



# DC Supporting Families Community of Practice Celebrating 5 Years of Partnership

December 8, 2017

# The Start Up

2/18/2013

Invitation for State Teams to apply to be in the **National CoP: Supporting Families Throughout the Lifespan**

4/12/2013

DDS and DDC partner to apply to join the National CoP.

We commit to:

- convening a state team,
- self-assessment
- action plan for making policy and program changes to effectively support families

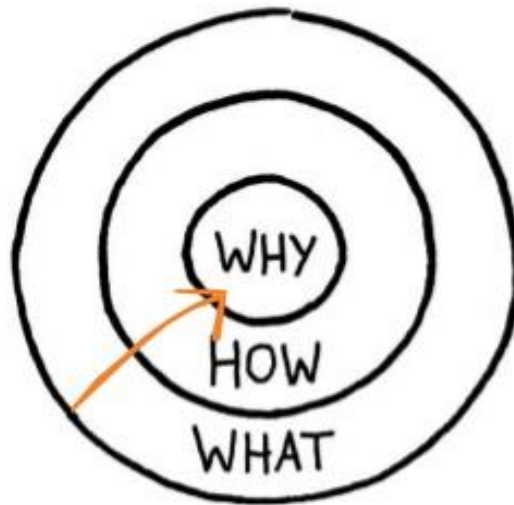
5/21/2013

DC is one of 5 states selected to join the National CoP!

- District of Columbia
- Connecticut
- Oklahoma
- Tennessee
- Washington
- + Missouri (mentor state)

# Start with Why

## The Golden Circle



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Why is a purpose,  
cause or belief.

It is the very reason  
the DC CLC CoP  
exists.

[http://www.ted.com/talks/simon\\_sinek\\_how\\_great\\_leaders\\_inspire\\_action](http://www.ted.com/talks/simon_sinek_how_great_leaders_inspire_action)

# DC Supporting Families Kick Off

## Principles

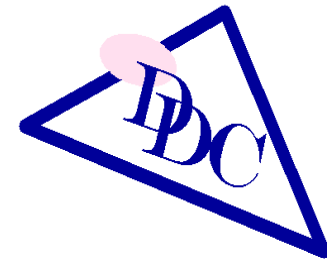


August 27, 2013  
Citywide Conference Center

- Shoot for the stars regardless of labels
- Programs work for families so that they have better quality of life
- People live the life they want
- Create the vision of adulthood and integrate it from the beginning
- Value diversity
- Our work thoughtfully supports people and families self-direction to a good life

# Initial Core Team

- Erin Leveton, Cathy Anderson, Rebecca Salon, DDS
- Mathew McCullough, DD Council
- Joan Christopher, Georgetown University Center for Excellence in Developmental Disabilities
- Rhonda White, Quality Trust for Individuals with Disabilities



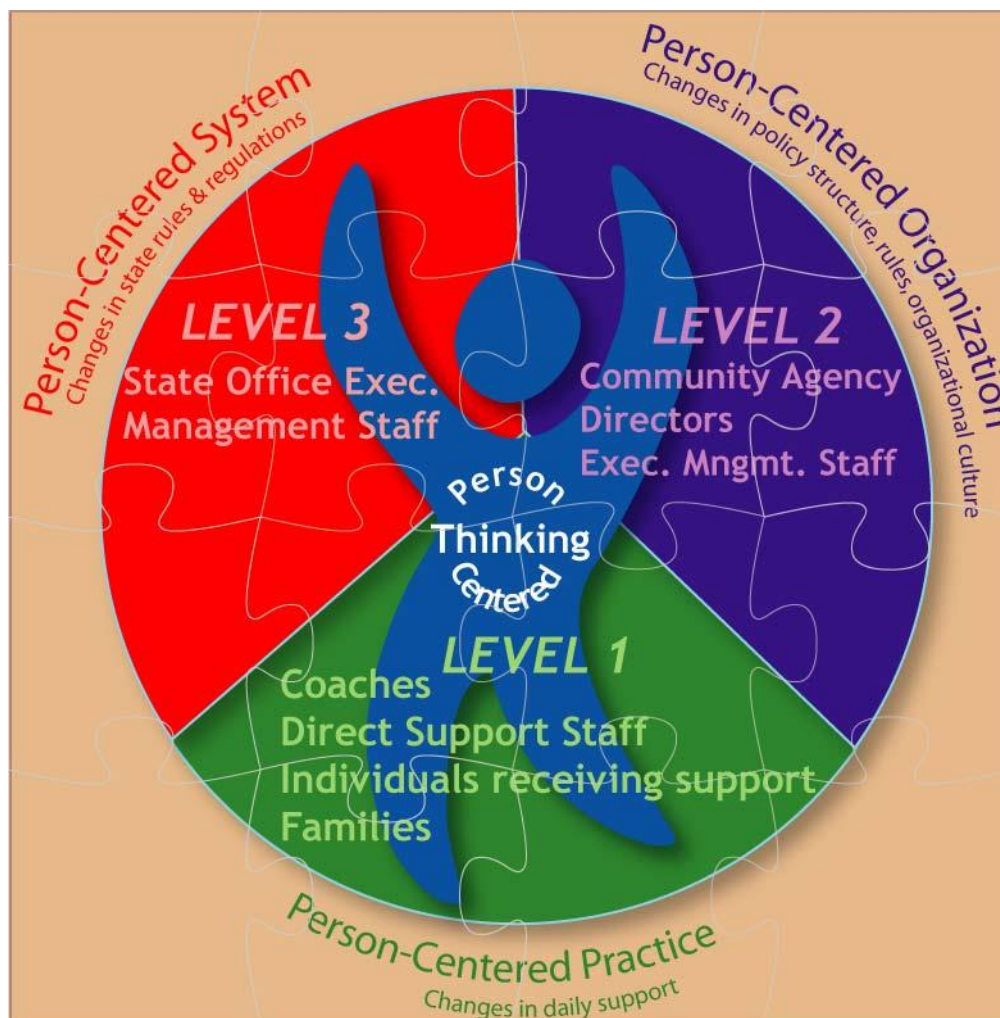
# Self-Assessment through Person-Centered Thinking

## Explanation:

Developing a person centered system requires changes at all levels. The changes should be driven by learning about what is working and not working in supporting people and their families.

## Key info:

Changes that you make in supporting people and families are level 1 changes. The changes needed that you cannot make drive the level 2 changes. Changes that you cannot make at level 2 drive the level 3 changes.



Credit: Learning Community for Person Centered Practices

# Andrew's One Page Profile

## What People Like and Admire about Andrew

- He's adventurous.
- He is always ready for fun - easy to smile, and his smile makes you smile.
- His sense of humor.
- Great at puzzles.
- Creative builder, with a talent for making bridges.
- He doesn't give up.
- He's charming. . . and a little devilish!



## What is Important to Andrew

- Having down-time and privacy to watch his favorite tv show with his cuddly and his I-Pad.
- Having something to chew (clothing, chewie, toy)
- Creative toys, especially model magic and Legos
- Water -- swimming, baths, water play of all kinds
- His mommy

## Supports Andrew Needs To Stay Happy, Healthy & Safe

- Take his medicine in the morning - put his patch in the middle of his back and cover it with surgical tape.
- Remind him to use the bathroom right before his bedtime and again before your bedtime. Use a pull-up too.
- Help him get enough sleep -- put him to bed by 9 and read him a story.
- If his mom is in the hospital, take him to visit if they allow it, but only stay as long as he wants to be there. If not, explain it to him. Tell him it's okay to feel sad about it and offer him a hug or to rub his head.
- Offer him a variety of meal options until he agrees to something. Waffles, dehydrated strawberries, toast with butter, ham, and chocolate milk will often work.
- He will wander - keep a close eye on him.

## Supports, continued

- Remind him to make eye contact and use his words -- full sentences are better than one word.
- Work with him in chunks on his site words, simple addition, more and less, and matching numbers or pictures to words.





# **TRINITY GABRIELLE**

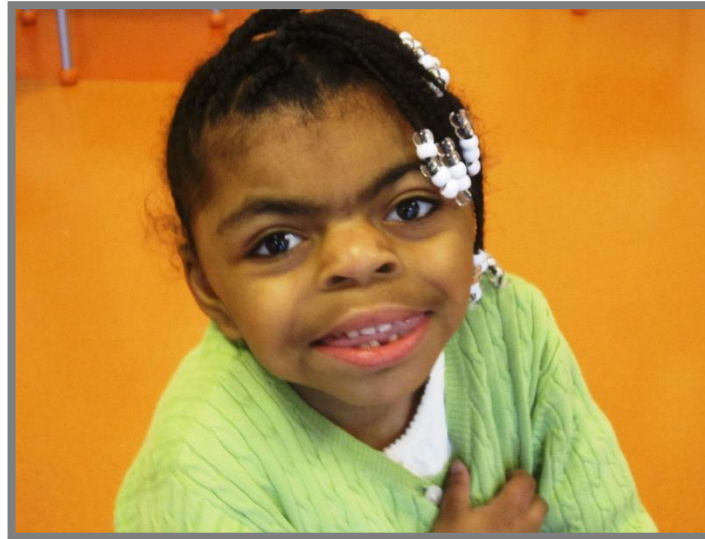


## **What People Like and Admire about TRINITY**

- Beautiful Smile and Spirit
- Incredibly Loving and Loveable
- Giver of great squeeze hugs
- Acts like little lady
- Rhythmic Ability
- Social Butterfly
- Comedian-Enjoys laughing
- Dancing Machine

## **I LOVE MY FAMILY!!!!**

Mommy-Rhonda  
Daddy-Robert  
Brothers-Tristan and Tyler  
"Sissy"-Tiffani



## **What is Important to TRINITY**

- I love music. I like to play the drums, piano, and tambourine.
- Sing songs with me and clap/dance to the rhythm of the beat.
- I am relaxed when I can feel my soft clothes and cross my legs.
- When I am tired, remove my shoes and braces so I can rub my feet.
- I like to play on the swings and slide at the park.
- My favorite food-grits and eggs; twizzlers

## **Supports TRINITY Needs To Stay Happy, Healthy & Safe**

- Obtain eye contact with me before giving instructions...try singing my name
- I can hear you best on my left side.
- Give me time to process your instructions.
- Use one word instructions, "Trinity....Come, Sit, Walk, Hands Down"
- Watch my facial expressions and gestures to understand what I am communicating.
- Allow me to visibly examine new things before accepting.
- I can feed myself and I get feeds through a gastronomy tube.
- Make sure my food is cut up into small pieces (no tough meat).
- I need assistance balancing my cup when I am drinking.
- Although I drink with a straw, help me control my cup so I do not choke.
- Help me walk up and down stairs.
- Use my wheelchair when I am tired and/or we take long walks.
- Keep your eyes on me because I am a determined explorer.

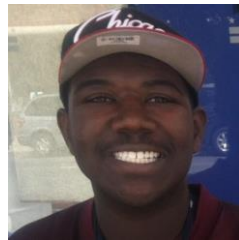
## **Supports, Etc.**

- If you see me flap my arms, eyes roll back in head and my body straightens (seizure), lay me on my left side and call 911.
- I need to get 8-10 hours of rest at night. If not, I may need cat nap in the day.
- After I eat, I need to sit up for at least 15 minutes.



### What People Like and Admire about Deion

- Warm personality
- Loves to laugh
- Enjoys helping others
- Compassionate individual
- Willing to Lead
- Appreciates simple things in life
- Loves his family



**Deion**

### Supports Deion Needs To Stay Happy, Healthy & Safe

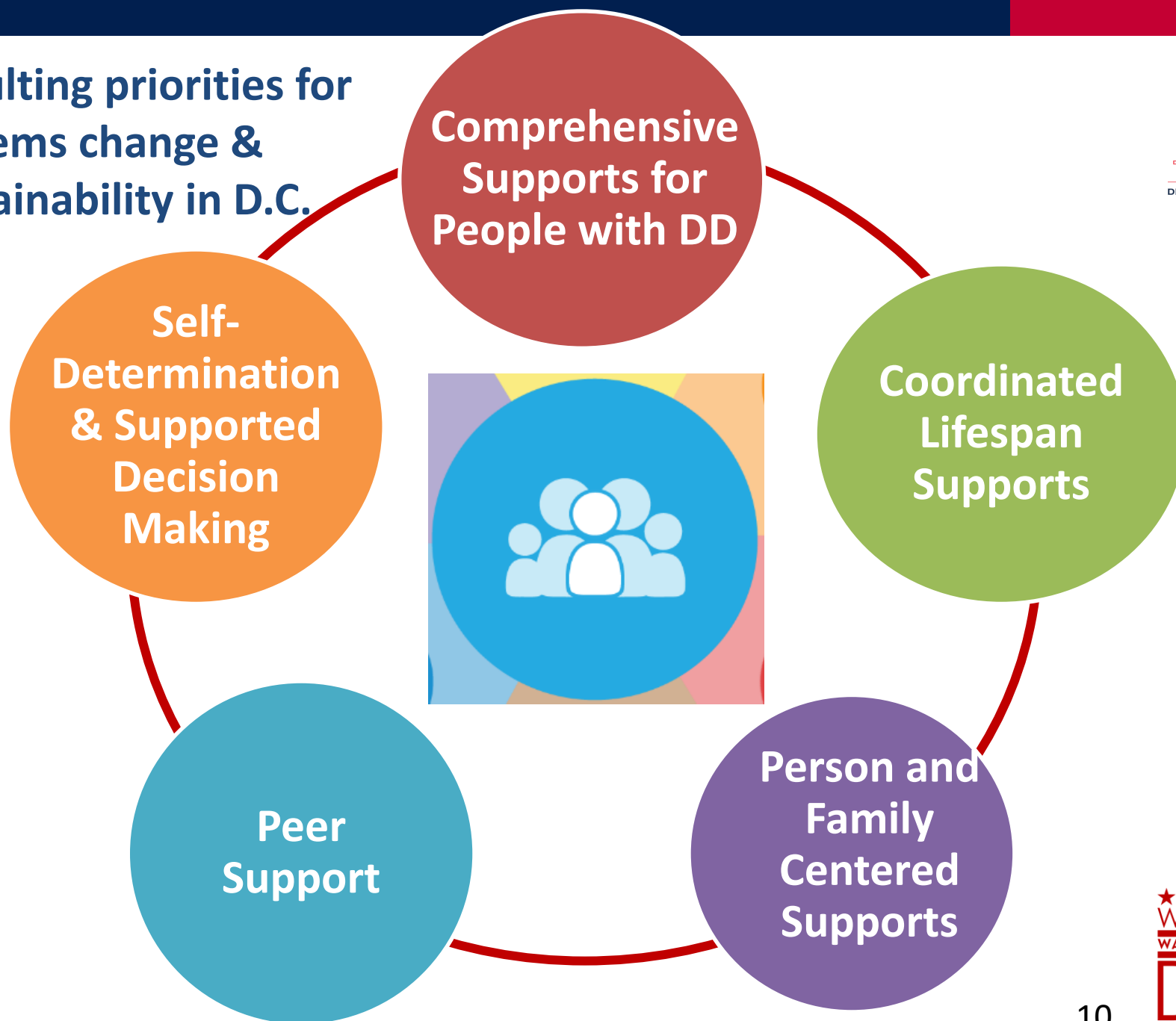
- Support in the community
- Support with social cues
- Quiet space
- Need to know his schedule
- Ongoing speech, ABA, social skills therapies, life skills training
- Exercise, medications



### What is Important to Deion

- Devoted to his Family
- Having his own computer
- Attending his Art and Hip Hop classes
- Going to social/exercise programs on weekends
- Cherishes friendships
- Requires quiet time and space
- Enjoys praise
- Eating favorite foods
- Loves animals

# Resulting priorities for systems change & sustainability in D.C.



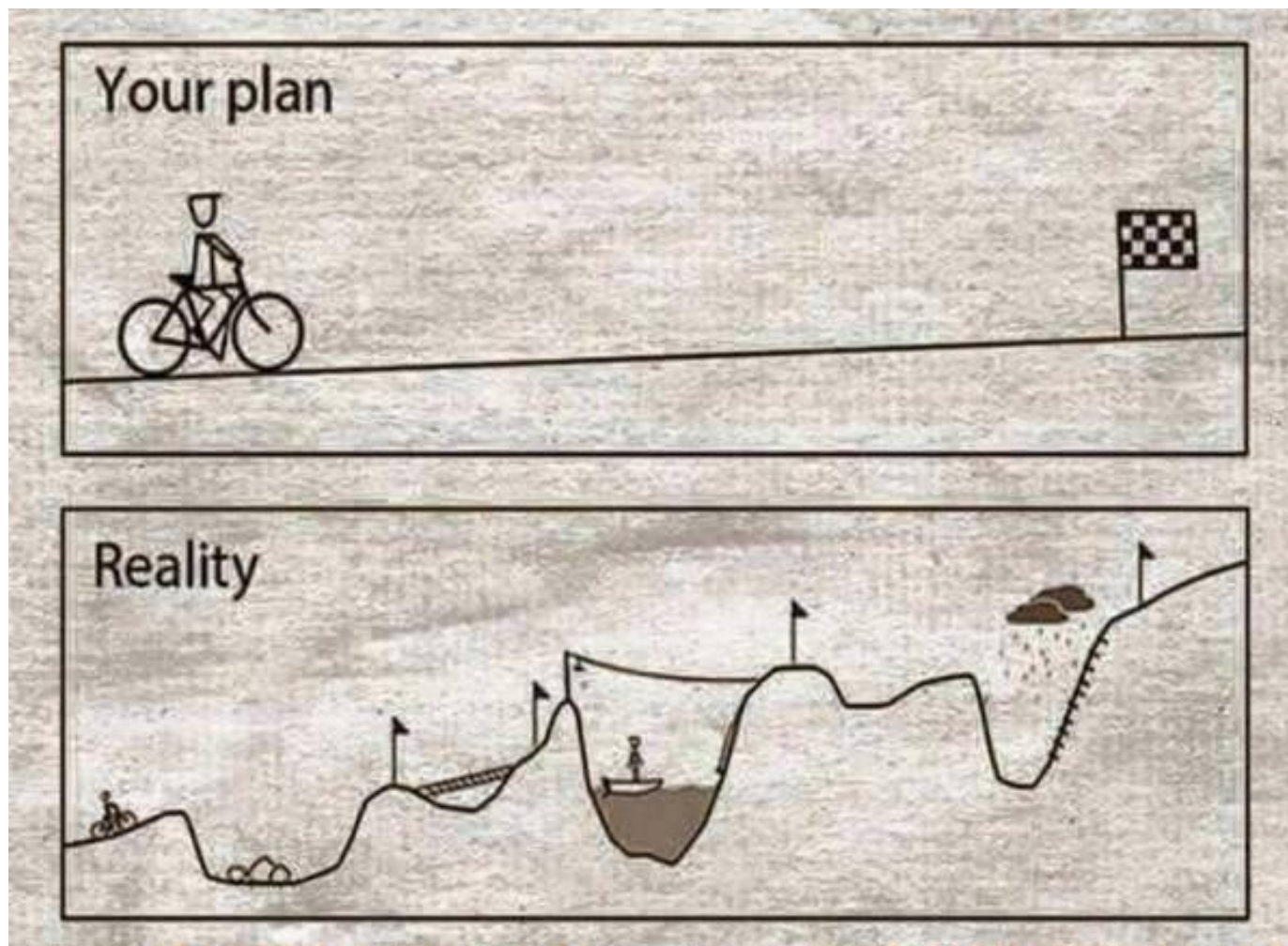
# Change happens at the speed of trust



©FSG | 5

Credit: FSG <https://www.fsg.org/>

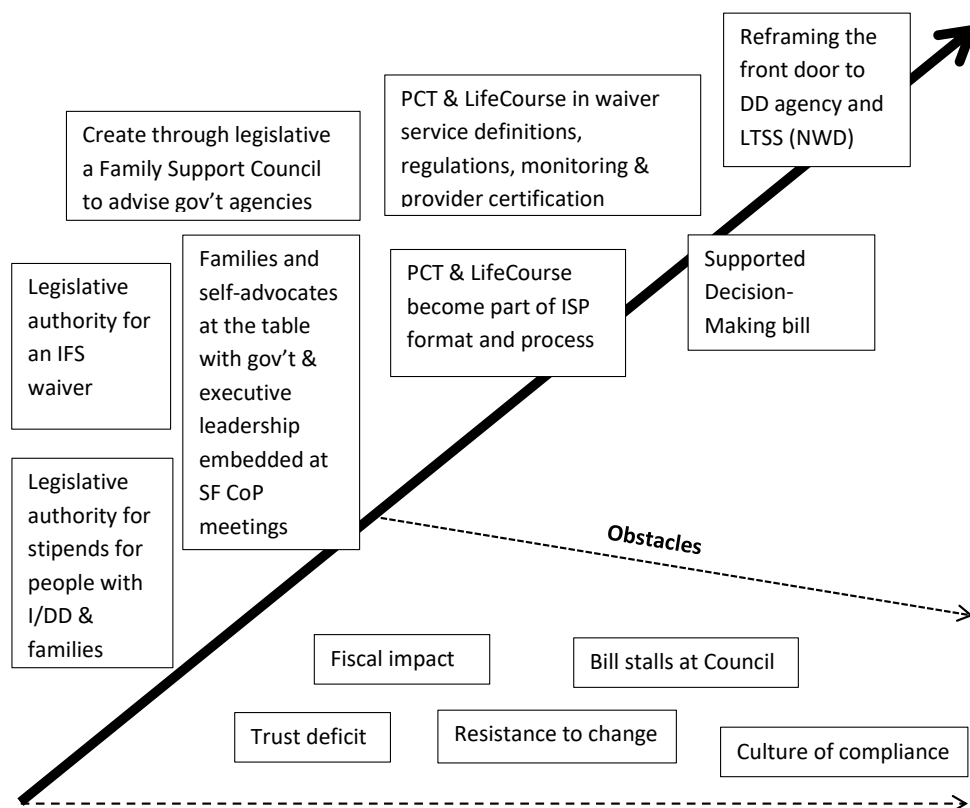
# The Path is Not a Straight Line



# DC Level 3 Changes

## Trajectory Worksheet: The Service System

### Person and Family Centered Support Through the LifeCourse



### Vision for a Person Centered LifeCourse System



### What we don't want

- When seeking services or supports, having to make multiple phone calls before we reach someone who can help, speaking with people who are annoyed with us for not understanding the "system," and having to share details about what we CAN'T do over and over again.
- Isolation from our communities and loneliness.
- Not having financial means to do things that make us happy.
- Services that create barriers between us and our families because professionals think they know best.



# Family Support Council

- Authorized through legislation to advise government agencies on how to best support families of people with intellectual and developmental disabilities
- Creates “teeth” for the ideas and recommendations that are born and discussed in the CoP
- FSC makes formal recommendations to government agencies, requires responses and dialogue with agencies
- Topics covered include: transition, coordination of services and supports, and healthcare



The image shows a sample of the Family Support Council Application form. It includes the DDS logo, the title 'Family Support Council Application', and the text 'Department on Disability Services, Developmental Disabilities Administration'. The form contains a paragraph explaining the purpose of the Family Support Council, a section for contact information (Date, Name, Best way to contact you), and a section for membership category with checkboxes for 'Person with an intellectual and/or developmental disability', 'Family member of a person with an intellectual and/or developmental disability', and 'Disability services or advocacy professional (please attach a resume)'. There is also a line for 'Other: please specify'. At the bottom, it says 'Please provide answers to the questions on the next page'.

Family Support Council  
Application

Department on Disability Services  
Developmental Disabilities Administration

There is established an advisory group called the "Family Support Council" to provide recommendations and assist and advise the Department of Disability Services and sister agencies on developing person and family-centered systems of support for families throughout the lifespan of their family members with intellectual and developmental disabilities. The Family Support Council will meet at least every other month and meetings will be open to the public. The Family Support Council will have 11 voting members that will serve 2-year terms and may have additional non-voting members.

If you are interested in applying to serve on the Family Support Council, please complete this application and submit it to Alison Whyte at [alison.whyte@dhs.gov](mailto:alison.whyte@dhs.gov). If you have any questions or need support to complete this application, please contact Alison Whyte at the email above or 202-870-9640.

Date: \_\_\_\_\_  
Name: \_\_\_\_\_  
Best way to contact you: \_\_\_\_\_  
Membership category (select all that apply):  
☐ Person with an intellectual and/or developmental disability  
☐ Family member of a person with an intellectual and/or developmental disability  
☐ Disability services or advocacy professional (please attach a resume)  
☐ Other: please specify \_\_\_\_\_

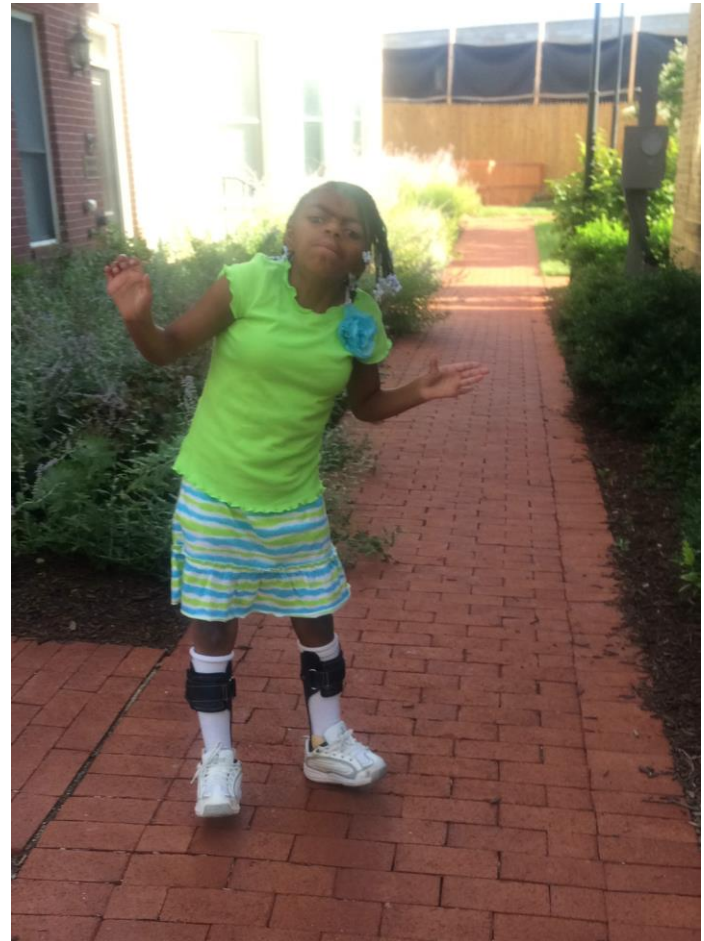
Please provide answers to the questions on the next page



# Fast Forward Five Years



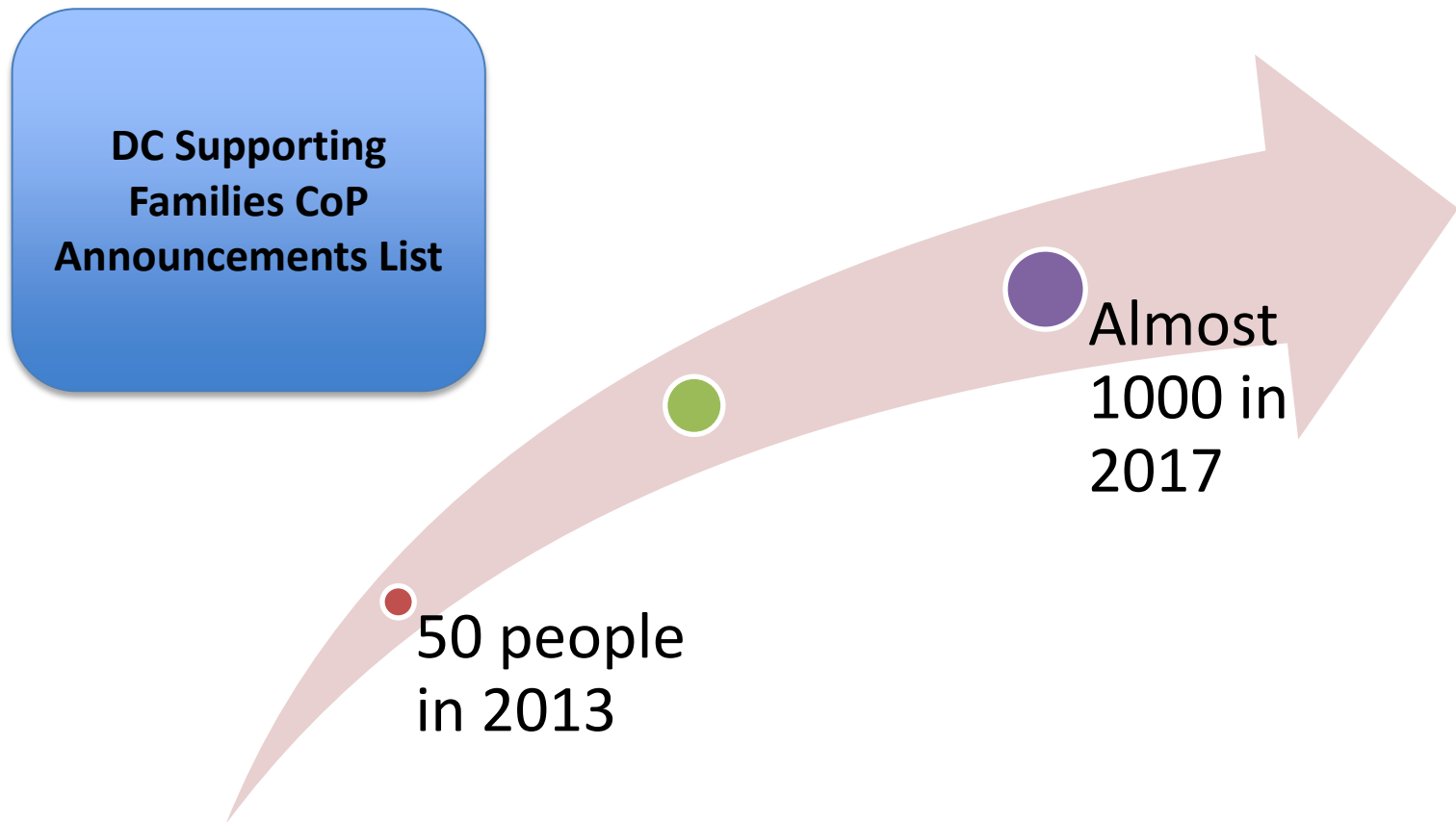
# Fast Forward Five Years



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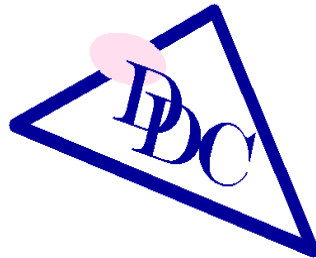
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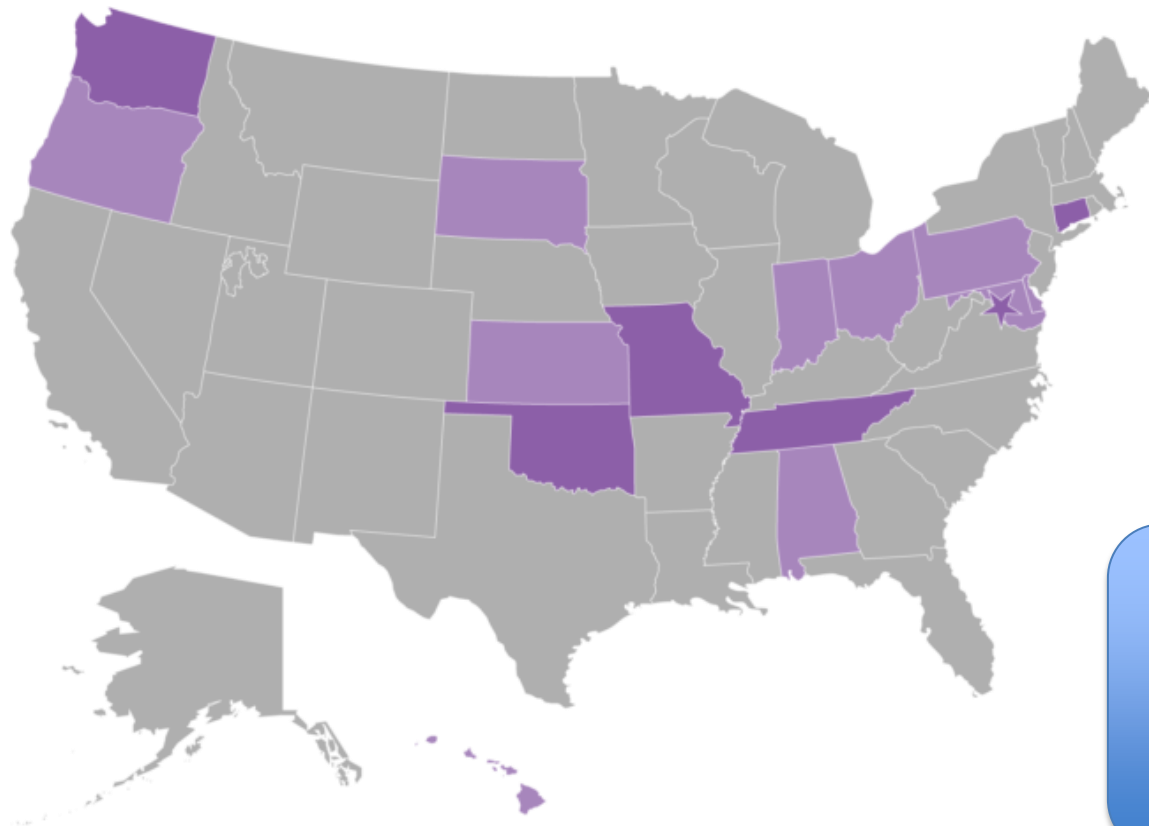
# Fast Forward Five Years



## DC Supporting Families CoP Core Team



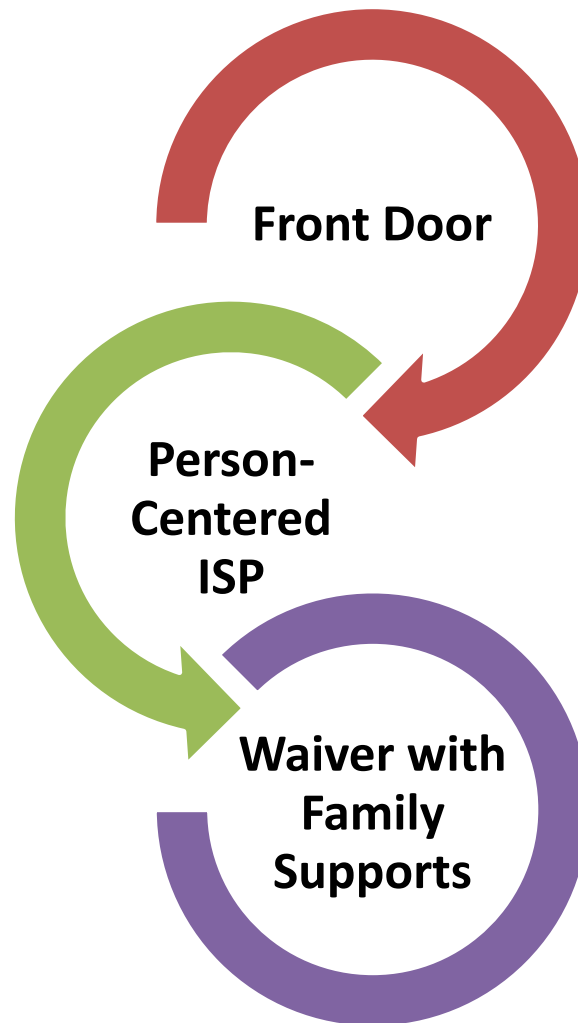
# Fast Forward Five Years



**From 6 to  
17 states**



# Fast Forward Five Years



# Fast Forward Five Years

- Citizens with Intellectual Disabilities Civil Rights Restoration Act
  - End commitment
  - Recognize Supported Decision-Making
  - Mark-up 12/12/17



# Fast Forward Five Years



You have a seat at the table, influencing policy & planning of the practices that impact you and your families.

# What's On the Horizon?



- DDS & DHCF are working on self-direction and an Individual and Family Support Waiver
- DDC is working on Family-to-Family
- NWD Team is launching a resource portal
- We are learning about cultural and linguistic competency
- And more

