

ISSUE BRIEF

Overview of the LifeCourse Framework
March 2015

All people have the right to live, love, work, play and pursue their life aspirations in their communities.

In not-so-recent history, the common practice of professionals in the medical field when a person with a disability was born was to suggest to their family they be institutionalized. People with disabilities were sent to live in institutions, separating entire generations from their families and the communities in which they were born, because people were afraid of the stigma of disability.

Today individuals with I/DD and their families embrace the idea that people with disabilities have skills, dreams, and feelings like everyone else and belong with their families. As principles of integration and inclusion are realized, a new generation of youth with disabilities are growing up in classrooms with their peers, going to college, getting married, and raising families of their own.

Embracing this shift in paradigm means thinking differently about what it means to support individuals with disabilities and their families. Our field is constantly growing and changing as we have been working hard for many years to steer our system away from an institutional focus to become a more person-centered system.

Thinking differently about supporting families means recognizing that people exist and have reciprocal roles within a family system, which adjust as the individual members change and age. The entire family, each of the individual members collectively but also the whole unit, needs support to ensure all of the members are able to successfully live a good life in the community.



THE LIFECOURSE FRAMEWORK

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COMMUNITY OF PRACTICE LEARNING

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BACKGROUND: Supporting Families and the LifeCourse

HISTORY OF FAMILY SUPPORT

It is important to understand how far the disability field has come. Systems began with an institutional focus; however, over the past 30-40 years have become more person-centered. As this evolution has taken place, the concept of family has been lost in conversations about policy and practices. All individuals live within the context of their family. As the system has evolved, we have tried to figure out strategies to support people with disabilities. As we have done that, we have made programs and services that enhance individuals' abilities. However, we failed to think about what that did to individuals. It actually cut them off from their family and community. With the best of intentions, the service system has created a barrier to family and community. As we move forward, we need to integrate supports so people get what they need, and when they need it, but are not cut off from their loved ones.

LIFE COURSE THEORY

Life course theory is being increasingly embraced by researchers and practitioners across fields. The roots of the life course theory can be found in the public health arena. The public health field has used the framework to explain health and disease patterns across populations and over time as well as health disparities within and among populations. Life course theory is tied to social determinants and social equity models. It doesn't look solely at the individual, but it looks at the individual in the context of the communities in which they belong¹.

Life course theory looks at life not as disconnected stages, but as an integrated continuum. "It is a conceptual framework, some people might even call it a paradigm shift, which recognizes that each stage of life is influenced by the stages that precede it, and it in turn influences the life stages that follow it."²

The main concepts behind the life course theory are¹:

1. **Timeline:** health develops over a lifetime, and improves or declines based on exposure to risk and protective factors.
2. **Timing:** health trajectories are affected at critical points of time and by life experiences.
3. **Environment:** health is inextricably linked to where people live, biologically, physically, and socially.
4. **Equity:** biology and human behavior do not explain inequality in health but only shine a light on part of a person's overall health.

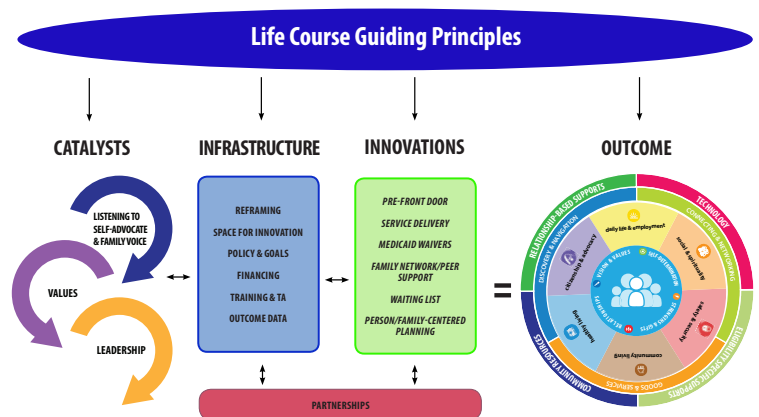
References:

- U.S. Department of Health & Human Services Health Resources & Services Administration Maternal & Child Health Bureau. (2010). Rethinking MCH: The Life Course Model as an Organizing Framework.
- Lu, Michael C. (2009) Improving Maternal & Child Health in America: A Life-Course Perspective. UCLA OB-GYN Grand Rounds.

THE NATIONAL COMMUNITY OF PRACTICE AND THE LIFECOURSE FRAMEWORK

The LifeCourse framework used by the Community of Practice was developed by Missouri Family to Family (MOF2F) and provides a guiding ideology and vision for any effort to develop or improve supports for families with the ultimate goal of quality of life for the individual with a disability. The initial framework was created with the assistance of the Missouri Family to Family Network with involvement from a stakeholder group made up of self-advocates, family members, and professionals.

The National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities constructed a framework for systems change adapted from the work of the Support Employment Leadership Network (SELN) with the LifeCourse infused. There are several components of the systems change framework and each component works with the others to drive systems change. The components include catalysts, leadership and principles, and a set of performance indicators. The principles of the LifeCourse framework influence not only the outcome but the components of system change as well.



Adapted from Hall et al., 2007

The ways in which I/DD systems developed over time, have often led to services and supports that are, for the most part, reactive and crisis driven, addressing isolated life domains or discrete episodes of need. The LifeCourse framework offers a more holistic approach to planning the life trajectories of both individuals and family units. This framework provides a way to understand supports to both persons with disabilities and their families across the lifespan. Additionally, the LifeCourse framework is not specific to disability but rather applicable to the human experience. Through the work of the Community of Practice, the LifeCourse framework continues to evolve and be validated.



The LifeCourse Framework

REFRAMING OUR THINKING TO ENHANCE SUPPORTS TO FAMILIES

Charting the LifeCourse is a framework that was developed to help individuals with disabilities and families at any age or stage of life 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. Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive productive life in the future. The framework was developed with individuals with developmental or intellectual disabilities and their families in mind. The framework is designed to help any citizen with a disability think about their life, not just individuals known by the service system. Although the framework was developed for people with disabilities, it is designed universally, and could be used by any family making a life plan, whether they have a member with a disability or not.

LIFE COURSE FRAMEWORK/PRINCIPLES

ALL INDIVIDUALS AND FAMILIES



ALL individuals and families, whether they are known to the DD system and/or receive formal services or not, are considered in our vision, values, policies and practices for supporting people with intellectual and developmental disabilities.

LIFE STAGES AND TRAJECTORY



Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life trajectory.

FAMILY SYSTEM AND CYCLES



People exist and have reciprocal roles within a family system, which adjust as the individual members change and age; individuals and families need supports that address all facets of life and adjust as roles and needs of all family members change as they age through the family cycles.

INDIVIDUAL AND FAMILY SUPPORTS



Supports address all facets of life and adjust as roles and needs of all family members change. Types of support might include discovery and navigation (information, education, skill building); connecting and networking (peer support); and goods and services (daily living and financial supports).

LIFE OUTCOMES



Individuals and families focus on life experiences that point the trajectory toward a good quality of life. Based on current support structures that focus on self-determination, community living, social capital and economic sufficiency, the emphasis is on planning for life outcomes, not just services.

INTEGRATED DELIVERY OF SUPPORTS



Individuals and families utilize an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility, community supports that are available to anyone, relationship based supports, technology, and that take into account the assets and strengths of the individual and family.

LIFE DOMAINS



People lead whole lives made up of specific and integrated life domains that are important to a good quality of life, including daily living/employment, safety and security, community living, healthy lifestyle, social and spirituality, and citizenship and advocacy.

POLICY AND SYSTEMS

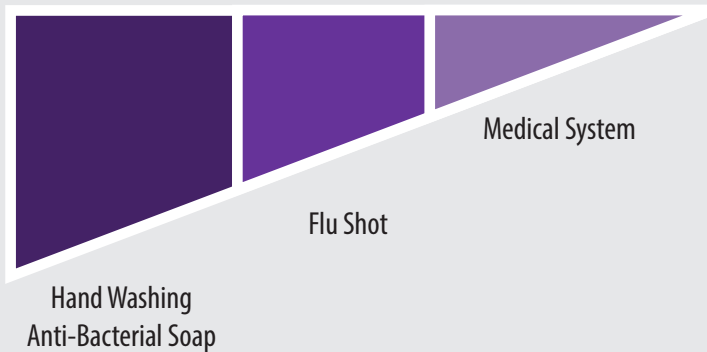


Individuals and families are satisfactorily involved in policy-making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them. Individuals and families design and direct the supports they receive to the extent possible with sufficient public funding allocated in ways that are fair to all individuals and families.

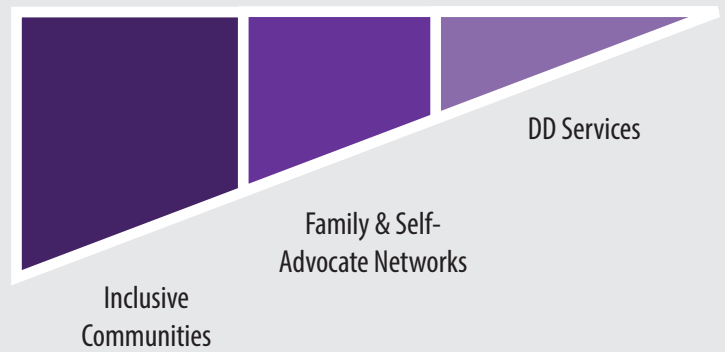


RECOMMENDATION: Reframing the Conversation at All Levels

CONSTRUCTING A UNIVERSAL STRATEGY



The field of public health has worked to solve the problem related to the spread of infectious disease like the flu using many different strategies and ideas. We know that if everyone contracted the flu, the medical system would not be able to treat everyone who came to the hospital-- it simply does not have the capacity. The public health field discovered that the flu shot is very successful in preventing its spread and lessening its effects and now promotes this widely as an intervention. Communities have embraced and accepted ownership of the intervention so you can now easily get the vaccine almost anywhere, including a drive-up clinic at your neighborhood church or at your grocery store. Even more impactful than the flu shot, however, is an intervention that has been picked up by our culture-- the simple washing of hands using anti-bacterial soap. Anti-bacterial soap is in restaurants, public spaces and is most likely in your bathroom right now. This innovation has single-handedly done the most to prevent the flu.



Supports to individuals with developmental disabilities and their families can be viewed using the same approach. While we know that the current state systems of services and supports simply are not set up to serve all families who need assistance, we can look to the disability community to fill the gap with support groups and networks that are geared toward providing information and opportunities to connect with other individuals and families through existing family and self-advocate networks. At the same time, we know that the most effective way to provide supports to individuals with developmental disabilities and their families is by offering them the same access to resources and supports that other families have. Even though we don't usually think of going to a place of worship as a support or intervention, the idea of going to your faith community for support when you need it is commonly accepted by our culture.

BUILDING FAMILY & SELF-ADVOCATE NETWORKS

MISSOURI

Missouri has been working for years to build a strong statewide Family to Family Network. The network consists 150 affiliates and over 900 self-advocate and family leaders. Affiliates include places like doctors' offices, churches, and other community agencies across the state. The state agency in Missouri also has contracted with the Family to Family Health Information Center (F2F HIC) to create a seamless front door. The goal of the partnership is to make the first contact families have with the service system as meaningful as possible. The F2F HIC and state agency partnership works to get families started in the process of service eligibility, but also connect with a parent or self-advocate to give them information and support they need.



DISTRICT OF COLUMBIA

The state disability agency is partnering with other state agencies and has contracted with Parent to Parent USA to start a chapter in the District of Columbia. In this partnership, they are working on integration and sustainability from the beginning.

District of Columbia is also training family facilitators on One Page Profiles. These profiles are helpful for families to communicate their family member's needs in a succinct way to service providers and others.

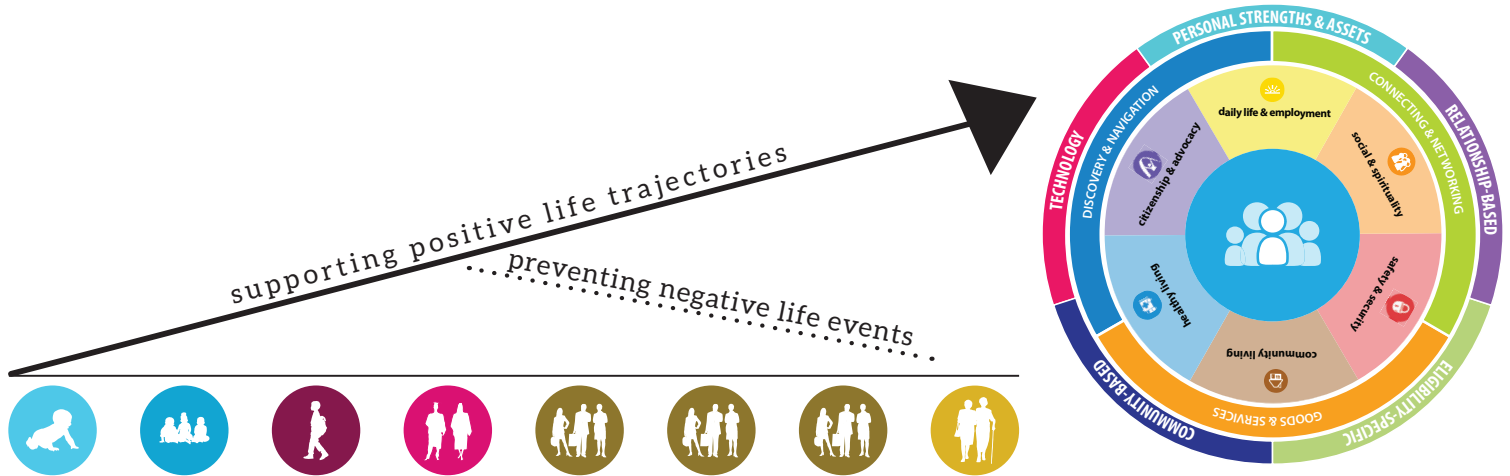


Visit **Parent-to-Parent Usa** (p2pusa.org)
to find out how you can start a P2P network in your state.

Connect with **SABE** (sabeusa.org),
to find out about starting a self-advocacy network in your state.



APPLYING THE TRAJECTORY TO POLICY, PRACTICE AND PLANNING



A good life is a good life, regardless of disability. A person with a disability shouldn't have different life outcomes. They want family and friends and economic stability—the same things that we all want.

To support people with disabilities to have a good life, it is important to always keep life outcomes in mind, not just focus on service outcomes. The **Life Trajectory Worksheet**, a LifeCourse Tool, allows professionals, individuals, and families to do that by asking questions beyond what services people need and digging into the life outcomes they are trying to achieve.

Whether we are working with an individual or a family or we are working with policymakers and program administrators, we begin this activity by asking people to reflect on what is important to them personally. Then, we ask: why it is any different for a person with a disability? Life outcomes are the same whether you have a disability or not—things like being happy, having a nice place to live, and having family and friends are universal.

In a field that is moving away from specialized services based on a diagnosis, sometimes professionals who work with families and families that have children with disabilities struggle with the idea of vision because they have been caught up in dealing with crises and struggling to find resources. Often we find we have to start with what they don't want for the person, things like segregation or loneliness. Once those are identified, they can begin working towards what they do want.

AT THE INDIVIDUAL PLANNING LEVEL

The Life Trajectory can be used to plan for the future of an individual and their family. Families and professionals can use the trajectory worksheet to jump start the conversation about a vision for a good life. It helps everyone involved understand the vision an individual with a disability holds for their good life by focusing in on what they want and do not want for their life.

In John's example, he was very clear about the things he didn't want for his life: losing his job, other people making his decisions for him, and not being dependent on staff all the time. Figuring out what he didn't want for his future helped him and his team identify steps and outcomes that he could work toward to have his good life.

AT THE PRACTICE LEVEL

The Life Trajectory is also helping examine practices that affect people with disabilities.

An example we often give that makes people think twice about the trajectory their focus person is headed on is when it comes to belonging in their community.

Most people learn how to interact with peers who are the same age in their early years of school. If we brainstormed current practices that are helping children with disabilities fit in with children their own age, we might list inclusive daycares and accessible playgrounds. On the other hand, if we thought about practices that created a barrier between students and their peers, we may discover that some practices currently in place—like segregated kindergarten classrooms, inadequate professional development for frontline workers—are setting children on a negative trajectory.

Once identified, stakeholders can begin working to change the practices that are hindering the trajectories and focus on improving those that support positive trajectories. Incidentally, some common practices and traditional ways of supporting people with disabilities may require more sweeping changes at the policy level.

AT THE POLICY LEVEL

The Life Trajectory worksheet is helping facilitate policy discussions. In one state, stakeholders gathered to discuss employment for people with disabilities. To start, the group was asked to identify what the ultimate goal was. Responses included careers and economic sufficiency. Then participants talk about what they didn't want, which included things like poverty or dependence. The beginning of this exercise works to get everyone on the same page.

Then, they took different life stages and thought about common life experiences and rites of passages people experience early in life and how they had an impact on employment outcomes when they were older. People listed things like chores, an allowance, volunteering, and belonging to a club at school. People with disabilities must have the opportunities to have those same life experiences. Families must be encouraged and supported to expose their children to those experiences that are building blocks to the lives they want.

Next, they thought about policies and practices that could set the project on the positive trajectory and which ones might send it on the negative trajectory. For example, the Employment First policies and people getting the message that employment is important would set it on a positive trajectory. However, inadequate funding and support for job training programs and competitive employment may set it on a negative trajectory.



INTEGRATING SUPPORTS AT ALL LEVELS

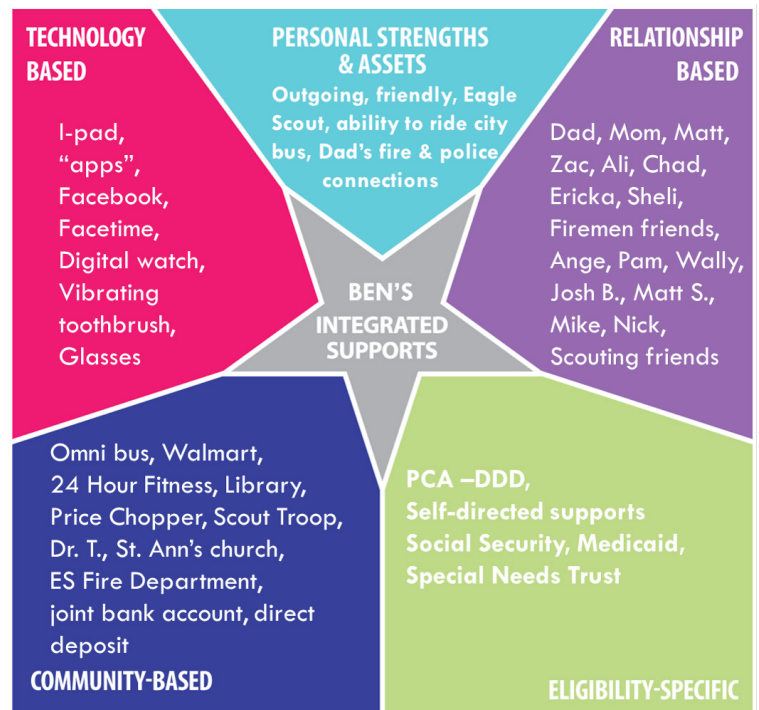
AT THE POLICY & PRACTICE LEVEL

The Integrated Supports Star can be applied to policy and practice level thinking by helping identify potential partners who should be at the table when talking about changing or creating policies or programs that will affect individuals and their families. It can also help point out who is not at the table so they can be invited!

In addition to helping ensure that all vested stakeholders are involved in the policies and practices that support families, the Integrated Supports Star can also assist systems and organizations see where capacity might need to be built when it comes to the types of supports available to families in a particular area.

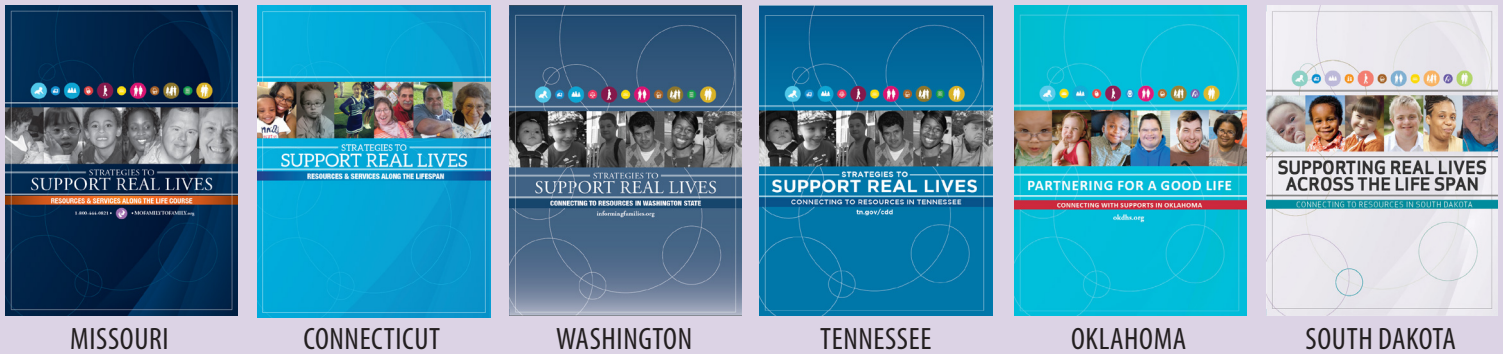
AT THE INDIVIDUAL LEVEL

The Integrated Supports Star can be applied at the individual level to identify where capacity might need to be built in that person's life to help that person become less reliant solely on paid, eligibility-specific supports. In this example (image on the right), Ben's family is working on building his skills, relationships, and connections with community and learning how to use technology to make his supports more integrated.



APPLYING INTEGRATED SUPPORTS AT THE INDIVIDUAL LEVEL

PARTNERING TO DISSEMINATE A CONSISTENT MESSAGE



In Missouri, the MODDRC/F2F Network has been disseminating a folder that started out as a simple tool to connect families with needed information and supports. Since the first edition in 2003, their network folder has grown along with the movement to provide quality information and support families, building on existing initiatives focusing on providing information and assisting families to navigate the system. The network folder unlocks access to needed services and supports, including information and emotional support. The MODDRC/F2F Network folder lists over 50 organizations that support families, from statewide service systems to parent support groups.

Five of the six Community of Practice states as well as states that are not official members of the Community of Practice have developed or customized materials using the LifeCourse framework in hopes that the tool will serve as a door opener to conversations about ideas like the good life, integrated supports, and a vision for the future when families receive it. However developing and

designing materials that are pleasing to the eyes when families pick them up is only the first step.

Since its creation over ten years ago, over 90,000 folders have been disseminated across Missouri to individuals with disabilities, parents and caregivers, professionals, and the general public through MOF2F Network partners. Partners can customize what they put inside the folder when they are working with families. The state DD service system even uses the folder and LifeCourse materials in their intake process.

Since the Community of Practice began, the state CoP teams who have developed their own materials have also begun working with their networks in their own states to spread a message of hope and vision for the future to the individuals and families they support.



Community of Practice Learning

OVERALL

- **Individuals Live within the Context of their Families:** We aren't talking about supporting families versus person-centeredness. Instead, we are talking about increasing supports to families as data shows us the reality that many people are supported by families or friends.
- **All People with Developmental Disabilities:** The concept of "all" has made major impact. Budgets don't allow us to serve all, but strategies should reach as many people as possible. We need to learn about these families outside of the service system so that we can support 100% of people.
- **Family Support vs. Supporting Families:** The phrase "family support" conjures up the old bureaucratic mentality of a program. Instead, we are reframing the conversation to discuss how we can actively support families where they are.
- **Challenging Tradition:** Aging families worked hard to help build the current service system and are comfortable with how it operates as it was designed to meet their needs. As our culture continues to change and inclusion and integration play a larger role in our communities, we must consider how we can redesign systems to meet the needs of all families. Furthermore, we need to educate the general public about where the field is and where we are headed.
- **Thinking about Integrating Supports:** The focus of supporting individuals and their families has shifted towards helping them think about their own personal assets, relationships, community resources, and using technology instead of, or in addition to, paid or formal supports.
- **Proliferation of Practical Tools:** People are ready for the message and concrete practical tools. Across the country, people are really taking it in.
- **Partnership is Essential to Success:** The skill of partnering with other entities and self-advocates and families is hard. While essential, it is also messy and complex. It's not easy, but we must continue to work.

SYSTEMS

- **Connect initiatives:** Often we are on the same trajectory, no matter which field or system we represent. We have the same goal in mind but interact with people in the different stages. We have so much in common, how can we help each other accomplish our goals?
- **Expanding our Thinking beyond DD:** Originally, we were focused on improving the policy and practices of state developmental disability systems. The LifeCourse framework is quickly spreading into other arenas.
- **Integrating Person-Centered and LifeCourse Thinking:** The LifeCourse Framework is not meant to replace person-centered planning or thinking but instead it is meant to serve as a complement.

PRACTICE

- **Reframing Messages based on Audience:** LifeCourse training materials and tools have been developed and piloted with different target audiences, including self-advocates, families, case managers, options counselors, teachers, and family navigators. Many of the tools came from people asking for them. We encourage people to use them and let us know how they used them, and work with us to continue improving them.
- **Executing a Strategy:** The initial phases of developing and implementation of the LifeCourse tools included working with facilitators and trainers to ensure competency and fidelity of practices. However, the end goal is for tools to be self-explanatory so anyone could pick them up and use them.

The screenshot shows the homepage of the Supporting Families website. At the top, there is a navigation bar with links for "About", "The States", "Resources", "Updates", and "Connect". Below this is a "LATEST NEWS" section featuring a graphic titled "Focusing on the Front Door - LifeCourse Framework Innovations Webinar Series, March 26, 2015". To the right of the news section is a "FUNDED BY" section listing the Administration on Intellectual and Developmental Disabilities, and a "NATIONAL PARTNERS" section listing various organizations like NASDDDS, UMKC, HSKI, CASAN, AUCD, and NACDD. At the bottom right, there is a "MAILING LIST" sign-up form with fields for "First Name", "Last Name", and "Email Address".

VISIT THE
COMMUNITY OF PRACTICE
ONLINE AT
supportstofamilies.org
to get the latest updates
about what we're learning
about supporting families
in your email inbox.

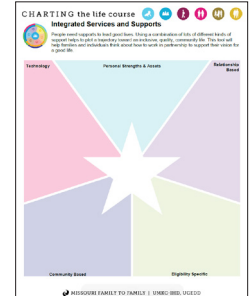
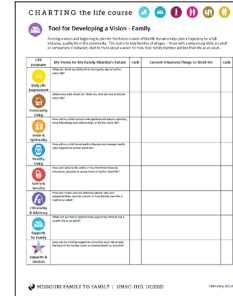
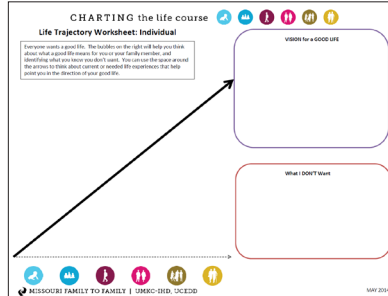
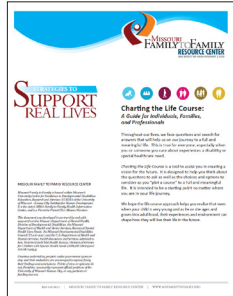
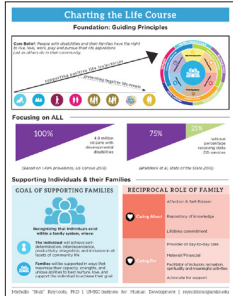


Resources



THE LIFECOURSE TOOLKIT

TOOLS TO HELP INDIVIDUALS, FAMILIES, AND PROFESSIONALS PLAN FOR A GOOD LIFE



LifeCourse Tools are tools developed for individuals, families, and professionals by family members of individuals with disabilities. The tools are developed using an iterative process, which means they are constantly being adapted and improved based on feedback from users.

The tools are free to use and customize. Many states have already adapted their own versions of the tools for professionals to work with families and to disseminate through their networks. Access the LifeCourse Toolkit at lifecoursetools.com



INNOVATIONS IN SUPPORTING FAMILIES

COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE WEBINAR SERIES

The *Innovations in Supporting Families* is a FREE webinar series focused on innovative strategies to enhance the systems that support families of individuals with intellectual & developmental disabilities. The series includes presentations from national experts about innovative strategies related to the experience of individuals and families as they navigate through their life course and use supports to assist them. Webinars will be hosted live every other month beginning January 2015 and archived for later viewing at nasdds.org and supportstofamilies.org.

initiatives, which share many of the same goals and objectives, complement and support each other?

- **Medicaid Waivers and Other Funding Sources:** How can we support individuals and their families in innovative ways with waivers?
- **Waitlist for Services:** How can we use the LifeCourse framework to understand waitlists in states and understand families waiting for services?

Topics will include:

- **Front Door to Long-Term Services & Supports:** How can we make the the first point of contact families have with the service delivery system as family-friendly and informative as possible?
- **Emotional/Navigational Peer Support:** How can connecting families with other to getting support emotionally or in order to navigate the service system make a difference?
- **National & State Data Projects:** How can we understand and use data to to best inform the work we do with families?
- **Person-Centered & LifeCourse Planning:** How do these two national

This webinar series is for stakeholders interested in enhancing the systems and policies that impact individuals with intellectual and developmental disabilities and their families, including:

- self-advocate and family leaders,
- leaders of community organizations and disability services, and
- state and federal policymakers.

The *Innovations* series is being hosted by the UMKC Institute for Human Development, UCEDD, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), and the Human Services Research Institute. Learn more about the series at supportstofamilies.org

Project Leadership



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.