

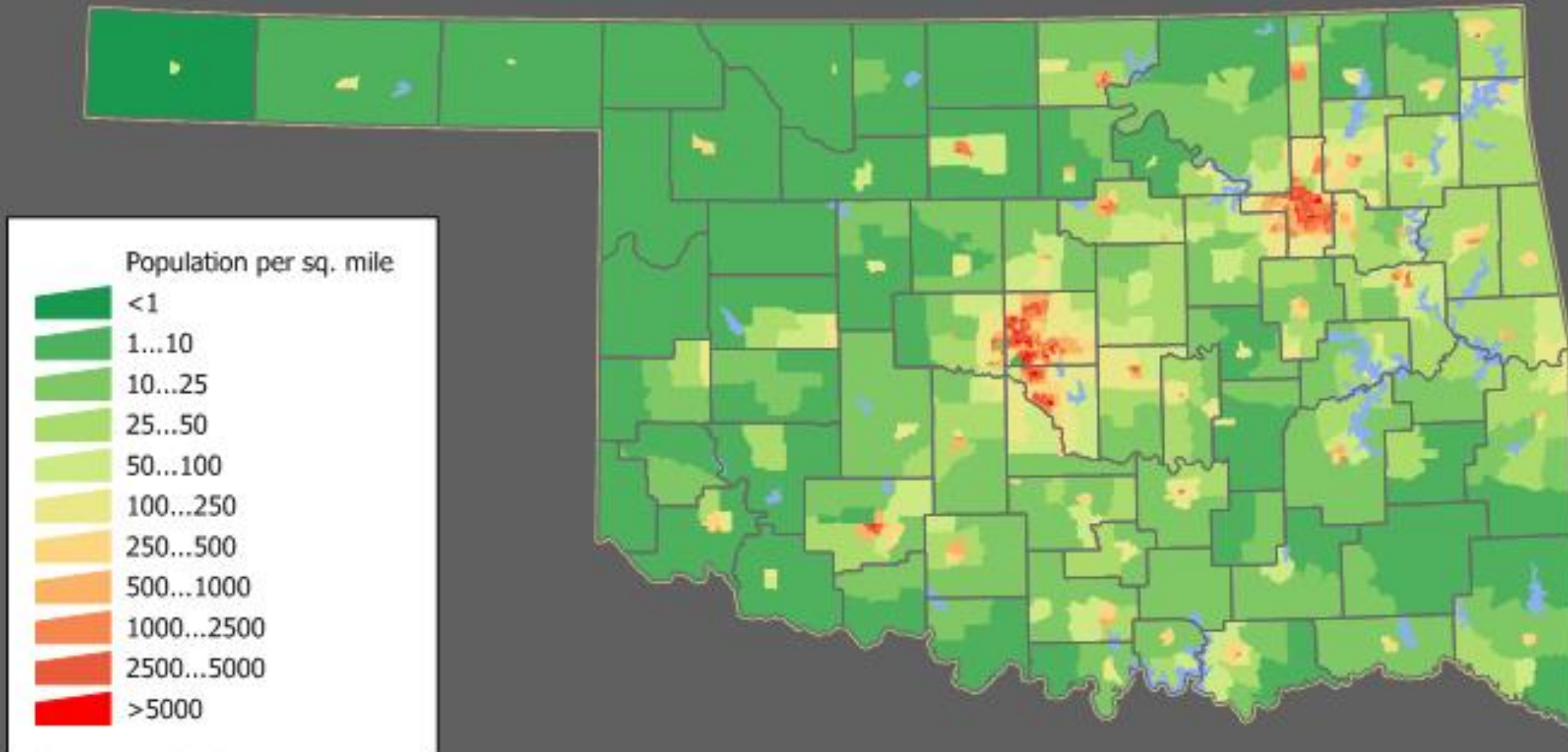
Supporting Oklahoma Parents with Disabilities: *the Oklahoma Model*



Developmental Disabilities
Council of Oklahoma

*Major funding for this project provided by the Developmental Disabilities Council of Oklahoma

Oklahoma: 69,960 square mile, 2 major cities



Source: U.S. Census Bureau
Census 2010 Summary File 1
population by census tract

How many Oklahomans with disabilities are current parents

▶ Total: 96,800

*** Some parents fall into more than one category.*

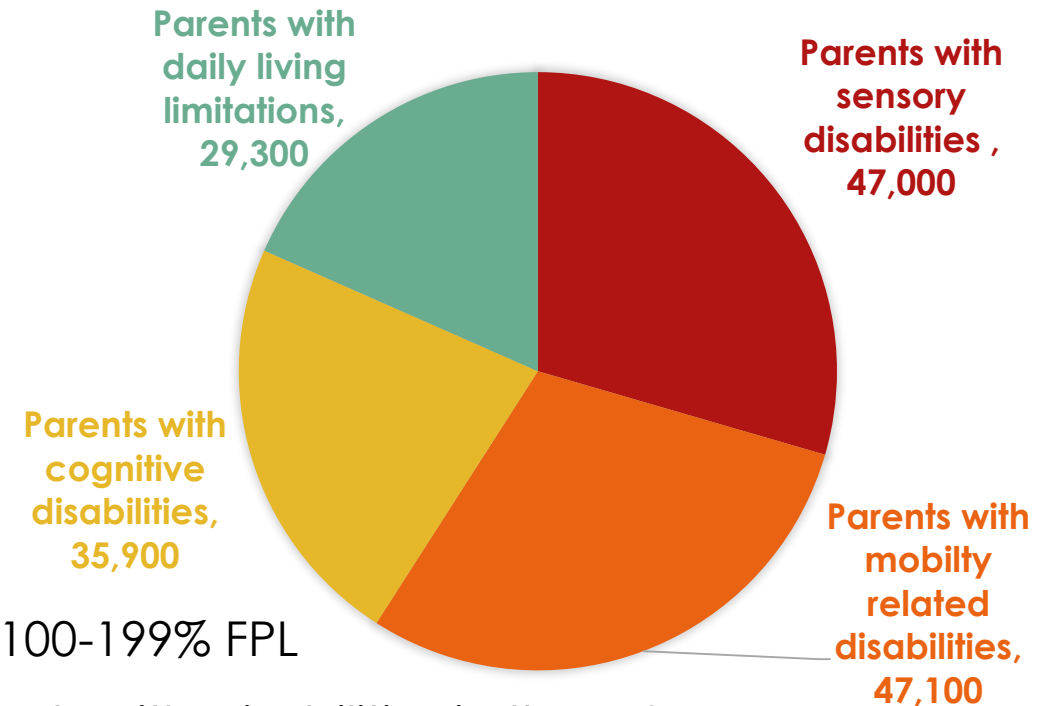
▶ 2/3rd are married and living with their spouse or partner

▶ Most frequent ethnicity: White (78,200)

▶ Only 13,100 are receiving SSI

▶ 1/3 live below federal poverty level; another 1/3 live 100-199% FPL

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)



What we thought we were going to do:

- ▶ Build awareness (how to identify)
- ▶ Build empathy (challenges they face)
- ▶ Build knowledge (rights under the ADA)
- ▶ Face reality (no \$\$/no hand off)



**Put a spotlight
on the needs
& rights of
Parents with
Disabilities**

Year 1: Starting the conversation

Educating ourselves:

- ▶ A visit to Through the Looking Glass
- ▶ The 2015 TASP conference in Memphis
- ▶ Training on Person Centered Thinking
- ▶ Interviewing self-advocates
- ▶ RESEARCH

Our first goal: Awareness & Education

Solution:

Bring TLG staff to Oklahoma to train our professionals

- ▶ 2 days in northern Oklahoma
- ▶ 2 days in southern Oklahoma
- ▶ General provider track
- ▶ Specific OT track - *Baby Care Assessment & Intervention for Parents with Physical Disabilities*

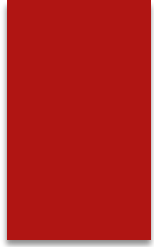
June, 2016 – TLG training =200 attendees

Who did we invite:

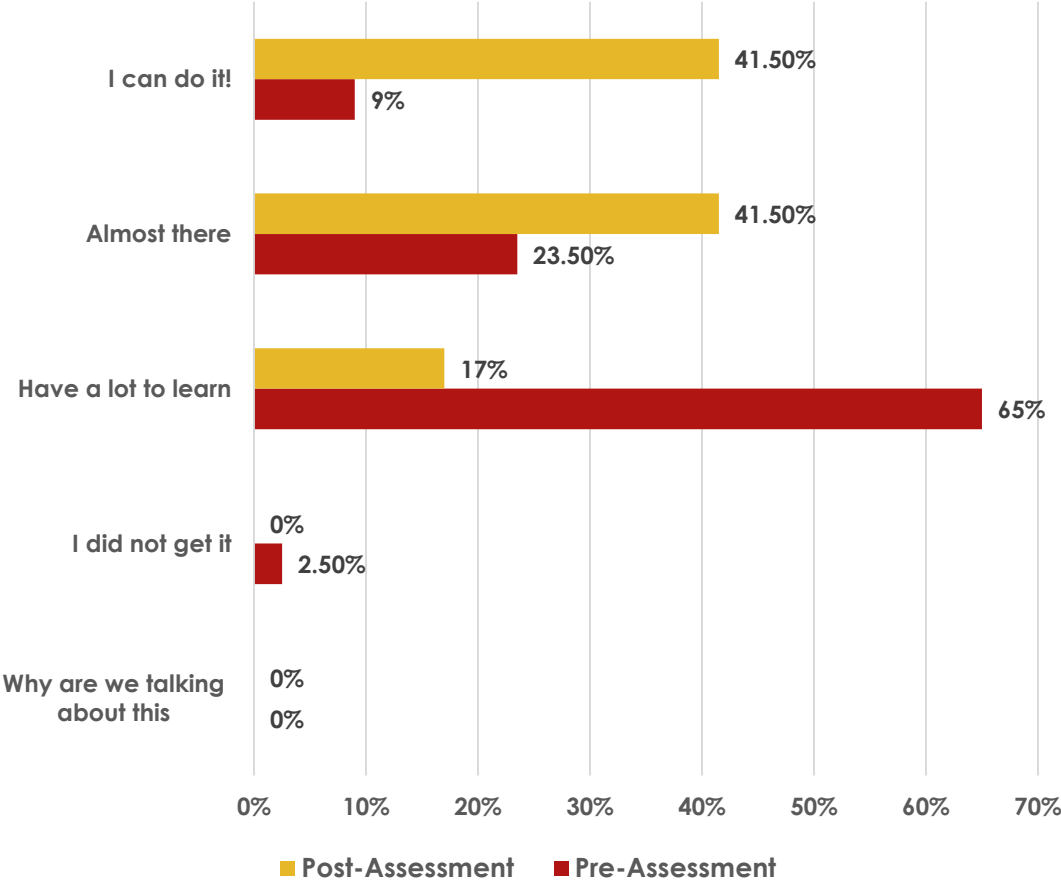
- ▶ Parent educators
- ▶ Child Welfare
- ▶ Independent living center staff
- ▶ Family court and legal service staff
- ▶ Community resource and referral staff
- ▶ Native community members
- ▶ Healthcare providers
- ▶ Behavioral health providers
- ▶ Therapy services (OT, PT, SLP) – specifically OTs with an interest in supporting physical disabilities
- ▶ Oklahoma ABLE Tech staff

What did we cover:

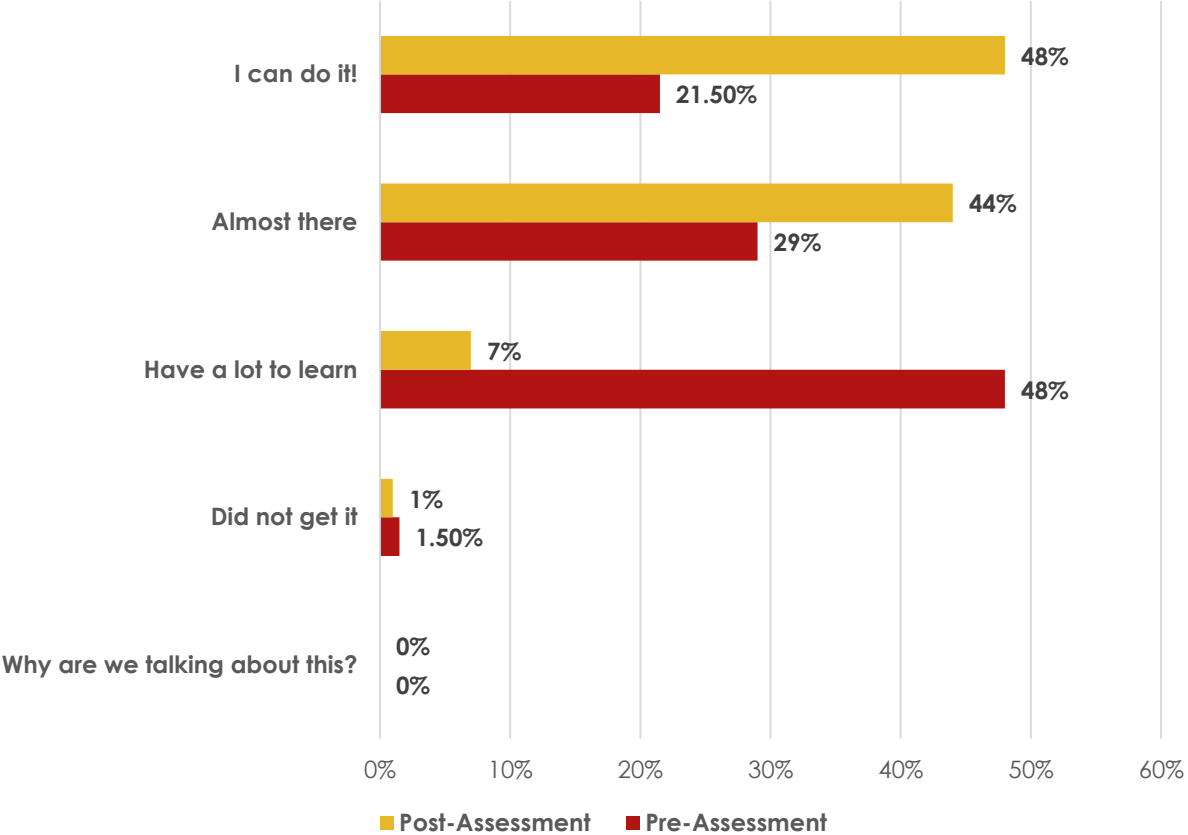
- ▶ Disability Culture
- ▶ Legal implications for professionals.
- ▶ Supporting parents with physical disabilities.
- ▶ Supporting parents with cognitive disabilities.
- ▶ Person-Centered Thinking with families.
- ▶ Family trauma and infant removal.
- ▶ Supporting parents with disabilities in Native American communities.
- ▶ Effective collaboration with school staff.
- ▶ Adapting Child Welfare Practice
- ▶ Designing a support group for parents with intellectual disabilities

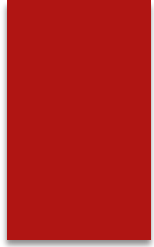


Recognizing Barriers Faced by Parents

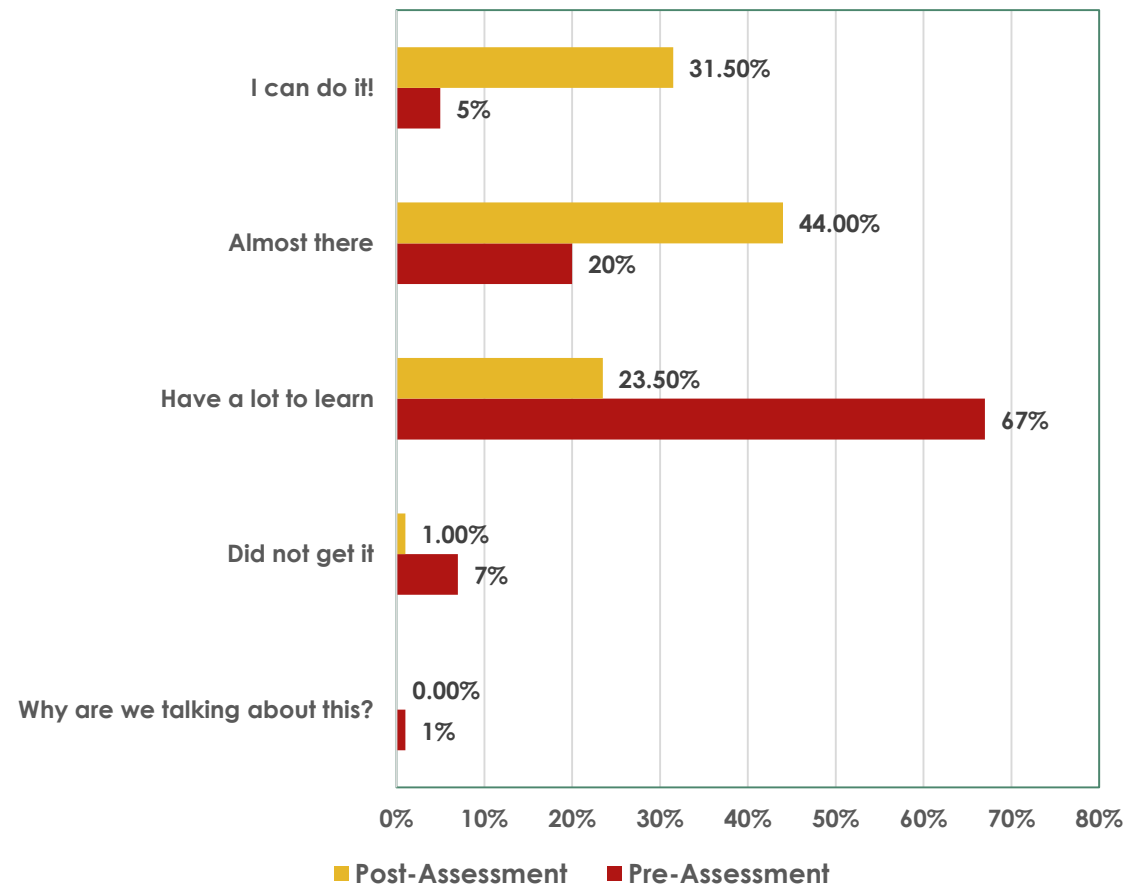


Recognition of What is Important to Parents

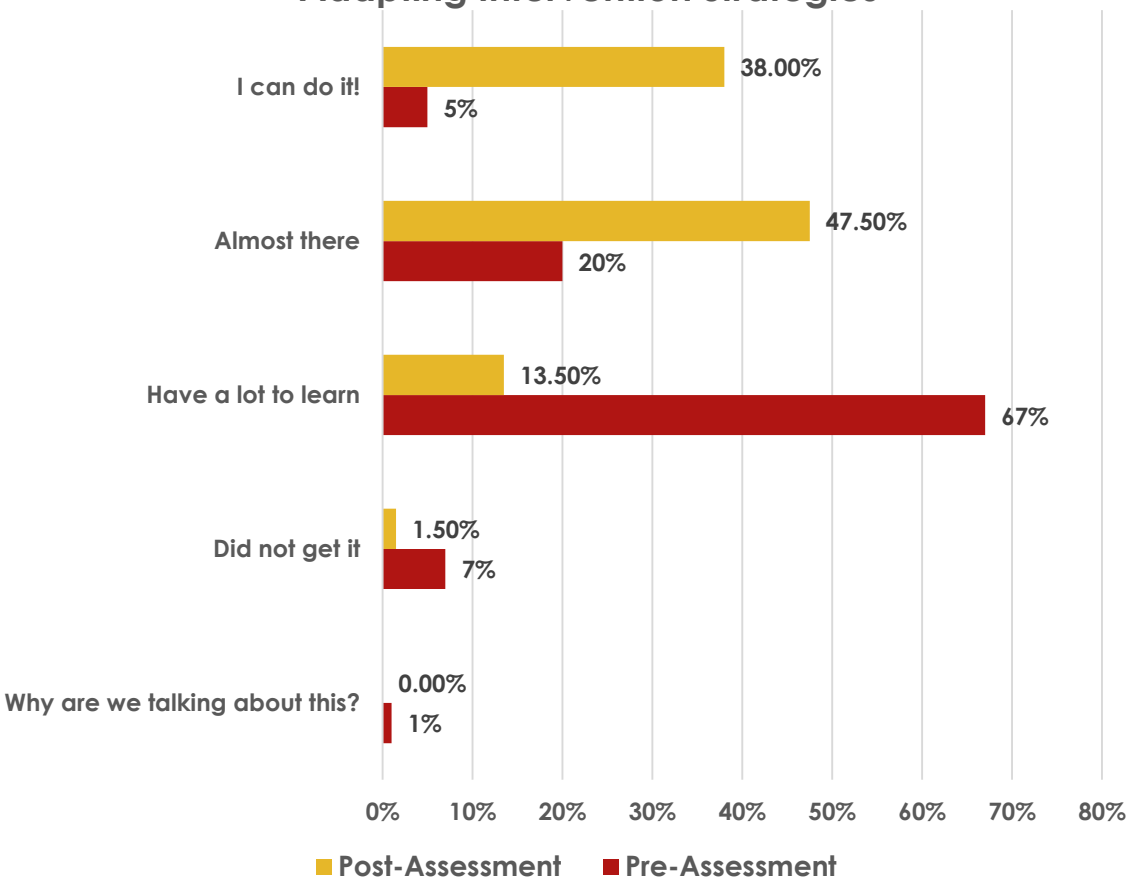




Adapting Child Welfare Practices

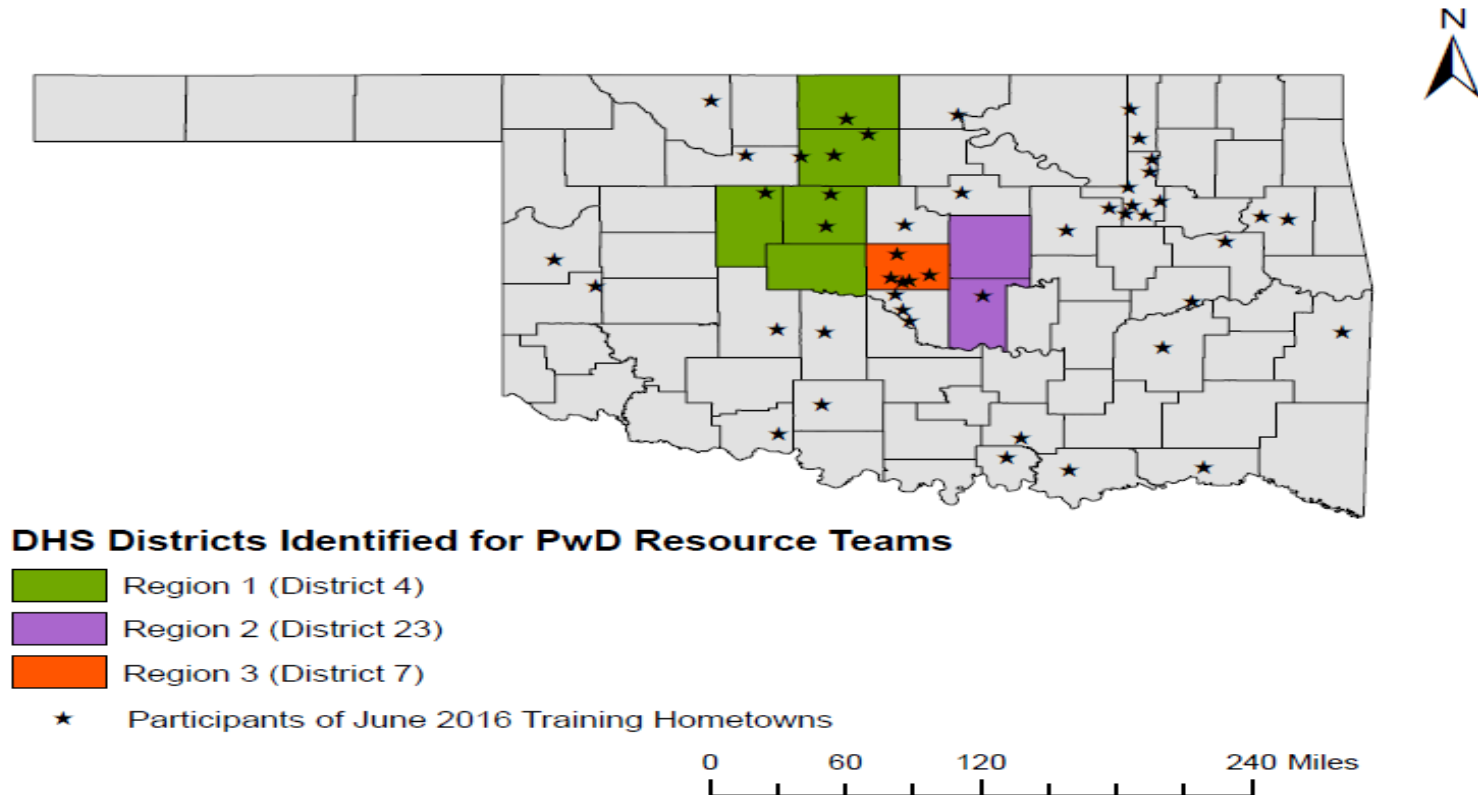


Adapting Intervention Strategies



Stars indicate home location of live training participants.

DHS Districts Identified for Parents with Intellectual Disabilities Resource Teams and Participants' Hometowns of Year 2 in Oklahoma



After the training.....

- ▶ “In almost all areas **I still have a lot to learn.** I feel that this training moved me further up in the continuum but know I still have a lot to learn”
- ▶ “**Still need ideas on how to specifically help families with ID.** Would be nice to have a list of creative ideas for different “typical” scenarios for families of parents with an ID diagnosis.”
- ▶ “Would love to see actual **samples of adapting curriculum/services using teaming approach** to deliver services.”

Year 2: Moving forward

Building a team:

- ▶ A parent with a disability
- ▶ Disability resource person
- ▶ OT/Healthcare person
- ▶ Mental health person
- ▶ Child welfare person
- ▶ Parent Ed. person

Our goal: Piloting a solution

Creating a viable team to provide “moment of need” technical assistance.

Solution:

3 Parent with Disability Resource Teams each covering 1 county.

Garfield – rural hub

Oklahoma – urban

Pottawattamie - rural

Parent with Disability Resource Teams

Technical Assistance in your moment of need:

When presented with a case involving a parent with a disability, the team will help each provider:

- ▶ **Understand the nature of the parent's disability.**
- ▶ **Adapt their services** to meet the parent's unique needs.
- ▶ Identify local **disability resources** that may benefit the family.
- ▶ Identify ways to **make community resources more accessible to** the family
- ▶ **Brainstorm solutions** to specific challenges and/or safety concerns.
- ▶ Identify or nurture potential **long term supports** within the parent's natural environment or areas of interest.

Process:

1. Simple Application
2. Meet by phone
3. List of resources/recommendations

Assessment

OT

Child
Welfare

Healthcare

Data

Supporting
providers

Recruited
CBPA
trainer

Created
ABC
equipment
program

Pilot:
PwDRT
3 Co.'s

Newsletters
and info
packs

Survey
of PwD

PDF
Resource
guide

Recruited
CBPA
Trainee

FUNDS
Christopher
Reeve
Foundation

Started
DHS
training at
county
level = 399

Recruited
RN to
help
connect

Requested
data
mining
from DHS

Facebook
page &
webpage

STOP

Taking Action

Developed
and piloted
training for
nursing
students

STOP

Phone
& email
support

Case study – Parent with intellectual disabilities

Parent is a **21 year old** mother with intellectual disabilities. She has 2 children - an **8 month old** infant and a **21 month old** toddler, both living in the home.

Support: Services through a **home visitation program**; **lived with her father**; and had a **neighbor who was a friend** of the family.

Primary areas of concern were:

- ▶ The family frequently **missed scheduled appointments** with the children's pediatrician due to lack of transportation or forgetting the appointment.
- ▶ Mother frequently **ran completely out of infant formula** resulting in emergency calls to her home visitation provider outside of business hours. She also occasionally missed her scheduled appointments with WIC which resulted in her receiving less formula that the family needed.
- ▶ There was a safety concern for the children when mother would step outside to visit with neighbors and leave the **infant and toddler inside unsupervised**.

The consultation team recommended:

- ▶ Using Mom's **iPhone reminder app**. Team worked with her physician's office to include a **final step in the exam room of assisting mother to use the appointment reminder app on her iPhone and set up reminders both for the next scheduled appointment as well as a reminder 2 days before the appointment to secure transportation** with a friend or on public transit.
- ▶ The home visitation provider **taught Mom how to use the public transit system**, going with her to practice until she was comfortable.
- ▶ **Home visitation staff** explained to Mom how missed appointments with **WIC** were reducing the amount of formula she received, something the mother had not previously understood.
- ▶ Set up a **system to number the cans of formula** when they were received by family (#1-8). **Father was willing** to go out and purchase additional formula if mother would let him know when she opened can #8.
- ▶ Mother has a history of using **visual signals**, home visitation staff worked with mom to develop a **visual signal to put by the door: "If you go outside, bring the babies"**. Her **neighbor** also agreed to act as a **safety net** and remind mother to bring her babies along if she saw mother outside visiting without the children.

Outcomes

Mother has shown growth and improvement in all areas.

- ▶ The number of **missed appointments** at her pediatrician's office are **significantly reduced** and she has **called ahead** to cancel 2 appointments she could not attend (a behavior never before demonstrated). **Children are current on their immunizations at this time.**
- ▶ **Formula system** has been effective, as there have been **no more emergency calls** to the home visitation provider.
- ▶ And reminder systems have improved **supervision**, with **no further incidents of children reported as unsupervised.**

Year 3: Expanding our reach

Pilot phase - 3 counties

- ▶ Garfield (rural hub)
- ▶ Oklahoma (urban)
- ▶ Pottawattamie (rural)

Expansion phase

- ▶ Logan (rural)
- ▶ Major (pioneer)

5 districts/15 counties

Our main goal:

Replicating our resource team approach across a broader geographic area. From counties to CW districts.

Solution:

5 Parent with Disability Resource Teams

Assessment

OT

Child
Welfare

Healthcare

Data

Supporting
providers

Provided
stipends
to help
with cost

Publicize
ABC
equipment
program

Expansion
+ 2 new
PwDRT = 5
15 Co.'s

Provided
training
for
nursing
students

Con't
Survey
of PwD
= 53

PDF
Resource
guide

Recruited
more
CBPA
Trainees

Continued
small
group
training =
227

Small
group
training =
152

Added
PwD
variable
to new
system

Facebook
page &
webpage

STOP

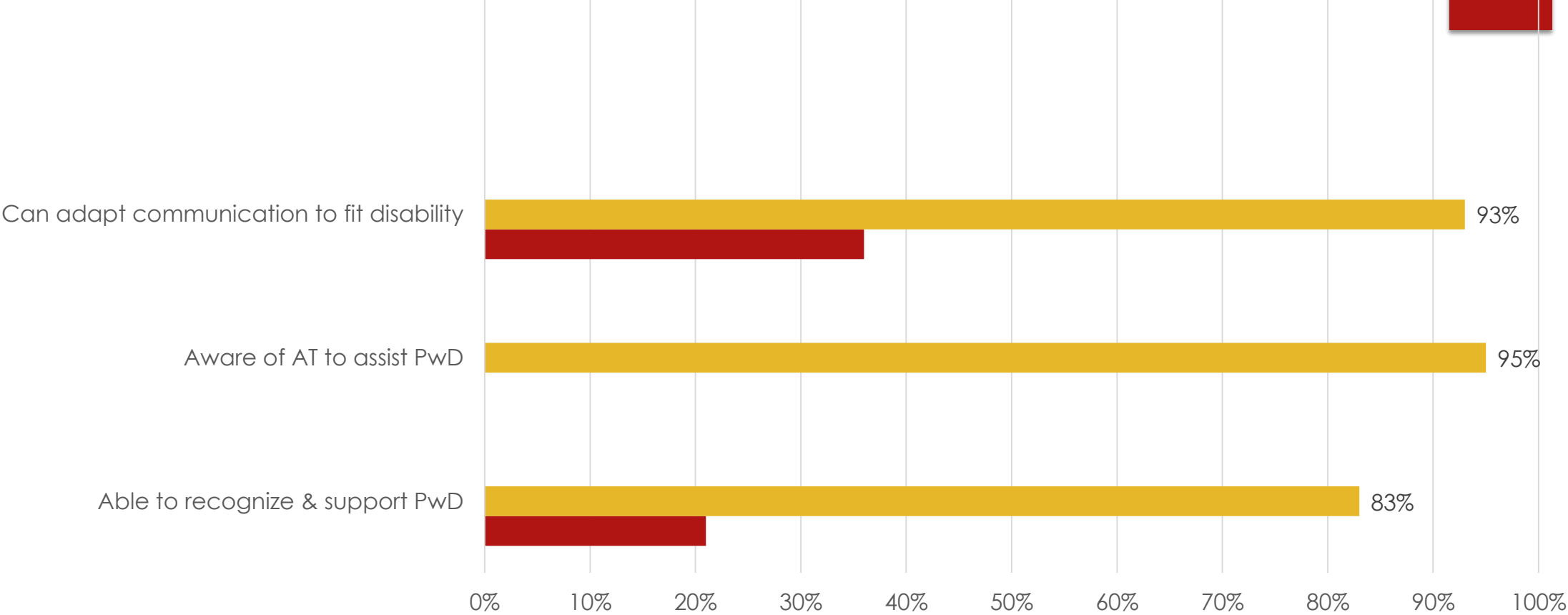
Taking
Action

Pilot - urban
Parents w/ID
support
group

Developed
redcap
data
system

Phone
& email
support

Pretest and Post Test – Training with nurses/nursing students



	Able to recognize & support PwD	Aware of AT to assist PwD	Can adapt communication to fit disability	
Column1				
Post Test	83%	95%	93%	
Pre-test	21%	0	36%	

Column1 Post Test Pre-test

Survey says..... what parents told us

Areas of concern for parents of infants and toddlers:

- ▶ Baby proofing their home for an infant
- ▶ Having enough help when they had a sick child (identifying when a child needs medical attention is also a key concern that has been raised by DHS in many of our consultation cases).
- ▶ Access to transportation
- ▶ Access to adaptive equipment that can make them more independent.

Areas of concern for parents of school aged children:

- ▶ Helping their children with homework.
- ▶ Responding to child's behavior.
- ▶ Access to transportation

What would have helped?

- **Information & referral** – finding support services that match their needs early in the process.
- More **in home help** – in home therapy, pre-made meals, respite, increased family or community support.
- **Someone to offer guidance and practical support** (this could be a parent mentor, a counselor, training, a formal program such as Children's First or Sooner Start)
- **Better trained school staff** (the parents wanted accommodations so they could be involved in their child's school life as well as support from school staff for their child when he/she needed something they couldn't provide).

Year 4: Exploring new territory

Pilot phase - 3 counties

Expansion phase – 15 counties

Expansion 2.0

4 CW regions/55 counties

Our main goals:

1. Reaching more of our state
2. Helping from early intervention to the court room.

Solution:

Looking beyond our Resource Teams to other areas of need.

Assessment

Trained
20
providers
on KIPS
and FAST

Education

Small
group
training
= 97

Education:
NRCPD
packet to
legislators

Child
Welfare

Expansion
4 CW
regions to
PwDRT = 55
Co.'s

Continued
small
group
training =
311

CSCF
grant for
Parent Ed
Library

Healthcare

Provided
training
toolkit for all
RN to BSN
programs

Small
group
training =
30

Research:
support in
the court
room

Support
group

2nd pilot
Rural
PwD
support
group

CSCF
Grant for
support
group

Sustaining
Our
Efforts

PDF
Resource
guide

Facebook
page &
webpage

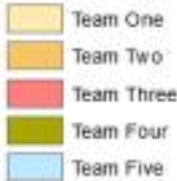
Online
training

ABC
equipment
program

STOP

Taking
Action

100

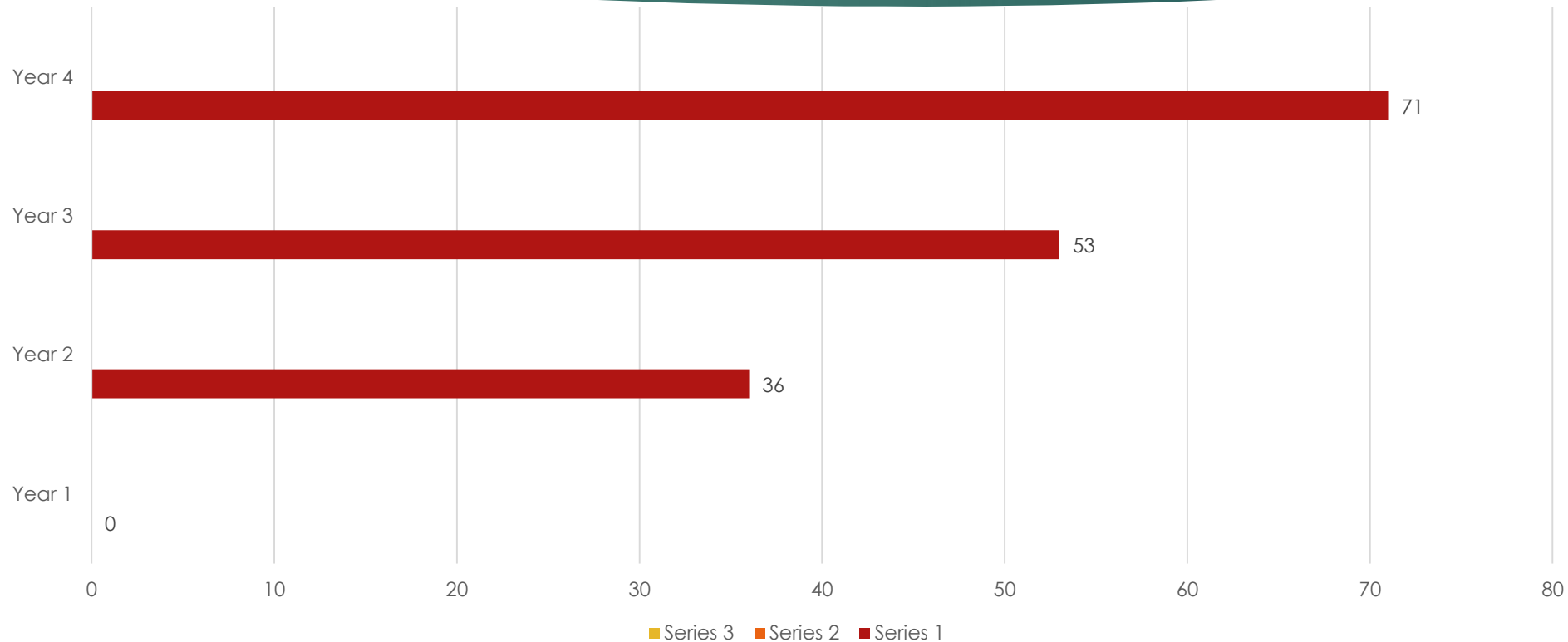


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PwDRTs assisted self advocates who had

- Intellectual disabilities
- Autism
- Learning disabilities
- Visual impairments
- PTSD
- Deafness
- Anxiety disorder
- Depression
- Physical disabilities
- Mental health condition

Consultations to date:



Disabilities supported: Learning disabilities, Mental health conditions, Intellectual disabilities, Physical disabilities, Vision impairment, hearing impairment, and combinations of these conditions.

Consultation outcomes

88% of providers increased knowledge about the disability in question.

97% of consults identified helpful strategies

84% of consults resulted in increased natural supports for the parent



Year 5: Sustainability

Pilot phase - 3 counties

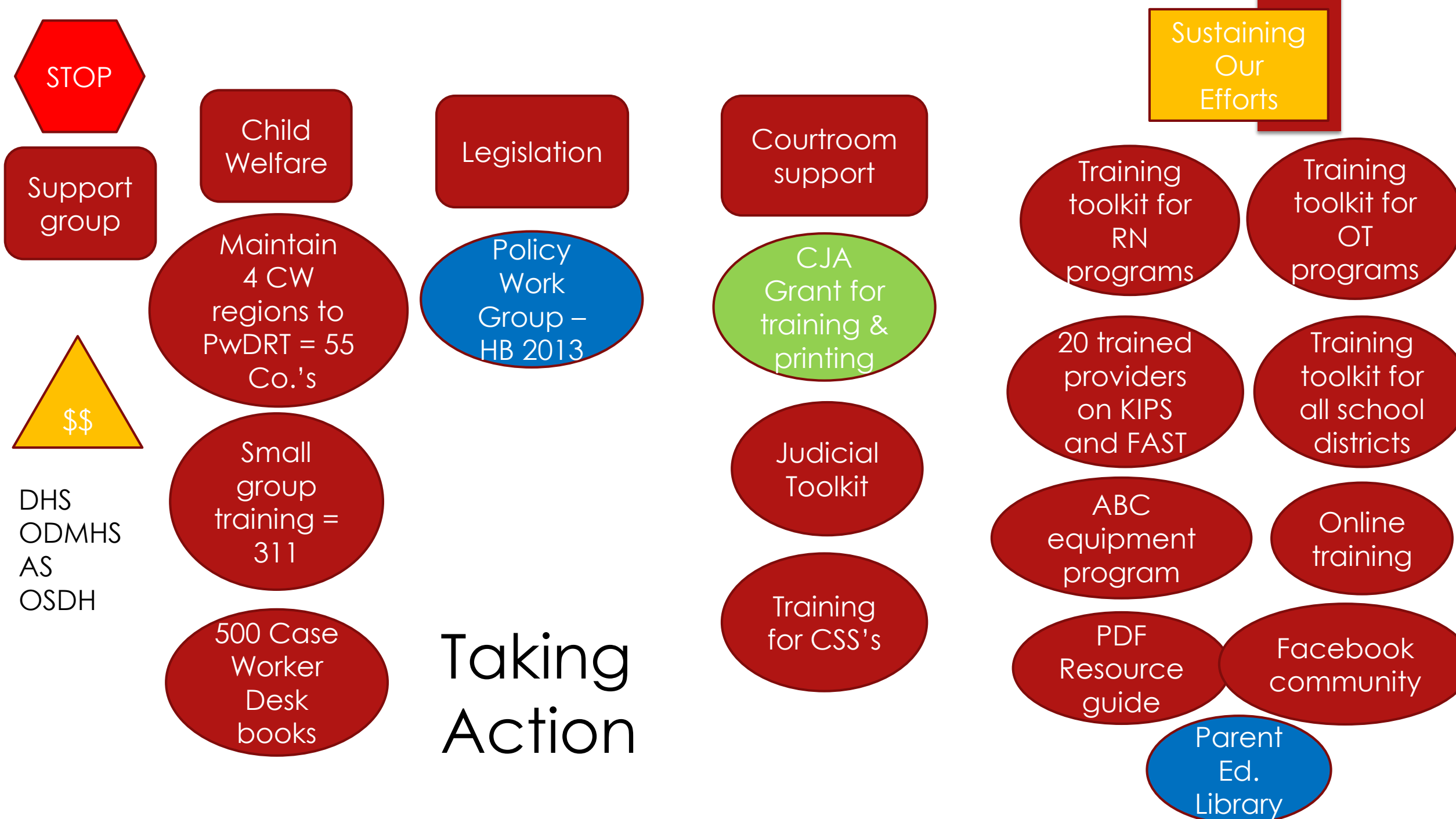
Expansion phase – 15 counties

Expansion 2.0

4 CW regions/55 counties

Our main goals:

1. Funding for resource specialists
2. Legal Supports for PwD
 - ▶ Bench book/card
 - ▶ Communication Support Program
3. Integration into Child Welfare systems



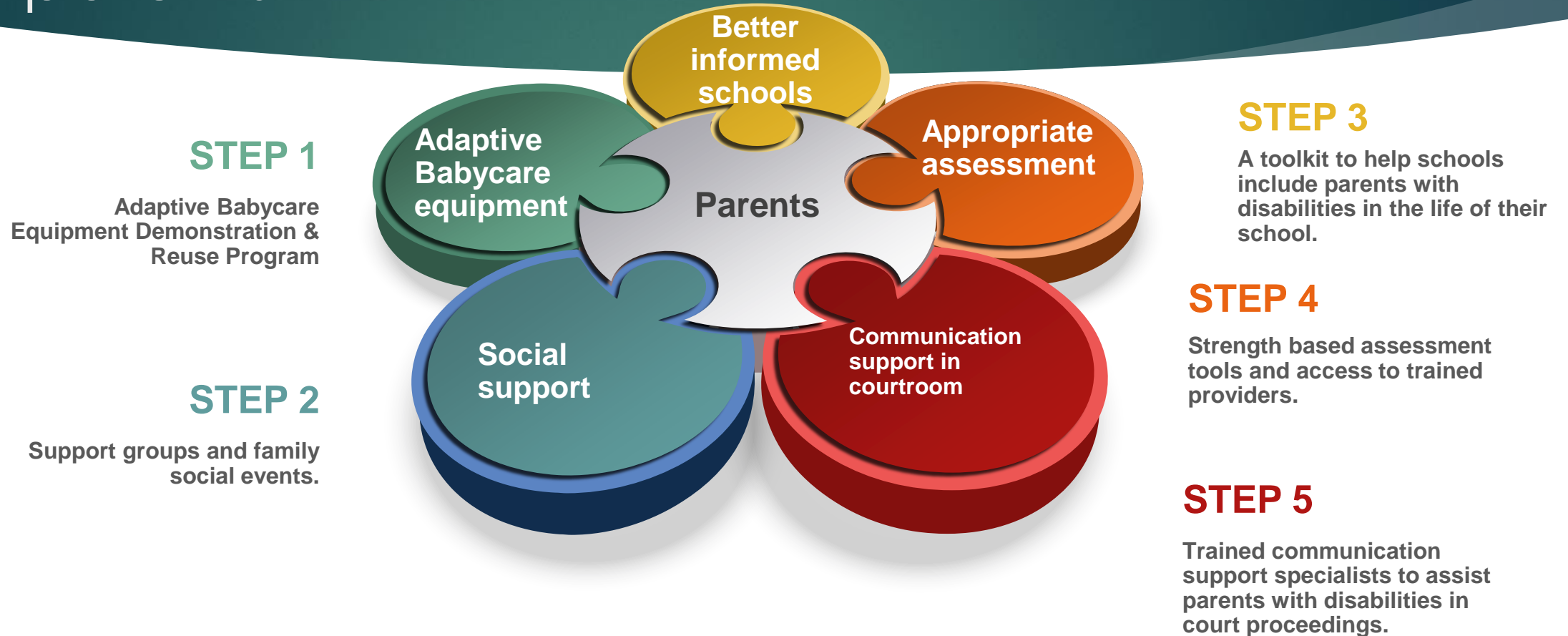
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- ▶ Build awareness (how to identify)
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- ▶ Face reality (no \$\$/no hand off)



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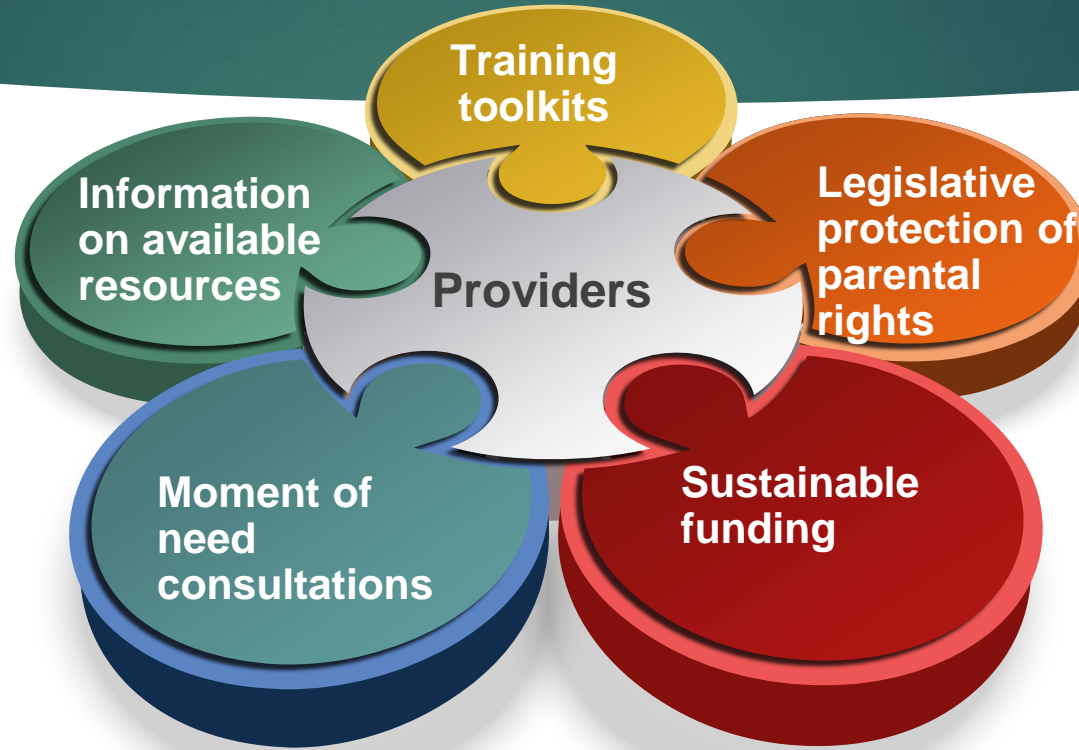
What we ended up doing.....for parents



What we ended up doing.... for providers

STEP 1
Access to resource guide, Facebook community, and online training.

STEP 2
Technical assistance available just when the provider needs it most – when they have a parent with a disability.



STEP 3

Customized training kits for RNs, OT's, Child Welfare & Parent Ed's, and Courtroom staff.

STEP 4

OK statute to ensure parents receive appropriate accommodations in state services.

STEP 5

State funding to support continuing these resources.

Where we want to end up

Professionals will:

- ▶ **Presume competence** when learning a parent has a disability.
- ▶ Evaluate a parents' competence, AFTER the parent **has needed modifications and accommodations in place** and has benefitted from services available to any parent.
- ▶ **Evaluate parents** in their natural environment, with modifications and accommodation in place and **within the context of their entire natural support system**.

Parents will have access to help:

- ▶ **Early** in their parenting journey (healthcare/parent ed. programs)
- ▶ When **natural supports are struggling** (family members/schools)
- ▶ When a **crisis occurs** (child welfare, courts)