

ISSUE BRIEF

Front Door to Long-Term Services and Supports, April 2015

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

The Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (I/DD) holds the core belief that **all** people have the right to live, love, work, play and pursue their life aspirations in their communities. Making this right a reality for all people means we must reframe our thinking about people with intellectual and developmental disabilities and their families and the supports they need to live a good life.

The Community of Practice (CoP) is working on discovering innovative strategies for supporting the entire family that are flexible and integrated, instead of focusing solely on formal services. This issue brief focuses on how states can look at the Front Door of long-term services and supports.

The Front Door of long-term services and supports is defined as the first interaction involving the family reaching out to the professional world for supports. Many times, the family is encouraged to engage with the service system but is unsure of what services may be available or what to request. The traditional response of professionals in the service system has been to provide families with information about services and set them on the trajectory to solely engaging in formal services.

Changing that very first interaction at the front door to better provide information and hope for the future, opportunities to connect with other families and networks, and think of options outside of the formal system for supporting people to achieve the good life is the focus of this issue brief. Read on to discover how two states have worked to make this initial encounter at the front door more functional and family-friendly and what they learned in the process.



INSIDE THIS ISSUE

THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

INNOVATIVE STRATEGIES FOR SYSTEMS CHANGE

FOCUSING ON TENNESSEE

SEIZING THE MOMENT: THE LEAN EVENT

INFRASTRUCTURE: REFRAMING THE FRONT DOOR

FOCUSING ON MISSOURI

INFRASTRUCTURE: REFRAMING THE FRONT DOOR

PARTNERSHIPS: MEETING FAMILIES AT THE FRONT DOOR

COMMUNITY OF PRACTICE LEARNING

THE LIFECOURSE FRAMEWORK

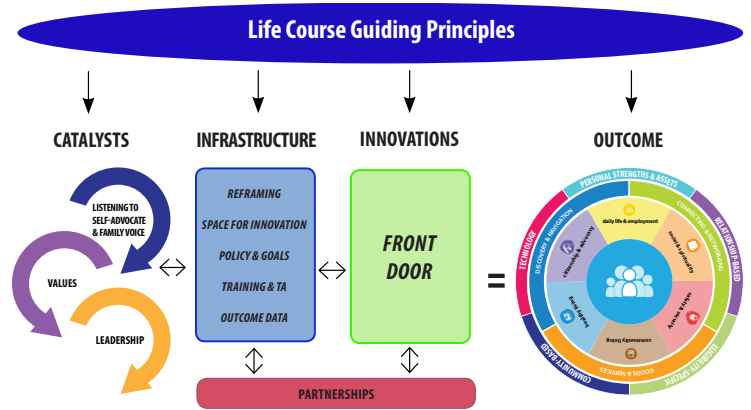
RESOURCES



INNOVATIONS IN SUPPORTING FAMILIES
COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS SERIES

THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

The Community of Practice (CoP) uses a framework for systems change adapted from the State Employment Leadership Network (SELN) (see right). The outcome of systems change is supports that help individuals and families achieve quality of life. Systems change is driven by innovations in supports offered to families, changes in infrastructure that make it more effective and flexible, and partnerships with organizations and the community. Family and self-advocate voices, values, and leadership are the catalysts that add fuel to the fire and make systems change more personal. Finally, all of this change is happening under the umbrella of the LifeCourse framework (see page 7), which promotes the idea that all people have the right to live, love, work, play and pursue their life aspirations in the community. Learn more about the framework for systems change at supportstofamilies.org.



Michelle "Shelli" Reynolds, PhD, UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et al, 2007

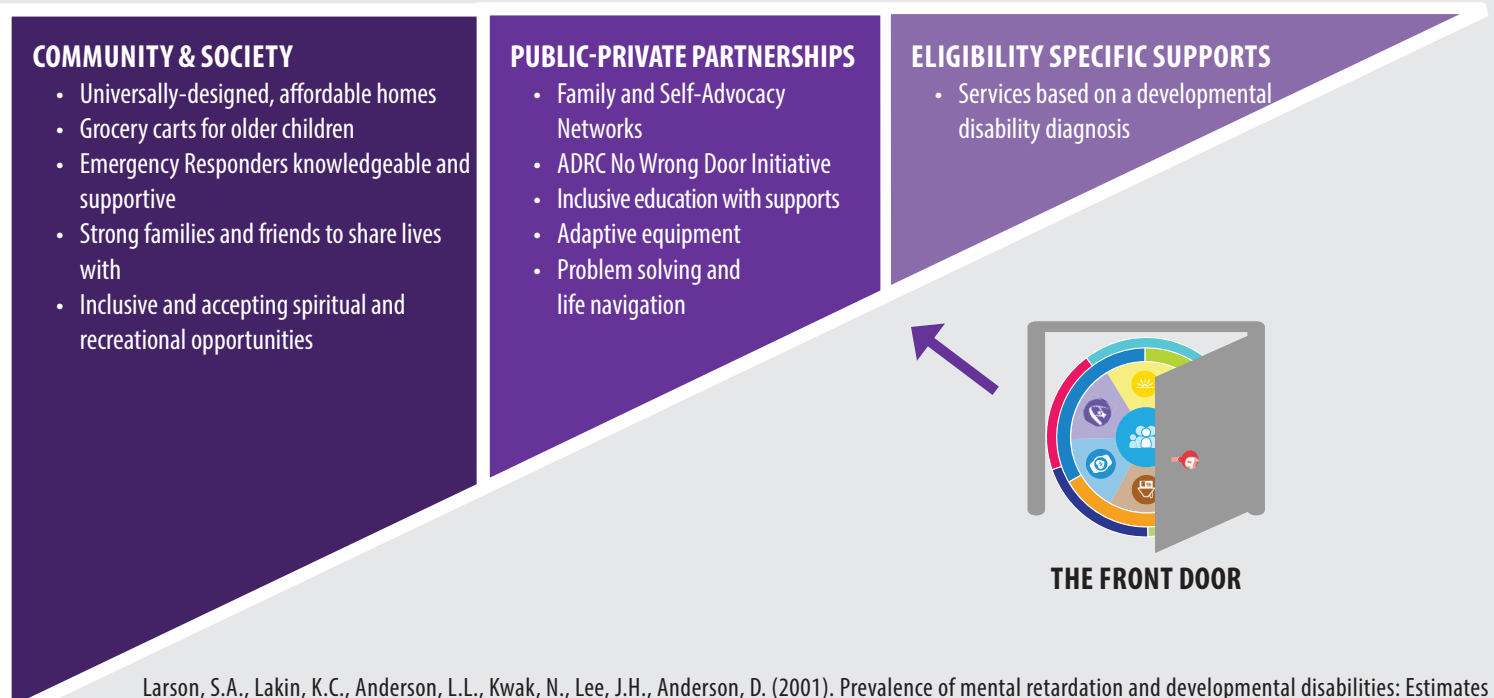
FOCUSING ON THE FRONT DOOR

The CoP has developed a universal strategy for providing supports, which is based on thinking that emerged from the public health field (see below). The left region of the triangle lists 'interventions' which can be implemented on a community-wide scale to improve access for all people. The middle region of the triangle describes policies and practices frequently used in the partnerships between public and private entities. Finally, the right region of the triangle portrays paid, formal service systems.

all people with disabilities. So, innovative strategies are needed to reach as many people as possible that acknowledge the changing paradigm .

The conversations with families that occur when they are first learning about services, or the Front Door, should not solely be focused on the service section of this triangle but provide families with network contacts and options that occur through the community and society and public-private partnerships.

Currently only 25% of people with I/DD receive paid supports from the DD service system¹. Dederal and state budgets do not allow systems to serve



Larson, S.A., Lakin, K.C., Anderson, L.L., Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American Journal on Mental Retardation, 106, 231-252.



HIGHLIGHTING INNOVATIVE STRATEGIES FOR SYSTEMS CHANGE

FOCUSING ON TENNESSEE

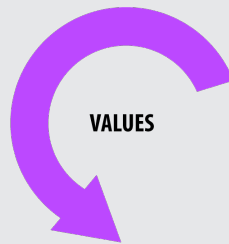
The Department of Intellectual and Developmental Disabilities (DIDD) operates in three regions with oversight by one central office. Each region has offices that are responsible for the front door. They are the point of contact for individuals and families seeking information and services. Each office employs case managers who manage the front door and work with people on the waiting list. DIDD supports over 12,000 people in waiver and family support services.



CATALYSTS FOR CHANGING THE FRONT DOOR



The Governor issued a directive to state departments to "lean up" their processes (see below). DIDD used the directive as an opportunity to focus on the Front Door. In addition, state leadership requested that DIDD explore ways to reduce the state's waitlist for services and offer additional supports to those on the list.



The state service system in Tennessee was recently recognized for their excellence in person-centeredness by the Council on Quality Leadership. Through the DIDD's participation in the CoP they were able to incorporate the idea of supporting the entire family into their value base and apply the LifeCourse Framework as a guide for their thinking and systems change in their state.



DIDD received feedback regarding the front door experience from families and recognized that change in policies and procedures was necessary. The TN team also worked with the agency to use additional formal and informal mechanism to gather more input from families and self-advocates. They then linked the existing feedback through channels in the state.

SEIZING THE MOMENT: THE LEAN EVENT

"Lean" is a philosophy and a set of tools used by the Tennessee government to improve efficiency and eliminate inefficient and unnecessary steps in state service processes. One of Lean's core values is focusing on the customer while minimizing roadblocks. DIDD took advantage of the opportunity offered by the Governor's mandate to review its processes to make them more family-friendly. They invited staff from DIDD offices, family members, and individuals with intellectual and developmental disabilities to provide input about the front door.

Families expressed that the front door to DIDD services was overwhelming, not accessible, unclear, and intimidating. Agency staff reported that there was duplication of paperwork, that processes were inconsistent across regions, and that the only thing they could offer families was 24-hour



The DIDD Intake process, mapped out from start to finish on a large length of paper on a wall at the LEAN event.

traditional services or a spot on the waitlist. As a result of the feedback from the Lean process, state leadership examined their processes and made changes, without which the front door might still be dreary and nailed shut in Tennessee.



INFRASTRUCTURE: REFRAMING THE FRONT DOOR

UPDATED INTAKE PROCEDURE AND MATERIALS

The original intake assessment form used by frontline staff when a family applied for services was long and outdated. One concern was that the form asked families for unnecessary information at that step in applying for services and resulted in duplicative information. The team spent a significant amount of time narrowing down the questions to just information that was necessary and omitted everything else.

Input from staff and families stated that the intake form also contained an overwhelming amount of information, often with jargon that was not family friendly, about the selection of available Medicaid waiver services. The form asked families to choose what they wanted at that point in time, when they were most likely experiencing a crisis or a serious life change. The family might not be emotionally ready to answer that question, or even aware of all the options available to them.

DIDD also invested resources in improving their phone line and website, which families expressed were difficult to navigate.

TRAINING AND TOOLS FOR FRONTLINE STAFF

Based on the feedback DIDD received while remodeling their front door, they found that families frequently did not understand the intake process or what to expect. Families said they often felt confused after they contacted the state agency.

The agency implemented the LifeCourse framework and its tools as a way to support families at the front door. DIDD worked to teach their staff how to offer ideas for support rather than just offering the typical formal services.

Staff began to provide information based on life stages and helped families think ahead. Case managers were trained to use the tools to help determine what information was applicable to the family. Case managers also helped families think through what supports they currently had in their lives and what resources and tools would provide the families with immediate assistance.



FOCUSING ON MISSOURI

The Division of Developmental Disabilities (DDD) is a division of the Missouri Department of Mental Health. The state has six regional offices and five satellite offices. Most counties also have a local tax leveraged through property taxes for disability services, also known as Senate Bill 40 Boards, which are an important part of how services are delivered and funded. About half of targeted case management is provided by County Senate Bill 40 Boards. The Division is also the operational agency for five Home and Community Based Medicaid waivers. In Missouri, there are over 30,000 individuals in the DD system: about 13,000 receive waiver services, the rest receive targeted case management only.

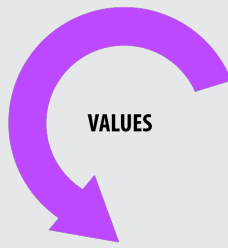
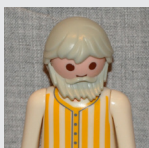


CATALYSTS FOR CHANGING THE FRONT DOOR



LEADERSHIP

The director of the Division, was dedicated to helping individuals achieve the good life and committed to supporting families in the state. The director, as well as agency leadership, recognized the value of connecting families to other families so they could share information and personal experiences.



VALUES

After restructuring their state agency, a process which began in 2008, DDD began supporting families with a new set of values, including self-determination, supporting families, and individualized supports. In addition, Missouri is the demonstration state in the CoP and the birthplace of the LifeCourse Framework.



LISTENING TO SELF-ADVOCATE & FAMILY VOICE

DDD collected input from individuals and their families during their restructuring process. In addition to their Regional Advisory Councils, the Division also utilized their partnerships with MO Family to Family and People First organizations to collect feedback directly from self-advocates and families.



INFRASTRUCTURE: REFRAMING THE FRONT DOOR

UPDATED INTAKE PROCEDURE AND MATERIALS

The Division was conscious of valuing families' time through the application process and worked to reduce the frustration that many families reported. They worked to shorten the application paperwork down to the essentials so it was not so overwhelming to families and information was not duplicated. They also created a standard form for the phone interview, which tied to a database that was auto-filled, eliminating the redundancy within much of the paperwork and questions.

Another change DDD made to help families meet their needs after their first point of contact was to provide them with LifeCourse materials and refer them to the statewide Family to Family Resource Center. Now families have immediate access to information and support from someone who knows what they are going through as soon as they get to the front door.

The Division also created a Statewide Diagnostic Review process, which is a resource for intake staff. The staff are now able to call in to the team to get information and clinical instruction. This team has led to more standardized eligibility decisions statewide.

IMPROVED OUTCOME DATA COLLECTION AND REPORTING

One step the Division took to overhaul their front door was to improve data collection. Previously, the process of collecting data was dispersed and inconsistent-- it was nearly impossible to look at statewide trends in services, demographics, and outcomes because each region had autonomy to choose what was important information for them to collect.

The statewide system was redefined so that all regions were collecting and reporting the same data by adopting a standard intake interview that tied to the statewide data system. In addition to the internal improvements made to the Division's IT system, they partnered with the statewide Family to Family Resource Center, enabling them to access additional data on supports provided to families and satisfaction data.

PARTNERSHIPS: MEETING FAMILIES AT THE FRONT DOOR

The Division established a partnership through a state contract with the Family to Family Health Information Center at the UMKC Institute for Human Development, Missouri's University Center for Excellence in Developmental Disabilities (UCEDD). Missouri Family to Family (MOF2F) has provided information to individuals, families, professionals, students and the public as the UCEDD's information dissemination arm for over 20 years. In addition, MOF2F has been connecting families with one another for over 10 years and became the statewide Parent-to-Parent network. Since then, MOF2F recruited an army of family leaders willing to serve in a peer support role.

When families contacted the Division for services, they were offered the chance to speak with MOF2F's trained Family Information Specialists, who are also family members. The DDD intake staff were trained so they understood MOF2F and to know how to refer families and self-advocates

to them. The process was created to make it as seamless as possible for the staff. Internally, the Division worked on their database so that referral forms were automatically submitted to MOF2F. This change kept the process efficient by ensuring that the family did not have to call another number or explain their story to another stranger.

The goal of the partnership was to benefit everyone who came to the front door of services, not just those who would become Medicaid waiver eligible. The vision was to make the experience families had with Missouri's DD system more useful and make the Front Door more person and family-centered. Without leadership that understood and embraced the value of connecting families and self-advocates to other families and self-advocates, this partnership would never have emerged. Now families can often get their life questions answered right away while they are still going through the eligibility process for the system.

The information that I received from the resource center was very helpful in offering me the tools to make my life better. When I have an issue about something, the resource center will be there for me to offer support.

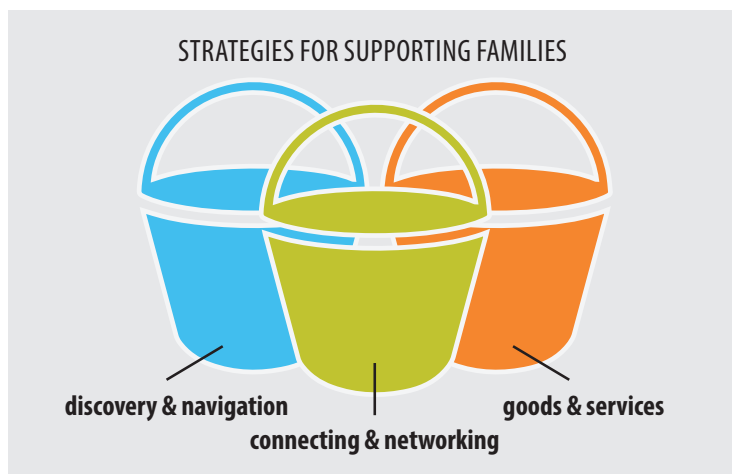


LEARNING FROM THE NATIONAL COMMUNITY OF PRACTICE

OVERALL

Thinking Differently about Supporting Families. The CoP teams have learned that supporting families means changing the way supports are provided to families across the lifespan. Often, when we think of supports for people with disabilities and their families, our minds go straight to the paid, formal systems of services.

Supporting families is not a program or service mindset, but rather a set of strategies that target the family unit, while ultimately benefitting the individual with I/DD. These 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. Supports should maximize the capacity, strengths, and unique abilities of the family so they can best support, nurture, and love their family members while facilitating achievement of self-determination, independence, productivity, integration and inclusion in all facets of community life¹.



Three 'buckets,' or strategies for supporting families have been identified:

- 1. Discovery & Navigation:** Information, education, and training on best practices within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.
- 2. Connecting & Networking:** Relating with other families, including parents with disabilities, self-advocates and siblings, and others for mutual support.
- 3. Goods & Services:** Specific to the daily support and/or caregiving role for the person with I/DD, such as planning for current and future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health/wellness management.¹

Hecht, E., Reynolds, M., Agosta, J., & McGinley, K. (2011). *Building an agenda for supporting families with a member with intellectual and developmental disabilities. Report of the Wingspread Conference on building a family support agenda, March 6-8, 2011. Racine, Wisconsin: Johnson Foundation.*

TENNESSEE

- **Front Door Experience Affects Families:** The CoP team discovered that the first contact they have with families had a huge impact on their future trajectory--they could send them down a service path or point them toward a family and community life, like any other citizen.
- **Try, Try Again:** The Tennessee team revised policies and practices many times, which required them to explain the the framework or reasoning for the changes they were trying to make.
- **Feedback is Critical to Change:** Listening to the voices of individuals and their families as well as staff is critical to not only enhancing the experience of those who receive supports but also efficiency. Changes DIDD made to their intake process and materials ended up saving staff time and reduced costs for the agency.
- **Consistent Messaging Puts Everyone on the Same Page:** By using the LifeCourse framework to reframe their greeting at the front door, DIDD empowered their staff in their work to change lives by providing tools to give families hopeful, helpful information no matter what age or situation. Families benefited from the tools by receiving clear information about what to expect from DIDD and learning about their options.

MISSOURI

- **Culture Change:** Sometimes convincing people that change is necessary or helping them understand why things need to change is the hardest part. The way services were formerly structured had staff stuck in an old-school mindset that needed overhauling.
- **Consistency is Key:** From region to region, each office was collecting different information and carrying out different processes. By creating a uniform process that everyone is following, the Division is able to create a more seamless experience for individuals and families.
- **Flexibility to Partner:** By partnering with the statewide Family to Family, the seamless Front Door is possible. Agencies must be empowered and feel comfortable with collaborating with outside organizations in non-traditional ways.
- **Training and Technical Assistance = Less Stress for Staff:** The frontline intake team has better resources and training in order to make decisions with families at the Front Door as a result of their partnership with MOF2F and the implementation of the new Statewide Diagnostic Review process.



The LifeCourse Framework

REFRAMING OUR THINKING TO ENHANCE SUPPORTS TO FAMILIES

The LifeCourse 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. It 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.

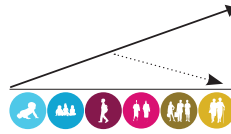
LIFE COURSE FRAMEWORK/PRINCIPLES

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.



RESOURCES

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.

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.

Webinars will be hosted live every other month beginning January 2015 and archived for later viewing at nasddds.org and supportstofamilies.org.

Learn more about the series at supportstofamilies.org

The screenshot shows the homepage of the Supporting Families website. At the top, there is a navigation bar with links for 'Connecticut', 'District of Columbia (DC)', 'Maine', 'Oklahoma', 'Tennessee', and 'Washington'. Below this is the main header with the logo and text: 'SUPPORTING FAMILIES of individuals with intellectual & developmental disabilities THE NATIONAL COMMUNITY OF PRACTICE FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES'. A secondary navigation bar includes 'About', 'The States', 'Resources', 'Updates', and 'Connect'. The main content area features a 'LATEST NEWS' section with a featured article titled 'Strategic Mapping Using the LifeCourse Framework: Focusing on Provider's Journey'. To the right of the news section is a 'FUNDED BY' section listing the 'ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES' and 'NATIONAL PARTNERS' including NASDDDS, UMKC, HSR, CASAN, AU CD, and NACDD. Below the news section is a 'Welcome!' message and a 'MAILING LIST' sign-up form with fields for 'First Name', 'Last Name', and 'Email Address*'. A sidebar on the left contains social media icons for Facebook, Twitter, and a plus sign for more options.

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.

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.