



SD Supporting Families CoP State Team

1.7.19





Core Belief:
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.



What is a Community of Practice?

- ⦿ Most simply, a community of practice brings together "people who share a concern or passion for something they do and learn how to do it better as they interact This model was chosen for this effort to provide means for:
- ⦿ Connecting people who may have never had contact;
- ⦿ Providing a shared context for people to communicate, collaborate, generate knowledge, share information; and solve commonly identified problems;
- ⦿ Stimulating learning by serving as a vehicle for communication, mentoring, coaching, or self-reflection; and
- ⦿ Helping people organize around purposeful actions.



What are the goals of the National CoP for Supporting Families?

- ⦿ The overarching goal of this project is to build capacity across and within states to create policies, practices, and systems to better assist and support families that include a member with IDD across the lifespan. More specifically, the two project outcomes are:
- ⦿ Enhanced state policies, practices, and systems that result in improved supports for families with a member with IDD through the development of a multi-level community of practice.
- ⦿ Consensus on a national framework for supporting families that addresses the needs of families with a member with IDD across the lifespan, and supports states to develop and sustain exemplary family support practices.



What is the role of the CoP State Team?

- ⊙ Organize a structure of leaders to drive the change in your state
- ⊙ Understand and use the Charting the LifeCourse "thinking"
- ⊙ Identify and develop an infrastructure in the state for other stakeholders to also learn about the framework
- ⊙ Identify statewide specific Innovation Areas for integrating and implementing the Charting the LifeCourse-thinking, tools and practices.
- ⊙ Leverage and bridge National COP opportunities with statewide stakeholders to learn from other states and to national technical assistance.

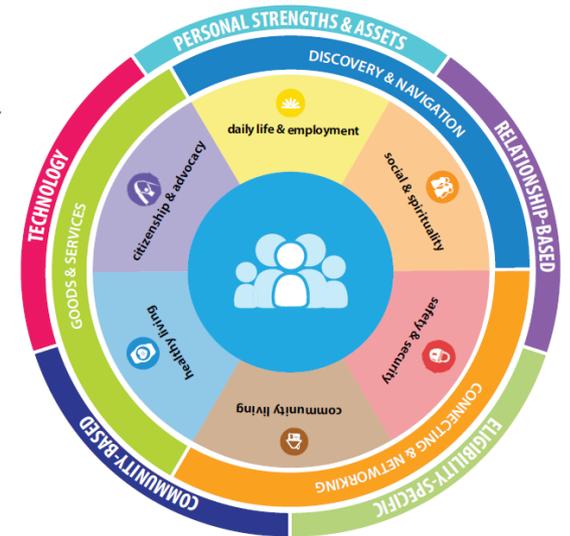


Charting the LifeCourse Guiding Principles

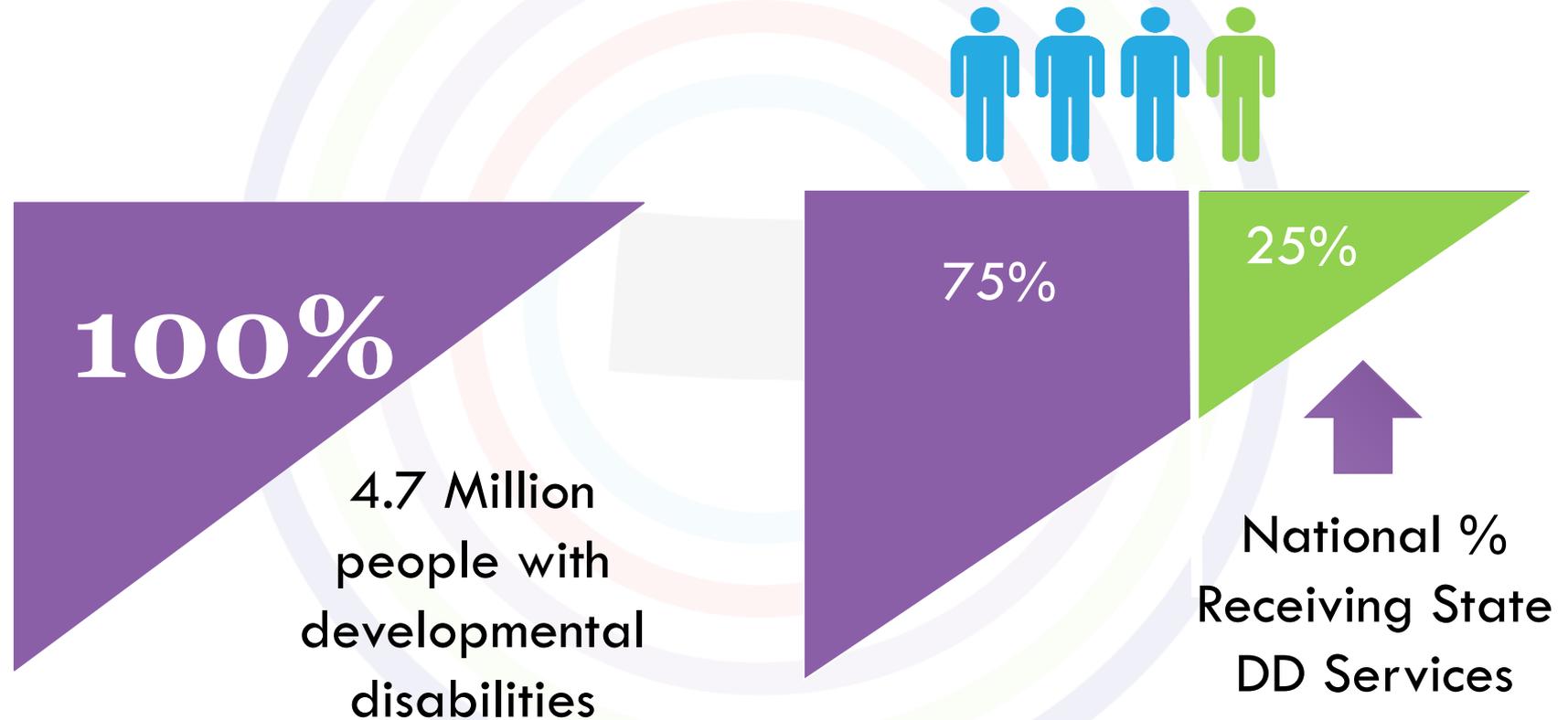
Core Belief: All people have the right to live, love, work, play and pursue their life aspirations just as others do in their community.

supporting positive life trajectories

...preventing negative life events



1 in 4 Persons with I/DD Receive Formal State DD Services

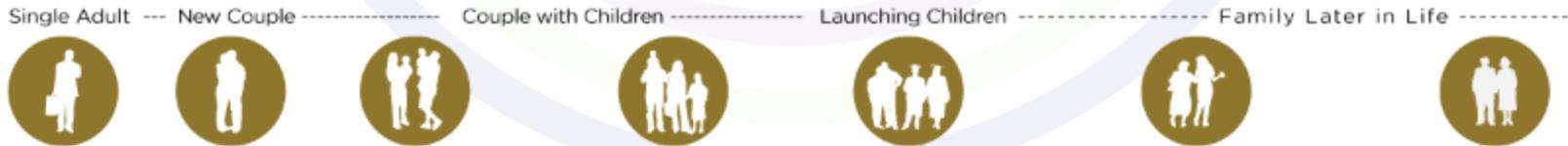
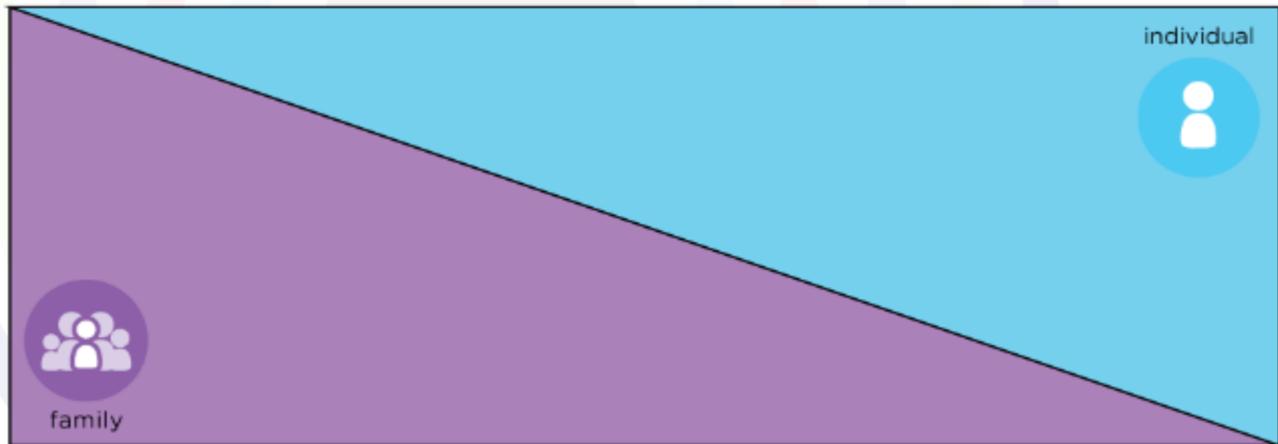


** Based on national definition of developmental disability with a prevalence rate of 1.49%



Life Stages and Individual and Family Cycles

Individual Life Stages



Family Life Cycle



Achieving Outcomes for Connected Life Domains



Daily Life and Employment
(school/education, employment, volunteering, routines, life skills)



Healthy Living
(medical, behavioral, nutrition, wellness, affordable care)



Community Living
(housing, living options, home adaptations and modifications, community access, transportation)



Safety and Security
(emergencies, well-being, legal rights and issues, guardianship options and alternatives)



Social and Spirituality
(friends, relationships, leisure activities, personal networks, faith community)



Citizenship and Advocacy
(valued roles, making choices, setting goals, responsibility, leadership, peer support)



Types of Supports

Discovery & Navigation

Knowledge and Skills

- Information on disability
- Knowledge about best practices and values
- Skills to navigate and access services
- Ability to advocate for services and policy change

Connecting & Networking

Mental Health and Self-efficacy

- Parent-to-Parent Support
- Self-Advocacy Organizations
- Family Organizations
- Sib-shops
- Support Groups
- Professional Counseling
- Non-disability community support

Day-to-Day Services

Instrumental Supports

- Self/Family-Directed services
- Transportation
- Respite/Childcare
- Adaptive equipment
- Home modifications
- Financial assistance
- Cash Subsidies
- Short/Long term planning
- Caregiver supports and training



Integrating Services and Supports



75%
People with I/DD not
receiving formal
DD services



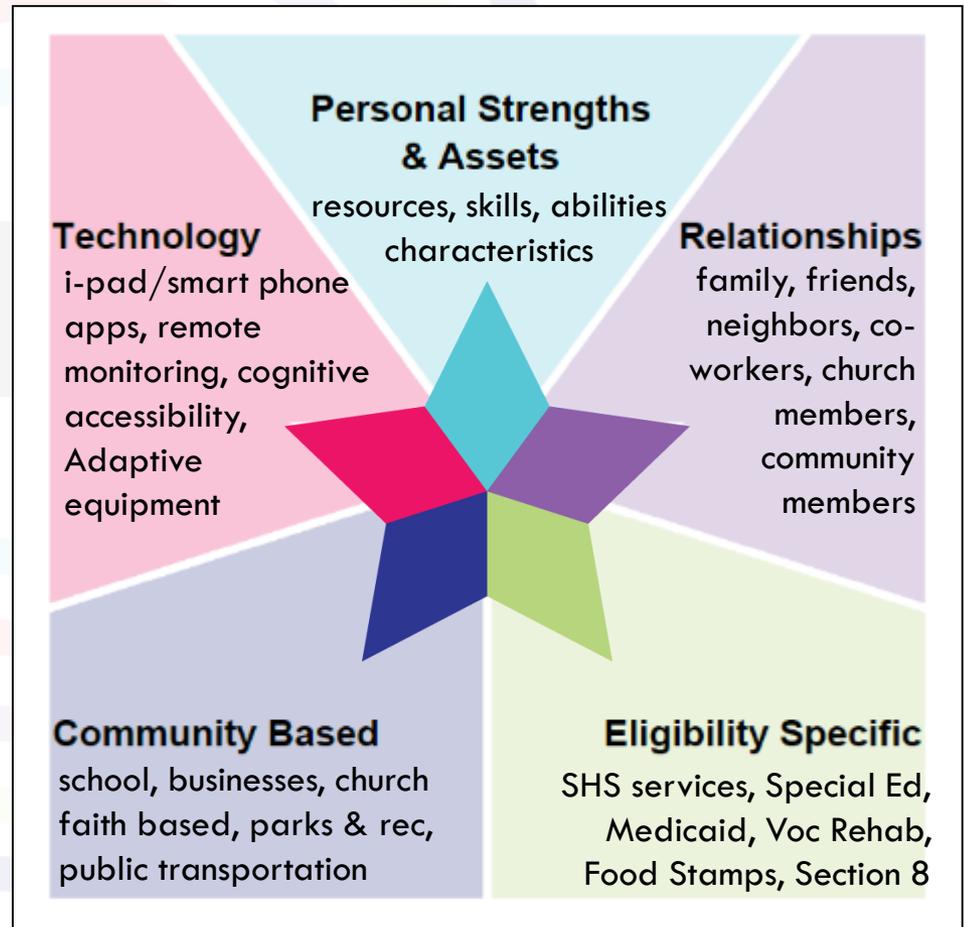
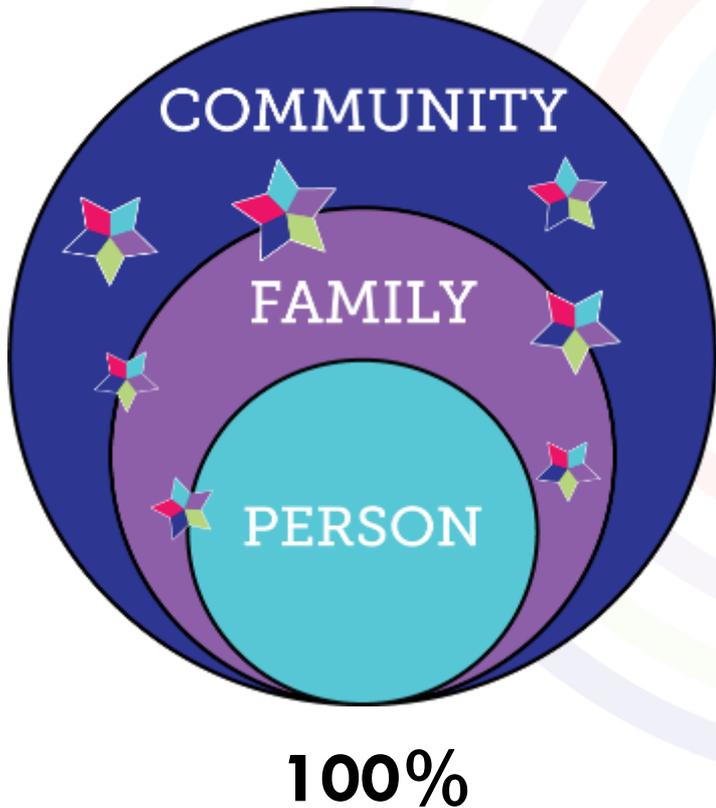
25%
People with I/DD
receiving formal
DD services



100%
People with I/DD
receiving integrated
services and supports



LifeCourse Integrated Supports STAR





Reciprocal Roles of ALL Family Members



Caring About

Affection & Self-Esteem

Repository of knowledge

Lifetime commitment



Caring For

Provider of day-to-day care

Material/Financial

Facilitator of inclusion and membership

Advocate for support

**Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)*



LifeCourse Tools: Reciprocal Roles

 Caring For	What's important to know/make happen/make sure continues?	WHO could be in this role? (can be more than one person in each role)
Provider of day-to-day care: Making sure the person's needs are met for food, shelter, comfort, medical care, and quality of life;		
Material and Financial Needs: Providing for OR helping manage money, property, other things needed to accomplish daily activities and needs		
Facilitator of Inclusion: Helping create and maintain friendships, community connections and opportunities for life experiences.		
Advocate for Support: Speaking up and supporting the person to speak up for their rights, support needs, and good life.		

	What's important to know/make happen/make sure continues?	WHO could be in this role? (can be more than one person in each role)
Affection & Self-Esteem: People who can have a mutual relationship; celebrate birthdays and holidays; honor family culture and traditions.		
Repository of knowledge: People who know the history and the vision for the future; knows what the person wants and needs to be successful, healthy and happy.		
Lifetime commitment: People who will be there for the long haul; Who will be in the person's life long term.		





CoP Innovation Workgroups

Based on feedback, new start in January 2019!
Opening up to others, please invite others in your agency, systems partners, advocates, providers.

- ⊙ Family and Self Advocate Engagement
- ⊙ Cultural and Linguistic Competency
- ⊙ Implementation and Practice
- ⊙ Systems Design and Quality



Family and Self-Advocate Engagement Innovations

Workgroup Description

identify and share ways to ensure active representation/engagement of self-advocates and families, including building or enhancing self-advocate & family groups and/or networks.

Dates of Workgroup Calls

April 4, 2019 ET



Cultural/Linguistic Competency

Workgroup Description

identify and share ways to enhance awareness of and improve cultural considerations in outreach & engagement strategies to diverse families. Development and implementation of policies/ practices responsive to supporting families from diverse cultural and linguistic communities across and within states.

Dates of Workgroup Calls

November 28-1:00 CT,
2:00 CT

March 12, 2019 1:00 CT,
2:00 ET

May 14, 2019 1:00 CT,
2:00 ET



Implementation and Practice Innovations

Workgroup Description	Dates of Workgroup Calls
<p>A workgroup to increase the competencies and confidence of practitioners in implementing the Charting the LifeCourse framework and tools for organizing thinking and day to day practice.</p>	<p>March 7, 2019 1:00 CT 2:00 ET</p>



System Design and Quality Innovations

Workgroup Description	Dates of Workgroup Calls
<p>A workgroup to identify and share ways to engage in overall system design and structural transformation efforts across programs that centers on the person within the context of family and community.</p>	<p>February 7, 2019 1:00 CT, 2:00 ET</p>



Leveraging the Innovation Series Workgroup Calls

- ⦿ Who do you include in each of the groups? And, why?
- ⦿ Because there are fewer calls, we have the opportunity to design them with more specific opportunities for dialogue. Who from your agency, partner agencies, provider community, advocacy communities would benefit from being a part of the workgroups, either because of their contributions, their learning or both?
- ⦿ Do you have a “structure” around innovation group calls? If so, what is it? How does it work? Do you listen to it together? Debrief on it later? Discuss what components could be/should be adapted in your state?
- ⦿ How do you engage/motivate those WITHIN the state CoP team and Ambassadors to participate?
- ⦿ How do you engage/motivate/communicate with those OUTSIDE of the state CoP team to participate?
- ⦿ What do you need from the National team?



Dona-Fielding Inquiries

CHARTING the LifeCourse



Integrated Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.

Technology

- plays educational games on IPAD
- uses computer at school

Personal Strengths & Assets

- Verbal
- has easy-going personality
- likes to hike
- likes to be outdoors
- enjoys riding his bike

Relationships

Mom
- currently her employer is letting her leave work early to be at home but temporary situation only

Neighbors
- mom put feelers out in her neighborhood about anyone being interested in supervising her son in late afternoon (3:10-5:00pm).

* has appointment/interview with a retired female neighbor this week

looking for options for after school for an 11 year old boy

- Mom plans to follow-up on services provided by a church across the street from the school, as recommended by the teacher.
- Resources suggested:
 - Outdoor Campus Youth Program
 - Just Gymnastics
 - Boys Club
 - YMCA
 - SD Parent Connection
 - Youth Sports Leagues

Community Based

- in self-contained classroom at middle school
- on IEP
- is too old for daycare centers
- he just started school this week (November). Had a late start? Mom did not share why?

Eligibility Specific

Access the LifeCourse framework and tools at lifecoursetools.com

Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at lifecoursetools.com

MAY 2016

DDD – Reframing Conversations

CHARTING the life course



Transition Age

LIFE DOMAIN	Vision for	Future	Current Situation/Things to Work On
Daily Life & Employment	What do you want to do during daytime (school) hours when school is over for good? What kind of supports do you need during the day, who will provide needed supports, and how will this impact finances or other family members ability to work? Have you thought about possibly attending college or vocational training for a specific job or career? What kind of job do you think you would like (what do you like to do or want to learn more about)?		
Community Living	Have you thought about whether you'd like to move out of your family home or even to another city or state, over the next few years (as you become an adult)? Will you continue to live with your parents, or would you like to have your own home or apartment, and can you think of someone you might want for a roommate? What are some places you might like to go in the community and how would you get there? Have you thought about technology or home modifications that would help you function better or be more independent in your home?		
Social & Spirituality	Are you building friendships by participating in extracurricular activities in the community such as clubs and other social outlets? Are you learning to use social media safely and responsibly (Facebook, Twitter, Instagram, Snapchat, etc.) to connect with and maintain contact with friends? Are you learning about sex and intimacy, including safe sex and sexual boundaries? Are you involved with a youth or young adult group in your faith community?		
Healthy Living	Do you understand and talk about your disability and special healthcare needs with others? What steps are you taking to begin to take control of your own healthcare? How do you find adult health providers who will understand your disability and special healthcare needs? Are you learning about the importance of healthy eating and regular exercise? Do you understand the changes in your body and your reproductive health?		
Safety & Security	What skills and abilities can you learn and practice now to prepare you to "be your own person" and so you will not need a guardian to keep you safe when you turn 18? What are some of the alternatives to guardianship that will keep you safe without restricting your basic rights? Are you able to stay at home or be in the community alone or without additional support, and do you know what to do in case of an emergency (fire, home invasion, etc)?		
Citizenship & Advocacy	Do you ask for accommodations for your learning and/or physical limitations when you need them? Are you allowed to risk making mistakes, experience the consequences and learn from it? Are you making choices and decisions for yourself with support from family, teachers, and others in your life?		
Services & Supports	Does your transition plan include volunteer or work experience that helps you and others around you to focus more on what you CAN do rather than limitations your disability might impose? Are you learning about the supports and benefits you receive or could receive; how to manage your money, services and supports; and lead your various planning meetings (IEP, IFSP, health, etc)? Should your family apply for benefits (Social Security, Medicaid, State DD services)? What are the pros and cons and how might it affect your future ability to earn income? What kinds of community (non-eligibility based) supports might help you now and as an adult (for example, public transportation)? Will you graduate/leave school at age 18 or continue until you are 21, and will you receive a high school diploma or a certificate of completion?		

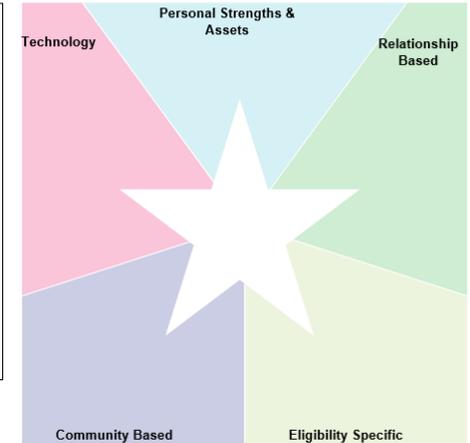
CHARTING the life course



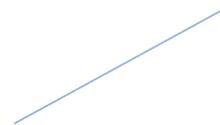
Transition Age

Date: _____
 Name: _____
 Address: _____

 Phone Number: _____
 Email: _____
 Referred By: _____
 Disability: _____



Supports Needed



Barriers

Action Plan:

What I Want...

What I DON'T Want



Deanna – Planning with Aging Mother

Tidd Bits about Barb!



Important to Me:

- Family and Friend visits, phone calls, emails and letters
- Make sure you face me speak loudly and slowly when asking questions something
- To understand what is happening with any minor or major life changes
- Being warm in any situation
- Deanna is my "go to gal", who I trust and love, please keep her informed
- I have a high threshold for pain, but if I complain, it is serious, please be comfortable as possible (adjust my bed, possible pain medication, etc)

Important Supports for Me:

- Help me with preparing, setting up for baths, bathroom assistance
- I enjoy sitting and talking with others, when eating me
- Need to wear my hearing aids both right and left, I may need help with hearing aid
- I use a wheelchair, but need assistance with moving from place to place
- I can wheel my own wheelchair, but at times gets tired and may need help
- I have figured out how to use my phone, but may need help to call numbers
- Deanna, Ben, Austin or Cydney will try to be available to take me to places
- Safely take a bath, enjoy whirlpools if there is time
- Safely using the bathroom, most of the time I need to go to the bathroom
- Help with washing, drying clothes, will do my best to put things away
- May need help with tying shoes, as wrist is weak

People Like:

- Prayer Warrior, has a strong faith
- Great resource for Bible trivia
- A woman with a strong sense of humor
- Caring, kind hearted, thoughtful towards others
- Devoted to family and friends

What Comforts Me:

- Friendly, pleasant, kind and caring people
- People with a sense of humor
- Lots of warm and fuzzy blankets
- Family being loving, supportive and encouraging
- Friends to visit in person, on the phone, or letters
- Seeing my dog Envy to brighten my day
- Having books available to read (Christian Romance Novels)

Barb's Trajectory - Vision for a Good Life

Experiences/What is it going to take:

- Physical Therapy to walk with walker
- Use the bathroom – call button, within arm's reach or with gait belt and walker
- Strengthen arms to transfer from chair to wheelchair, bed to wheelchair...
- Occasionally sit and visit with C.K. during a meal.
- Care givers mindful of taking care of my personal hygiene, when or if unable to do so myself.
 - *specific shampoo, body wash, deodorant, Bath and Body Lotions...
 - Graduate from ground to chewable food.

Want to see

- People to come and visit
- Daily visits with friends
- Enjoy an ice cream
- Build strength to walk
- Go outside when to sit, stroll, ride in wheelchair
- See or talk with C.K.
- Rest and relax in pain when sitting in wheelchair.
- Seasons on the farm when served in retirement
- Someone to have with at the dinner
- If having problem phone, someone making calls.
- Continue to read but if my reading someone to read
- Independent as possible being clean, feed
- Keep my senses

Barriers to address or be mindful of:

- UTI comes back
 - ~provide meds/pain meds
- Bed sore gets worse
 - ~monitor progress, creams, positioning
- Health declines
 - ~monitor and provide comfort care
- Further loss of hearing
 - ~Speak slowly, louder & closer
- Skills decline (hand writing, reading, understanding or use of electronics (preferably phone)
 - ~help me write, read to me, show me how to use or operate for me.

Don't want to see

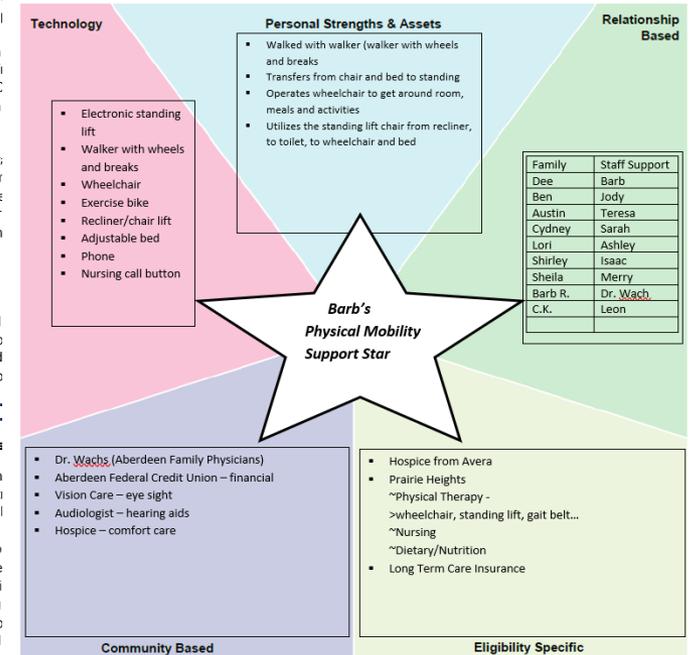
- To be left alone and to feel alone
- Figure things out myself – elect wireless head phones, phone, I can't
- Feel sorry for myself.
- Children, grandchildren stop coming
- Children, grandchildren see me
- Sit for long periods of time wait
- Day or days go by & not seeing
- Seeing myself unkempt (bath, combbed, clothes matching, and

CHARTING the life course



Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.



Deanna – Planning with Aging Mother

CHARTING the LifeCourse



Mapping Family Roles

This tool is to help families think through the roles they play in their loved one's life, and to help them plan for who else could help fulfill those roles now and in the future.

Reciprocal Roles	People's Roles in <u>Barb</u> 's life	Looking Ahead	What's important to know, make sure continues, or make happen?
 Caring ABOUT	Affection and Self-Esteem Who loves and cares about him/her? Dee, Lori, Joel, Ben, Austin, Cydney Jarod, Lauren, Shirley, Sheila, Barb R., Deb S., Marcene	Who else makes him/her feel loved? Alan, Bev, Justina, Roommate, Teresa	Dee or Cydney encourage visits from family and friends, via phone, txt... Facetime family in Tx or Sioux Falls
	Repository of Knowledge Who else knows things that others don't know well? (celebrations, traditions, habits, history) Dee, Cydney, Austin, Ben, Shirley, Sheila, Marcene	With whom does he/she have special memories or experiences? Her mother, Elva; Husband, Loren; Sister, Carol; Friend, Del	Barb's Birthday is 5/11/1939; anniversary is 1/3/1960; she likes to send cards to family and friends for birthdays and Christmas; she does not like to be alone
	Lifetime Commitment Who has a lifetime bond with him/her? Dee, Lori, Shirley, Sheila, Austin, Ben, Cydney, Bev, Barb R., Marlene	Who else would step up when/if needed? Alan, Deb S., Jerod, Lauren, Paige, Pastor Gary, Mike Salem, Simon Wipf	Barb appreciates people, when they take time to visit with her and not rush time or conversation.
 Caring FOR	Provider of day-to-day care Who makes sure activities of daily living and healthcare needs are met? Barb, Jody, Teresa, Tina, Dee, Ashley	Who else could provide oversight for these needs? Prairie Height Nurses and CNAs, Hospice Team, Cydney, Austin, Ben	Barb's Routine: breakfast, a bath, with specific shampoo (dry scalp, body wash (fruity), lotions (bath & body). Brush teeth in the am & pm.. read newspaper...
	Material and Financial Needs Who makes sure his/her day-to-day basic and quality of life needs are met? Barb, Dee, Karen, CNAs, RNs, both Prairie Heights and Hospice Teams	Who else could help make sure this happens? Cydney, Austin, Alan, Shirley, Sheila,	Monthly benefits and bills noted and paid in ledger; to do list of the benefits and bills are noted in monthly section of her financial canvas zipped binder
	Facilitator of Inclusion and Membership Who helps connect him/her to inclusive opportunities and maintain relationships? Dee and Cydney	Who would be good at helping him/her connect with and maintain inclusive activities? Austin and Ben	Within her home – going to listen to music with others; attending church services when strong enough; grandkids inform familv/friends of ups or downs
	Advocate for Support Who helps him/her advocate in planning meetings? Barb from Prairie Heights	Who else could help advocate for/with him/her? Jody from Hospice, Dee or Cyd	Continue current communication through Care Conference Meetings in person, conference calls...

Developed by the UMKC Institute for Human Development, UCEDD. More tools at lifecoursetools.com

MAY 2017

Other Stories and Examples?

- ⦿ Which parts of the Charting the LifeCourse framework have you practiced?
- ⦿ Which parts make the most sense to you?
- ⦿ How might you apply the framework to your work or day to day life?



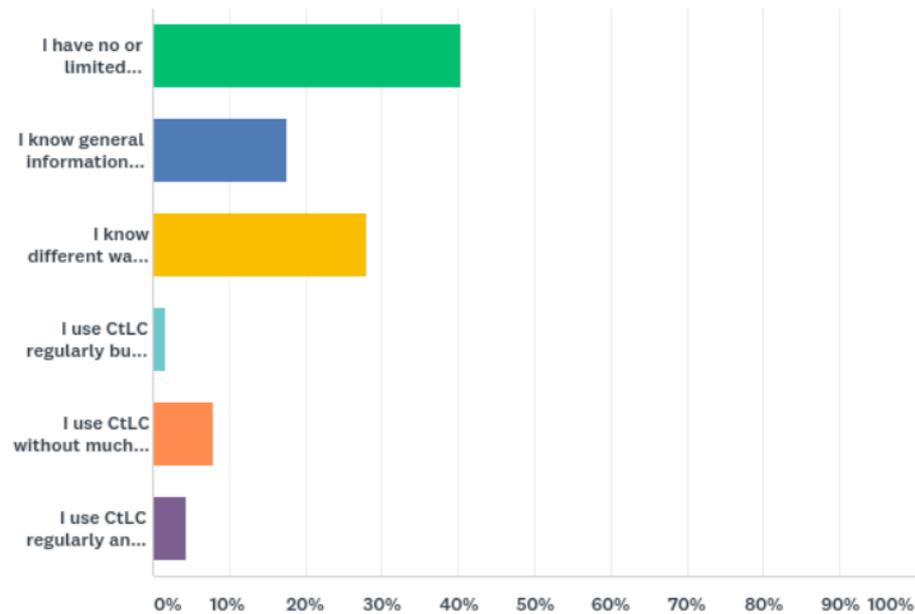
SD CoP Network for Charting the LifeCourse

- ◎ Objectives of State CoPs in the 3rd year (ending 6/30/19)
 - ★ Plan for sustainability of both infrastructure and innovation,
 - ★ "Scale up" implementation according to identified outcomes with systems planning and strategies.
- ◎ Effort identify various groups by their familiarity with CtLC
 - ★ Define specific activities for each group – both formal and informal
 - ★ Identify a "lead" with the State Team to take responsibility for each group and related activities
 - ★ Identify how to best leverage National CoP resources and connect each group to the "big picture" in SD



SD CoP Network for Charting the LifeCourse

Q3 Please select the statement that best reflects your level of use of Charting the LifeCourse (CtLC):



SD CoP Network for Charting the LifeCourse

- ◎ **Brenda Smith: LifeCourse Ambassadors**
 - ★ Ambassadors who those who are “making it happen”, facilitating, training and teaching others about the guiding principles
- ◎ **Carrie Geppert: CtLC Champions**
 - ★ Stakeholders who are opening doors to use CtLC in different ways – either at an implementation or systemic level
- ◎ **Teri Bukowski: Early Adopters**
 - ★ People who are excited and who are using and trying CtLC in different ways
- ◎ **Elaine Roberts: General**
 - ★ People who may be hearing about CtLC but aren’t necessarily using it



Upcoming Activities for Charting the LifeCourse in South Dakota

- ◎ Introduction to Charting the LifeCourse & Charting the LifeCourse in Action
 - ★ Rapid City & Spearfish - February 2019
 - ★ Brookings – Spring 2019
 - ★ Huron – Spring 2019
- ◎ March 26-27
 - ★ SD CoP in person meeting – location TBD
 - Meet with the CoP State team members to support structure and goals of CoP and provide training or technical assistance on specific topics (CtLC and innovation areas).
 - Year 3 Objectives: Plan for sustainability of both infrastructure and innovation, "Scale up" implementation according to identified outcomes with systems planning and strategies.



Upcoming Activities for Charting the LifeCourse

- ⦿ Annual CoP Meeting in Kansas City **April 30th, 2019**
 - ★ Participate in shared learning
- ⦿ Charting the LifeCourse Showcase – **May 1-2, 2019**
 - ★ Provide a platform for in-person and virtual opportunities to come together with national and international stakeholders to share how the CtLC framework and tools are being used to implement change at all levels. Annually attendees come together in person to showcase their learning in breakouts, tool in action sessions, expos and more.
- ⦿ Person Centered Thinking Trainer - Ambassador Series
 - ★ Exposure and understanding of the Charting the LifeCourse framework, provide participants an opportunity to receive a comprehensive overview of the foundational principles of the Charting the LifeCourse framework and its accompanying decision making and planning tools.



Staying Connected

National CoP website

www.supportstofamilies.org

**Examples, Videos, and
Downloadable materials**

www.lifecoursetools.com



<https://www.facebook.com/SDCharteringtheLifeCourse/?ref=bookmarks>



SD LifeCourse Ambassadors:

- ⊙ Brenda Smith
- ⊙ Carrie Geppert
- ⊙ Elaine Roberts
- ⊙ Teri Bukowski

2018-2019 LifeCourse Ambassador candidates!

- ⊙ Bobbie Jo Leggett - Edgewood Senior Living, Flandreau SD
- ⊙ Becky Israelson – FS 360 Coordinator, Sturgis SD
- ⊙ Brooke Nelson – DDD Resource Coordinator, Brookings SD
- ⊙ Nikie LaFortunue – RHD Case Manager, Dell Rapids SD
- ⊙ Deanna Wollman – SDDC, Redfield SD