

Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

*State Team Meeting, March 13, 2015, 9:30 am-3:30 pm
DLA Piper Offices, 500 8th Street NW, Washington, DC, 20004*

Agenda

9:30-10am – Welcome, Introductions and Brief Overview of the CoP

10-10:30am – Family Member Stories

10:30-12pm – Guided Discussion and Information Sharing about Supported Decision Making

12-1:15pm – Lunch and Discussion Tables – Grab your lunch and choose the discussion table you want to participate in! You can move around and join a couple of discussions.

- Advocacy
- Parent to Parent
- No Wrong Door
- Outreach
- Lifespan Respite Coalition

1:15-1:30pm – Discussion Tables Report Out

1:30-3pm – Creating a Vision for SDM in DC

3-3:30pm – Wrap up including:

- Launch of working group to review legislation in DC around guardianship, commitment and SDM
- Announcements
- Stipends
- Gratitude



DC Supporting Families of People with I/DD Throughout the Lifespan Community of Practice

March 13, 2015

Our Core Team Members



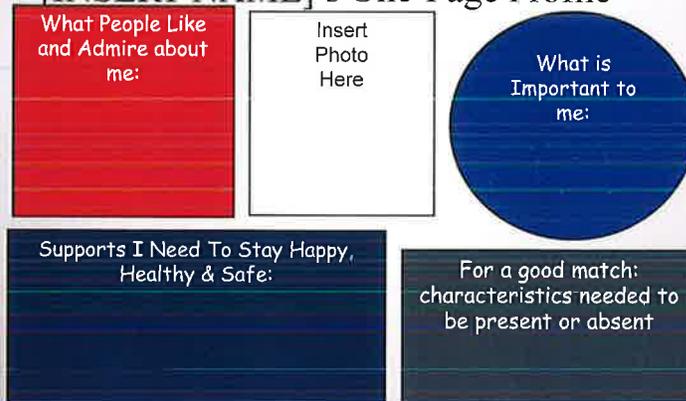
The HSC Health Care System
Health Services for Children
with Special Needs, Inc.
(HSCSN)



Person Centered Thinking Drives Systems Change

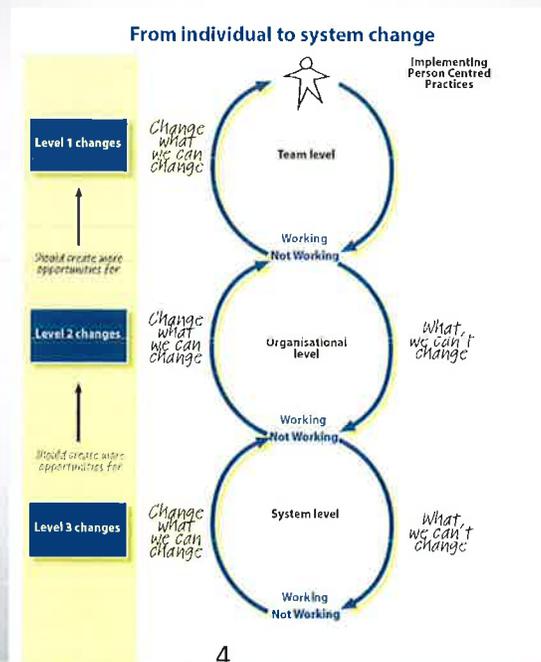
One Page Profile Template and Sample

[INSERT NAME]'s One-Page Profile



3

Levels of Change



4

Levels of Change



5

Level 3 Changes Needed in DC

- Peer support throughout the lifespan
- Coordinated services and supports
- Supports for self-determination
- Person and family centered supports
- Comprehensive supports for people with DD throughout the lifespan

6

No Wrong Door



Our vision for Long Term Services & Supports:

- Person and family-centered
- Culturally and linguistically competent
- Excellent customer service
- Inclusive and integrated
- Community-based

7

Supported Decision-Making



What is “*supported decision-making*” (SDM)?

Supported decision-making is:

“a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”

– Robert Dinerstein

8

Work in Progress on Level 3 Changes in DC



- DC Advocacy Across the Lifespan Guide
- DC Parent-to-Parent Chapter
- No Wrong Door to LTSS
- Outreach to Families
- Lifespan Respite Coalition
- And more!!!

Family Support Council

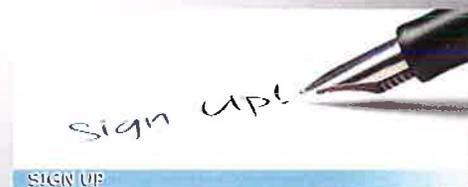


The FSC is established to provide recommendations, assist and advise DDS and sister agencies on developing person and family-centered systems of support for families throughout the life course of their family members with intellectual and developmental disabilities.

Support for Decision-Making Work Group



Review DC laws and advise on changes needed to keep decision-making in the hands of people with disabilities and their families.



11

Ending Commitment in DC



- Is your family member with an intellectual disability going to turn 18?
- Do you want to make sure that you and your family member will have a say in his or her life as an adult?
- Do you want to help restore the civil rights of other people with intellectual disabilities in DC?
- If so, your voice is needed!

12

GOVERNMENT OF THE DISTRICT OF COLUMBIA
DEPARTMENT ON DISABILITY SERVICES



DISTRICT OF COLUMBIA'S NO WRONG DOOR (NWD) PLANNING GRANT

I. Overview of the NWD Planning Grant

On October 1, 2014, the District of Columbia received a one-year grant from the Federal Administration on Community Living (ACL), in partnership with the Centers for Medicare and Medicaid Services (CMS) and the Veteran's Health Administration (VHA), to develop a three-year plan to transform current Long-Term Supports and Services (LTSS) programs and processes in the District into a single, No Wrong Door system for all populations and all payers.

Long-Term Supports & Services: Services and supports for people of all ages with disabilities and/ or chronic illnesses who need help with everyday tasks like bathing, getting dressed, preparing meals, taking medications, and managing their home.

The NWD plan is being developed in collaboration with people in need of LTSS, their families, advocates, public and private sector partners, community-based service providers and other partners. If the District is awarded a NWD Implementation Grant by ACL, the District's NWD Plan will be implemented over a three-year period from October 1, 2015 through September 30, 2018.

II. Our Goal

A coordinated, District-wide, No Wrong Door system that will support all D.C. residents in need of LTSS, regardless of where they enter the system. (Please see attached Mission and Vision.)

We aim to design a NWD system that is:

- **Person and family-centered** so that we are connecting people with LTSS based upon what is important to and important for them and their families;
- **Culturally and linguistically competent**-being responsive to cultural preferences, needs, and the diverse languages spoken by people in the District of Columbia;
- Respectful and provides **excellent customer service**;
- **Inclusive and integrated**, supporting people to live at home, with the services they prefer and need to be independent and fully included in all aspects of their community life;
- **Community-based**, linking people with LTSS through a coordinated and comprehensive network of public and private supports.

III. Overview of District's NWD System Approach

Key Steps in the District's NWD System	For Users of Long-term Services and Supports (LTSS)	For Providers of Long-term Services and Supports (LTSS)
Entering the NWD System	A single application process that is easy to use, available in multiple languages, and linked to the full range of LTSS across agencies and programs available in the District.	LTSS providers, traditional and participant-directed, are part of a well-coordinated and linked system of supports.
Service Planning Provided Through the NWD System	Service planning is centered around the unique needs and preferences of each person and family, and is responsive to their culture and language.	LTSS providers use similar person- and family-centered approaches to service planning, making it easier to collaborate with other agencies and for people to be served by multiple agencies.
Using LTSS Identified Through the NWD System	LTSS are a blend of family, community, and paid services that support people to live as independently as possible in their homes and be fully included in their communities.	LTSS are tailored and delivered by providers (traditional and participant-directed) to each person's preferences, strengths, and needs and promote independence.

IV. Your Feedback

We need your help to develop the NWD System for the District of Columbia. Please share your thoughts and experiences with us so we can design a system that is comprehensive, flexible, and responsive to all District residents in need of LTSS.

1. What has been your experience learning about and getting connected to LTSS in the District?
 - a. What was helpful?
 - b. What made the process difficult?

2. What has been your experience receiving LTSS in the District?
 - a. What has worked for you?
 - b. What has not worked for you?

3. What do you think of the proposed NWD project?
 - a. NWD Mission,
 - b. NWD Vision,
 - c. NWD Approach, and
 - d. Please share your thoughts on the other qualities that are important for the District's NWD System.

If you are comfortable, please share your name and contact information with us, so that we can keep you informed of our progress and reach out to you for continued feedback and help with planning.

Name: _____

Phone: _____

Email: _____

Thank you! If you would like to stay involved and help us plan for a NWD system, or if you have more feedback for us, please contact Erin Leveton, D.C. Department on Disability Services, at (202) 730-1754 or erin.leveton@dc.gov.

I. Vision of the District’s No Wrong Door System

The vision of the District of Columbia’s NWD System is to implement a coordinated, District-wide, No Wrong Door System that will support all D.C. residents in need of long-term services and supports (LTSS), and their families regardless of where they enter the system. When accessing the NWD system, people with disabilities and their families will encounter staff who are knowledgeable; serve them with respect; support their goals, service needs, preferences and cultural and linguistic diversity; promote their independence and community inclusion; and link them to community and/or public LTSS.

II. Mission of the District’s No Wrong Door System

The District’s mission is to create a “No Wrong Door” system for people in need of Long-Term Supports and Services (LTSS) that:

- Connects people to desired services and supports regardless of where they start seeking services;
- Responds to a person’s stated and assessed needs through either the provision of direct services or linkages to other appropriate community-based and/or public services and supports;
- Uses uniform methods to collect and/or summarize intake, assessment and planning information and provides for streamlined application and eligibility processes for all LTSS regardless of payer.
- Uses an electronic infrastructure to connect agencies so people can authorize the release some or all of their information between agencies, thereby streamlining their access to services and supports between and among public and private sources of LTSS.
- Utilizes consistent person-centered approaches regardless of the LTSS for which a person is eligible and/or the door through which they enter the LTSS system;
- Coordinates information, referral and assistance;
- Supports a knowledgeable, well-trained, respectful, skilled staff that excels in customer service; have access to information about the resources and supports available from public and private sources; are helpful in connecting people and their families to supports and services quickly, offer assistance, as needed, to people navigating multiple service delivery systems; assist people in accessing formal and informal LTSS from neighborhoods and communities in addition to that which is available from the formal, publicly-funded LTSS; are skilled at linking people to a broad range of formal and informal LTSS; and are culturally and linguistically competent in their interactions, communications and outreach.



GOVERNMENT OF THE DISTRICT OF COLUMBIA
Department on Disability Services
Office of the Director

MEMORANDUM

TO: Supporting Families Community of Practice
FROM: Laura Nuss, Director, Department on Disability Services
SUBJECT: Launch of Family Support Council Membership Recruitment
DATE: March 12, 2015

The Department on Disability Services (DDS) is pleased to launch the recruitment of members for the Family Support Council (FSC). The FSC is being established to provide recommendations, assist and advise the Department on Disability Services and sister agencies on developing person and family-centered systems of support for families throughout the life course of their family members with intellectual and developmental disabilities.

The work of the Supporting Families Community of Practice, since it began in August 2013, has illuminated the need for ongoing and meaningful engagement between government agencies and people with intellectual and developmental disabilities and their family members. The FSC will provide a sustainable forum for this engagement and ensure that government agencies are held accountable to the needs of the people they are serving.

The FSC will have 11 voting members, the majority of which will be people with intellectual or developmental disabilities and their family members and may have additional nonvoting members. Members will serve 2-year terms and meetings will be held every other month beginning in April 2015.

In order to best facilitate participation by people who are not working or would forfeit wages to attend meetings or for whom transportation or child care costs would pose a hardship, DDS will provide stipends according to the DDS Stipend Policy. DDS will also provide reasonable accommodations upon request.

To apply, please fill out the attached application and return it to Alison Whyte at alison.whyte@dc.gov. If you have any questions or need support to complete the application, please feel free to contact Alison at 202-870-9640.



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@dc.gov. If you have any questions or need support to complete this application, please contact Alison Whyte at alison.whyte@dc.gov or 202-870-9640.



Date:
Name:
Best way to contact you:
Membership category (select all that apply): <ul style="list-style-type: none"> <input type="checkbox"/> Person with an intellectual and/or developmental disability <input type="checkbox"/> Family member of a person with an intellectual and/or developmental disability <input type="checkbox"/> Disability services or advocacy professional (please attach a resume) <input type="checkbox"/> Other: please specify: _____

Please provide answers to the questions on the next page.

Why do you want to be involved in the Family Support Council?

Please list three issues that you would want the Family Support Council to consider:

- 1.
- 2.
- 3.

How will you ensure that you maintain a family-centered perspective when participating in the Family Support Council?

Are you willing to serve a 2-year term on the Family Support Council?





INNOVATIONS IN SUPPORTING FAMILIES

COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE WEBINAR SERIES

FOCUSING ON THE FRONT DOOR OF LONG-TERM SERVICES TO ENHANCE SUPPORTS TO FAMILIES

Reaching out to find information or to get necessary services and supports can be a hard first step for many families. Two of the Community of Practice states, Missouri and Tennessee, have been working to make this initial contact with the state developmental disability systems a more person- and family-centered experience. Staff from the state Intellectual and Developmental Disabilities (I/DD) agencies will provide an overview of the changes they are making to the front door of services to better meet the needs of persons with I/DD and their families and to serve as a no wrong door to other supports.

PRESENTERS

Key staff from the state I/DD agencies in



MISSOURI
DMH Division of
Developmental
Disabilities



TENNESSEE
Department of
Intellectual &
Developmental Disabilities



LOG IN AT

<https://nasddd.adobeconnect.com/familynetworks/>

CALL INTO

(888) 407-5039

MARCH 26, 2015

2PM Eastern / 1PM Central / 12PM Mountain / 11AM Pacific / 10AM Alaska / 9AM Hawaii

Webinar will last approximately one hour and a half.

This webinar is part of a series focused on innovative strategies to enhance the systems that support families of individuals with intellectual & developmental disabilities.

For more details about the series, please visit supportstofamilies.org.

HOSTED BY



NASDDDS



Human Services
Research Institute

The *Innovations* Webinar Series is brought to you by the National Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities. This project is funded by the Administration on Intellectual & Developmental Disabilities, grant number ACF 90DN0298. AIDD is dedicated to ensuring that individuals with developmental disabilities and their families are able to fully participate in and contribute to all aspects of community life in the United States and its territories.

2015 Winter/Spring State Employment Leadership Network (SELN) Series
The Role of Family: Sharing the LifeCourse Framework

The LifeCourse Framework helps individuals with disabilities, at any age or stage of life, to develop a vision for a good life. Individuals and their family members can use the Framework to guide them in accessing natural supports and achieving meaningful community life experiences, including integrated employment.

Developed by the University of Missouri-Kansas City Institute on Human Development, Human Services Research Institute, and National Association of Councils of Developmental Disabilities, the Framework guides policy, service provision, and planning. Families and field professionals use the Framework in state systems and on project teams.

Using the Framework as a backdrop, the SELN is hosting a series of discussions on ways to reframe expectations around employment.

THANK YOU TO EVERYONE WHO JOINED US FOR SESSIONS 1 & 2!

Session 1: Strategic Mapping Using the LifeCourse Framework

Archived at: <http://www.selnmembers.org/events/families>

Session 2: LifeCourse and Employment Outcomes

Archived at: <http://www.selnmembers.org/events/families>

Session 3: Implementing Lessons Learned

April 14, 2015: 3:30 pm

Hear first-hand stories on how the Framework has been used to change policy and practice, promote self-determination, and improve planning.

Viewing location TBA, or you can register at:

<http://www.selnmembers.org/familyregistration>.

Accessibility: The SELN tries to accommodate all people. The LifeCourse series features closed captioning on all sessions. If you have questions about other accommodations, contact Sheila at sheila.johnson@umb.edu .



Quality Trust

for Individuals with Disabilities

Supporting and Assisting Decision-Making by People with Intellectual Disabilities

Decision Making is a Skill – People Can Improve with Practice!

- No one is born with the capacity of a great decision maker – these skills are learned through different life and learning experiences over time.
- People with intellectual and developmental disabilities deserve and need a variety of support and opportunities to acquire decision-making skills.
- When we withhold support or limit experience when decision making is limited, we create situations and circumstances that reinforce beliefs about links between intellectual disability and limited capacity for decision making.
- The assessment of individual decision making ability and "capacity" should be conducted in real life situations and take into consideration prior life and learning experience.
- The person's ability to make decisions should be developed and supported to over their lifetime through varied, real life learning opportunities and supports.
- People can develop capacity by taking an active role in everyday decisions like:
 - what to wear,
 - what to eat, and
 - what to do today.
- People who have not had the opportunity to participate in decision making should not be determined to lack capacity without additional opportunities and support to learn – unless it is an emergency situation.

The opportunity for self-direction is an essential part of dignity and respect for all people. We can all help by providing opportunities for people to express preferences and direct decisions about their lives and how they are supported.

Want to learn more? Contact Morgan Whitlatch at (202) 459-4004
email mwhitlatch@dcqualitytrust.org or visit us at www.dcqualitytrust.org.

Some People May Need Help with Decision-Making Now— But Everyone Can Learn to Make Some Decisions for Themselves

- Guardianship is a legal intervention to assist people who lack capacity for decision-making.
- Establishing guardianship removes rights and freedoms from a person and assigns control to someone else.
- A careful and comprehensive assessment should be made to determine if guardianship is the most appropriate and least restrictive support option available to the person.
- This assessment should focus on the person's:
 - decision-making skills,
 - experience,
 - capacity, and
 - circle of support.
- Guardianship should be pursued after all other alternatives have been considered and found insufficient to meet the person's needs for assistance.
- Many people with intellectual disabilities are capable of making some decisions for themselves with minimal supports even if others require the assistance of a guardian.
- Efforts should always be made to involve the person in decisions about his or her life and provide opportunities for the person to build decision making skills even when a guardian is appointed.
- Conduct annual reviews to see if guardianship can be terminated or reduced.
- Each year, you should also assess the effectiveness of support and learning experiences to see if the person is making progress in building decision making skills.

Capacity is not static and can change over time. With education, support and practical experience, many people can develop their decision-making skills and reduce or eliminate the need for surrogate decision making support.

For information about training or consultation designed to meet your specific needs, call Tina Campanella at 202-448-1442 or email tcampanella@dcqualitytrust.org.



United Way
of the National Capital Area
Designate # 9339



Designate # 33317

QUALITY TRUST FOR INDIVIDUALS WITH DISABILITIES
5335 Wisconsin Avenue NW, Suite 825, Washington, DC 20015

www.dcqualitytrust.org



Guardianship: It's not for everyone

Is a parent automatically the guardian of their adult child with a developmental disability? No. Although a parent may have been their child's guardian when that child was a minor, they stop being their child's guardian when he or she becomes a legal adult (age 18 in DC). The court must appoint the parent to be their adult child's guardian. Appointment of a guardian cannot occur without the appropriate court holding a formal hearing.

What is guardianship? Guardianship is a legal intervention that removes some or all decision-making authority from an individual and assigns it to a designated person called a guardian. It is a very invasive form of decision-making support and protection because it takes away rights. It should only be used as a remedy after all other less restrictive alternatives have been considered.

Does someone need a guardian just because they have a developmental disability? No. People with developmental disabilities are presumed by law to be able to manage their own affairs and to be able to make all their own decisions, the same as any other citizen. Often people with developmental disabilities can make many, if not all, of their own decisions, even if that means that they need to have a little extra support to do so. A substitute decision maker, like a guardian, should not be appointed for a person with a developmental disability until that person is given the opportunity and support to make decisions on his or her own. If a guardian does need to be appointed, he or she should act with extreme care and diligence when making decisions on behalf of the person. According to the Model Code of Ethics for Guardians, "all decisions should be made in a manner that protects the civil rights and liberties of the person and maximizes the opportunities for growth, independence, and self reliance."

What can be done to support a person with a developmental disability to make all or some of their own decisions? The most important support is to ensure people are included in every decision made about their life especially those connected with their formal habilitation and support process. A true assessment of individual decision making ability is difficult to make if the person has limited or no experience with making real life and day to day decisions. Real life experiences are critical to give people access to learning opportunities. Support strategies may include the use of family, friends and individual, voluntary advocacy relationships to assist the person to exercise personal autonomy.

Want to learn more? Contact The National Guardianship Association, Tucson, AZ, (520) 881-6561, www.guardianship.org or The Quality Trust for Individuals with Disabilities, Washington, DC (202) 448-1450, www.dcqualitytrust.org.

This document is intended for informational purposes only

Lifespan Respite



- The Lifespan Respite program is designed to help connect caregivers with the necessary resources to assist them with regaining perspective and finding comfort in even the most difficult caregiving situations. Some Lifespan Respite programs are:

Online Chats— every other week online chats discussing various care giving issues, topics, and needs.

Flex spending—is designed to address affordability barriers for care givers. The Lifespan Respite Flex Account system can reimburse or give caregivers funds to use for respite care expenses. By giving caregivers these funds they can afford respite services so they do not burnout.

For more information, contact Linda Irizarry at (202) 535-1442 or email linda.irizarry@dc.gov



District of Columbia Office on Aging
Aging and Disability Resource Center
500 K Street, NE, Washington, D.C. 20002

