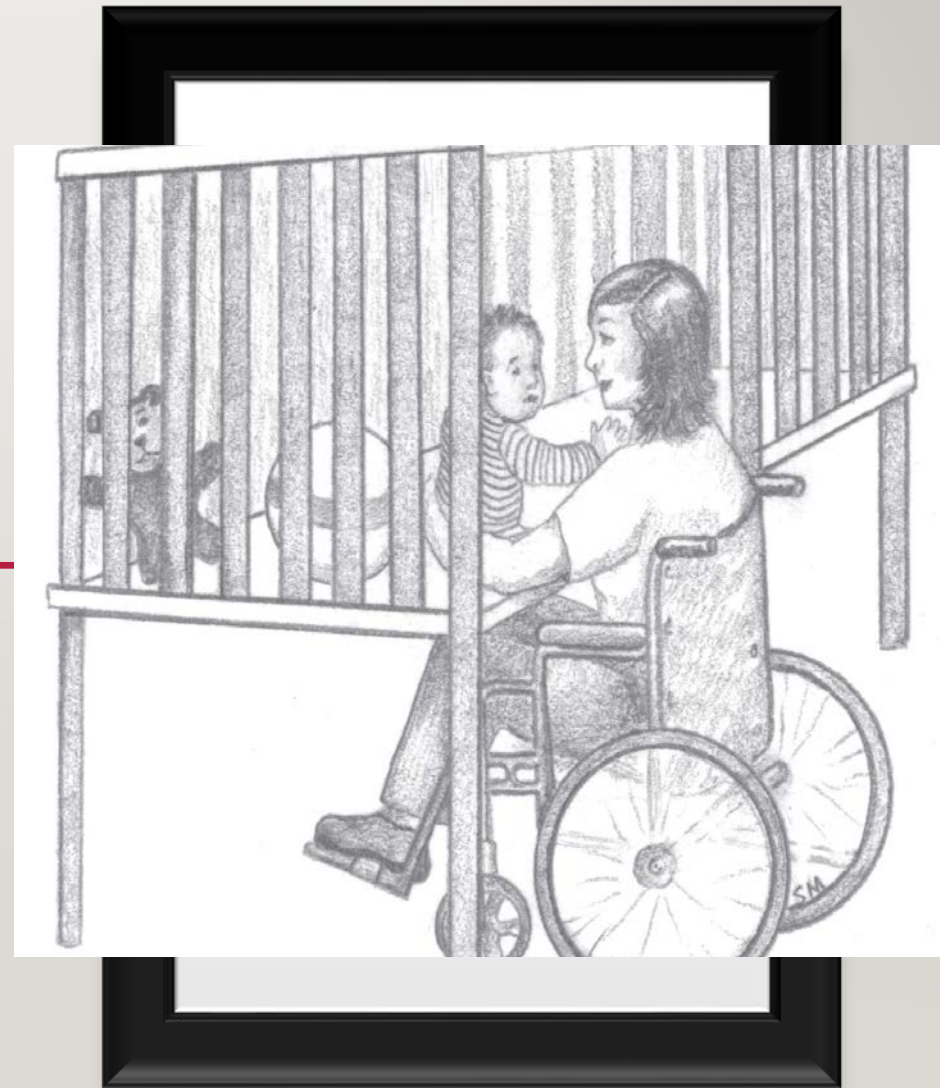
ADAPTED CHANGING TABLE

- A height-adjustable table to accommodate the need to sit while changing diapers.
- The storage compartment can be used to store diapering supplies or can be removed if it hinders parents from rolling a wheelchair up under it.



ADAPTED BABY CRIB

- Helpful for parents with decreased mobility and other physical limitations such as back pain.
- Crib is modified so that the front gate slides
- Height of crib is raised so that a parent in a wheelchair can roll directly to the edge of the crib and safely transfer an infant or toddler between the crib and their lap





Area most likely to need support: Navigating unfamiliar spaces, reaching objects, child safety

Facilitators and Barriers to Breastfeeding among Mothers with Physical Disabilities in the United States

<http://heller.brandeis.edu/parents-with-disabilities/pdfs/powell-breastfeeding-1.pdf>

Recommendations for Clinicians Working with Pregnant Women with Physical Disabilities
Recommendations for clinicians, all derived from research and first-hand experiences of women with disabilities affecting their mobility.

<http://heller.brandeis.edu/parents-with-disabilities/pdfs/smeltzer-for-clinicians-1.pdf>

Assistive Technology for Parents with Disabilities – Room by room

http://idahoat.org/Portals/60/Documents/Services/Resources/AT_ParentsHandbook.pdf

ACCESSIBILITY - VISUAL DISABILITIES

- Introduce yourself by name & role when approaching
- Ask if assistance is needed—offer your arm rather than taking theirs
- Don't touch a guide dog or can without the owner's permission
- Have large print format if needed
- Use Braille signage to the right of doorways
- Announce when you leave the room or someone else enters



Areas most likely to need support:

Navigating unfamiliar spaces; accessing adaptive equipment; safety

Parenting without Sight: What Attorneys, Social Workers, and Parents Should Know about Blindness

<https://nfb.org/Images/nfb/Publications/brochures/BlindParents/ParentingWithoutSight.html>

Oklahoma ABLE Tech - Toll Free: (888) 885-5588 or <http://okabletech.okstate.edu/>

Visually impaired parents raising sighted children

<http://www.vickieparkermft.com/viparents.php>

"Hands on Parenting: For Parents who are Blind or Partially Sighted" available at:

http://www.lookingglass.org/store/product_info.php?products_id=63&osCsid=df74ec1c60d3383382904d4e2d033be1

If parent does not already have access to a white can or guide dog, contact National Federation of the Blind or DRS visual services. <http://okrehab.org/job-seekers/sbvi>

ACCESSIBILITY - LEARNING DISABILITIES

KNOW:

- Areas of difficulty can include: Difficulty with reading, writing and/or math, poor memory, difficulty following directions, eye-hand coordination problems, difficulty putting things in the right sequence, disorganization and difficulty adjusting to change

DO:


- If you see behavioral indicators, ask if they have difficulty with certain skills (reading, writing, or math). If they acknowledge a LD, **ask what helps**.
- Give them an example with an offer to help “This document can be hard to understand, I’m happy to (read or point out) the things you need to do if that helps you.” (or **highlight**, **bold**, **enlarge**, separate list)

WORK SMARTER, NOT HARDER – TIME VS. TECH

- **Read up** on their specific type of learning disability and **learn how your approach or materials may need to be adapted.**

For example, for someone with dyslexia

- **Allow them to record** you on their phone as you read the intervention plan to them and discuss exactly what they need to do.
- Ask if any parenting education they need can be taught using “**easy read**” materials or computer **software that will read** the material to them.

The logo features a stylized spotlight with a grey body and a yellow beam of light. The text "Resource Spotlight" is written in black below the beam.

Area most likely to need support: Processing and organizing information (auditory, written, or numerical)

Learn about specific LDs. Each section provides signs and symptoms of the LD, as well as helpful strategies to engage with those impacted by the specific LD.

<https://ldaamerica.org/adults/>

Supporting parents with learning disabilities: Good practice guide
This guide pairs simple statements with supporting pictures – an example of how to make materials easier for parents with LD to understand.

http://www.changepeople.org/Change/media/Change-Media-Library/Project%20Media/CHANGE_good_practice_guidance_2006.pdf

ACCESSIBILITY - MENTAL HEALTH CONDITIONS

KNOW:

- The parent's condition **can change from day to day** due to not taking medication, medication side effects, emotional impact of trauma counseling, emotion impact due to lack of counseling, stresses of poverty.

DO:

- **Make sure mental health services are in place. Work cooperatively with that provider.**
- **Help the parent plan ahead.** Help the parent arrange for respite (back up childcare) for times when their mental health condition makes it impossible for them to parent.
- Make sure that not just the parent but also school age children and a **trusted adult nearby** know how to set the plan into motion.

PLAN FOR THE CRISIS

- Help them connect with NAMI or other mental health support groups.
- Help the **parent** connect with **natural supports** in their neighborhood, child's school or daycare, local parenting groups, their church. Help **kids** build their own natural support network. Everyone will need an ongoing network of support to be a successful.
- If the parent seems confused or overwhelmed, be willing to **break things down step-by-step** to help them understand what steps need to be completed.

How to help someone in crisis de-escalate

<https://www.nami.org/Blogs/NAMI-Blog/September-2017/How-to-Help-Someone-in-Crisis>

DON'T TAKE THINGS PERSONALLY. DON'T GET FRUSTRATED. BE PATIENT.

- **Respect a person's choice of language** or terminology. For example, if they ask you to refer to something as a “mental health condition” instead of a “mental illness”, listen to their request. If they say they don't have a mental health condition, but identify mental health treatment as a medical need, don't disagree. Just help them select a plan with appropriate treatment.
- If a parent brings an assistor, be sure to **speak directly to the person, not to the assistor**. They may be there for moral support or simply as a 2nd set of ears, so that important information is heard by more than just the parent and can be retained and acted on.



Areas most likely to need support:

Medication & household management, crisis planning

Webinar: Family Mental Health Begins with Parents

Covers different types of interventions for parents with mental illness and their families, the advantages of leveraging access to mainstream resources, and the need to enhance existing practices to make them parent-informed and family-focused.

<https://ensemble.brandeis.edu/hapi/v1/contents/permalinks/Mj2b6E7P/view>

Parenting with a mental illness: programs & resources

<http://www.tucollaborative.org/parenting/>

Navigating a Mental Health Crisis: A NAMI Resource Guide for Those Experiencing a Mental Health Emergency

https://www.nami.org/About-NAMI/Publications-Reports/Guides/Navigating-a-Mental-Health-Crisis?fbclid=IwAR0ACw_Qz_hb_2S-Xd6_ofW07TUKEG2CieYXma2xOSi6cBP30wIj6RBGgg0

INFORMATION FOR YOU, THE PARENTS, THEIR PROVIDERS & THEIR NATURAL SUPPORTS

- Resource guide for providers supporting parents with disabilities (LINK)

<http://soonersuccess.ouhsc.edu/ServicesPrograms/SupportingParentswithDisabilities.aspx>



Supporting Oklahoma Parents with Disabilities (LINK)

<https://www.facebook.com/OKpwd/>

ADVICE FOR PROFESSIONALS FROM MOTHERS WITH DISABILITIES

- *Don't ask [yes/no] questions about how we live. Ask how. 'How do you do X?' versus assuming we don't."*
- *"Presume competence."*
- *"Understand that there is a long history of mistrust (for good reason) and that you are working within that context."*

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- *“Listen to all of our concerns instead of being dismissive, disabled moms often have heightened sensitivity levels.”*
 - *“Keep an open mind and help find resources instead of assuming [disabled mothers] can't do things.”*

Source: National Research Center for Parents with Disabilities, 2017. www.centerforparentswithdisabilities.org

QUESTIONS?

Lisa Simmons

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Region I Sooner SUCCESS Coordinator

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580-747-1004



**Call our statewide helpline at:
405-271-2710**

or visit our website:

<http://soonersuccess.ouhsc.edu/>

Information and Resource Specialist on staff that will assist families and providers