SLIDE #1

The Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities exists to enhance and drive policy, practice, and system transformation to support people with intellectual/developmental disabilities within the context of their families and communities.

Nineteen member states are committed to developing systems of support for families of people with intellectual and developmental disabilities (I/DD) throughout the lifespan, and receive technical assistance, products, opportunities for shared learning, and support from a National Team to integrate innovative practices into existing and ongoing state systems change efforts.

SLIDE #2

The Community of Practice for Supporting Families is a partnership between the University of Missouri - Kansas City Institute for Human Development and the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

The Community of Practice network supports states in

* Listening to and learning from families of people who have disabilities about the way that systems can best change to support people across the lifespan
* Creating a feedback loop with the system to cultivate mutual support and accountability between the system and grassroots (families and self-advocates)
* Leveraging partnership that enable systems to have growth and connectivity to effectuate culture change for systems innovation
* Innovating and sharing learning about best and promising practices, innovations, and implementation strategies for person- and family-centered practices and policy enhancement

SLIDE #3

Supporting people with disabilities to live and fully participate in their communities throughout their lives has emerged as a fundamental right and consideration in disability policy and practices. Because of the role that families continue to play in the lives of their family members, future policies and practices must reflect the family as part of the system of support. Supporting the family is defined as a set of strategies targeting the family unit but that ultimately benefit the individual with I/DD.

Supporting the family strategies are intended to assist family members who have a key role in the provision of support and guidance of their family member with I/DD to address the emotional, physical, and material well-being of the entire family. Strategies must be designed, implemented, and funded in a manner directed by the family unit. They should be flexible, comprehensive, and coordinated.

SLIDE #4

DDDS became a member of the Supporting Families Community of Practice in 2016. DDDS has held state-wide annual “kick-off” events with support from the national CoP team since that time to engage individuals, their families, case managers, and providers to become more familiar with this new person-centered planning philosophy.

DDDS continues to use its annual National CoP technical assistance hours to engage provider agencies, service recipients, families, and other external stakeholders to continue to grow the Delaware Community of Practice.

SLIDE #5

The Charting the LifeCourse framework evolved as the model framework that members of the CoP used to think and speak differently about people with IDD, their families, what they needed, and how systems of support might align along a new paradigm.

Delaware has fully integrated the Charting the LifeCourse framework in the person-centered planning process. DDDS now uses tools from the LifeCourse toolkit to assist and encourage individuals and their families to develop their plans in accordance with their vision for their “good life”.

The Charting the LifeCourse framework was created to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. The framework is the keystone for supporting a community of learning that champions transformational change through knowledge exchange, capacity building, and collaborative engagement.

SLIDE #6

The Charting the LifeCourse framework consists of 8 key guiding principles:

1. **Focusing on All People**

All people, regardless of age, ability, or family role, are considered in our vision, values, policies, and practices for supporting individuals and families. All families have choices and access to the supports they need.

1. **Recognizing the Person Within the Context of Their Family**

People exist and have reciprocal roles within a family system defined by that individual. Roles adjust as the individual members of the family system change and age. The entire family, individually and as a whole, needs support to ensure they all are able to successfully live their good life.

1. **Trajectory of Life Experiences Across the Lifespan**

Individuals and families can focus on a specific life stage, with an awareness of how prior, current, and future life stages impact and influence their trajectory. It is important to have a vision for a good, quality life and have opportunities, experiences, and support to move the life trajectory in a positive direction.

1. **Achieving Life Outcomes**

Individuals and families plan for the present and future life outcomes that take into account all facets of life and have opportunities for life experiences that build self-determination, social capital, economic sufficiency, and community inclusion.

SLIDE #7

1. **Holistic Focus Across Life Domains**

People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. Life domains are the different aspects and experiences of life that we all consider as we age and grow.

These include:
• Daily Life & Employment
• Community Living
• Safety & Security
• Healthy Living
• Social & Spirituality
• Advocacy and Engagement

1. **Supporting the Three Buckets of Need**

The three strategies for supporting individuals and their families can be organized into three categories (or buckets):

* Discovery and Navigation: having the information and tools you need to navigate life
* Connecting and Networking: making connections with peers and resources to help you navigate
* Goods and Services: the day-to-day tangible items you buy or use from public and private organizations in your community
1. **Integrated Services and Supports Across the LifeCourse**

Individuals and families access an array of integrated supports to achieve their envisioned good life. These include those that are publicly or privately funded and based upon eligibility; community supports that are available to anyone; relationship-based supports; technology; and the personal strengths and assets of the individual and their family.

1. **Transformational Policy and Systems Change**

Individuals and families are truly involved in policy making so that they influence planning, policy, implementation, research, and revision of the practices that affect them. Every program, organization, system, and policymaker must think about a person within the context of family and community.

SLIDE #8

The Charting the LifeCourse framework uses a set of tools to help individuals discover and move toward their good life.

Life is a journey for everyone. Each stage of life paves a path that leads towards a vision for the future. This path or Trajectory will have ups and downs where there is a need to stop and consider what to do next. The Trajectory Principle and tool helps to define a person’s vision and how their past experiences have helped or hindered them in meeting their goals. They will be able to set goals and list out what may get in their way. The higher the expectations, the more opportunities and experiences will be possible, and will lead toward achieving goals and dreams.

The Trajectory is a strengths-based concept designed to help think about life, both short and long term. It can also be used to promote discussion, self-awareness, shared knowledge and facilitate planning with a person and their support team. It is a visual aid to guide and help a person explore and plan things in their life.

SLIDE #9

Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help individuals of all ages start to think about a more specific vision for life in the future and narrow down what life domain(s) to focus on.

SLIDE #10

The Reciprocal Roles tool will help individuals identify the people in their life and ways they support the individual. It also helps the individual explore ways that they support other people and roles each individual play in their lives. It can identify gaps as well as the potential for building even stronger relationships.

SLIDE #11

This principle serves as a reminder that everyone accesses a variety of supports to meet their day-to-day needs, support the achievement of long-term or short-term goals, solve problems, or enhance their quality of life.

Historically, planning for a person’s and/or family’s supports focused mainly on the government-funded or specialized services available and often left out the many assets and resources that could be leveraged to meet a person’s needs.

The Integrated Supports Star encourages accessing five main areas of supports:

* Public or privately funded based on eligibility
* Community places and services that are available to anyone
* Relationships
* Day-to-day and adaptive technology
* The assets and strengths of the individual and family.

SLIDE #12

The Lifespan Waiver provider network supports the work of the Community of Practice by integrating person-centered care into all aspects of service delivery, by supporting the efforts of the network to enhance policy and service delivery system, and by joining with DDDS to create a robust network that supports the best lives for our participants and their families.