ISSUE BRIEF

Technology & Supporting Families, November 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. Across the country, our culture is embracing this belief. It is necessary to change not only our conversations, but the way we think about people with I/DD and their families and the supports they need to live a good life.

The Community of Practice (CoP) is working on discovering integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. As we move forward as a society that becomes increasingly dependent on technology to function, thinking differently about supporting families means asking how we can use both technology designed specifically to help people with disabilities, as well as everyday technology that is used by everybody.

This issue brief focuses on
- how technology can be used as a support to achieve the good life
- real stories of how individuals with disabilities and their caregivers found technology solutions to meet their needs
- resources available to help individuals, families, and the professionals who support them, to connect with the technology that make sense for them.

Read on to find out how families are making technology work for them to enhance independent living or support caregiving. ◎
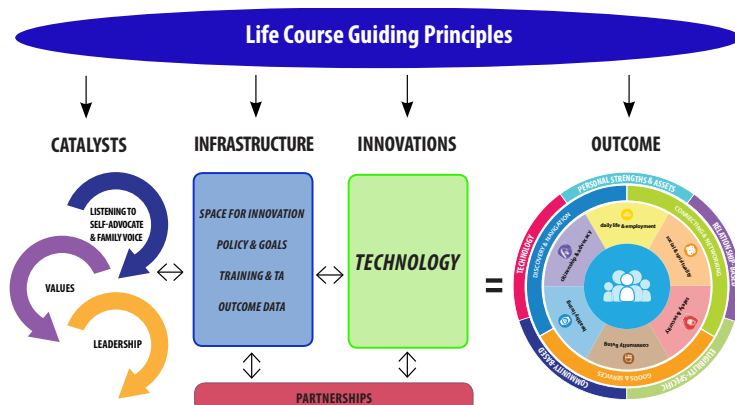

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INNOVATIONS IN SUPPORTING FAMILIES
COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS SERIES

THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

The 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 a good 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**.

Life Course Guiding Principles

CATALYSTS — INFRASTRUCTURE — INNOVATIONS — OUTCOME

LISTENING TO SELF-ADVOCATE & FAMILY VOICE / VALUES / LEADERSHIP

SPACE FOR INNOVATION / POLICY & GOALS / TRAINING & TA / OUTCOME DATA

TECHNOLOGY

PARTNERSHIPS

Michelle "Sheli" Reynolds, PhD. UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et all, 2007
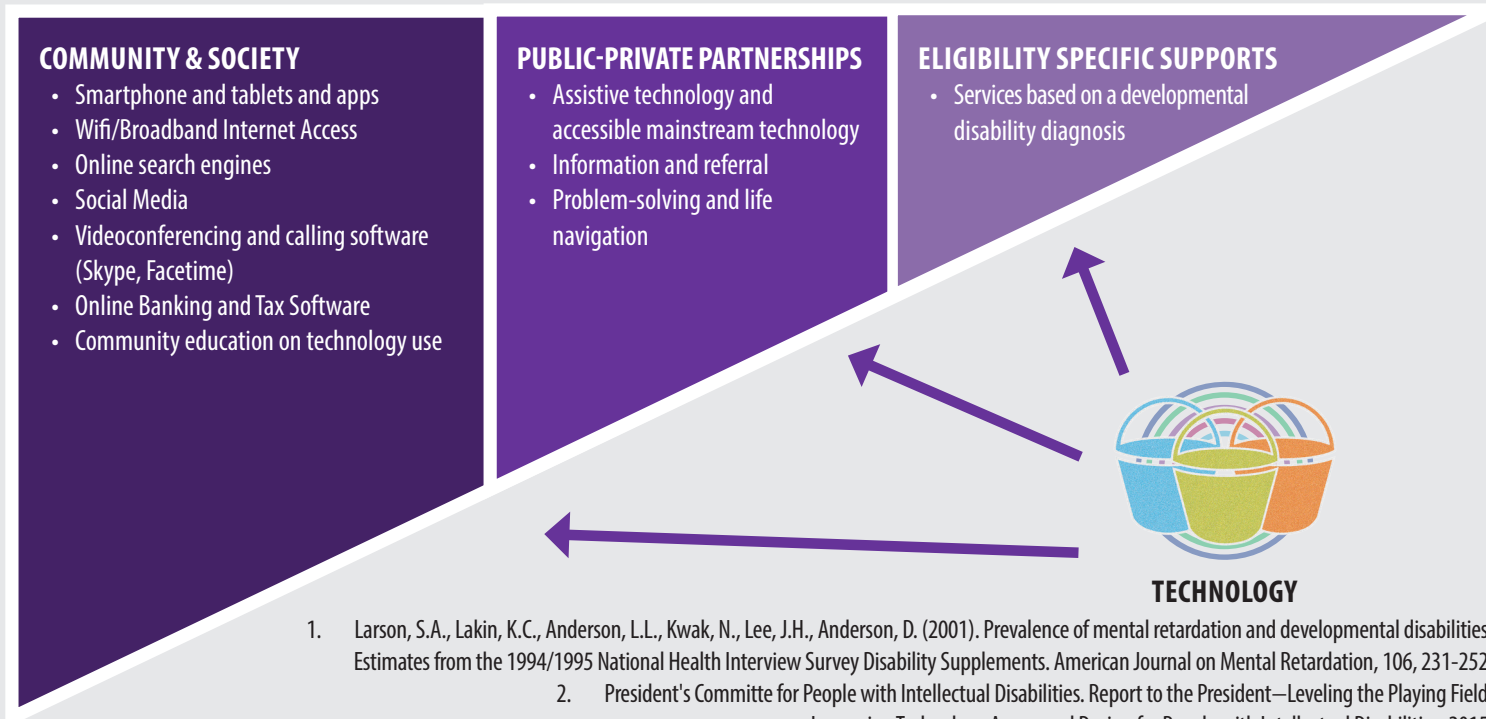
UNIVERSAL STRATEGY FOR PROVIDING SUPPORTS: FOCUSING ON TECHNOLOGY

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

While only 25% of people with I/DD currently access paid supports from the DD service system[1], everyone can access technology. Technology is unavoidable and mandatory to function as a citizen of today's world. "Interacting with technology should no longer be considered optional. Participating in education, communicating with friends and family, having access to various forms of

transportation, working in competitive employment, and performing activities of daily life, such as cooking or washing clothes, all typically require the use of keypads, touch screens, and other forms of interface with displays and controls." (The President's Committee for People with Intellectual Disabilities, 2015).

Federal and state budgets do not allow systems to serve all people with disabilities, so innovative strategies which acknowledge the changing paradigm calling for real jobs, relationships, and lives in the community are needed. The Community of Practice has been working on discovering not only innovative uses of technology but also looking at how ordinary, everyday tools and gadgets are being used to by people with disabilities to have the life they envision. Read on to find out how four families used technology to find solutions to enhance their quality of life or support caregiving. ◎

COMMUNITY & SOCIETY
- Smartphone and tablets and apps
- Wifi/Broadband Internet Access
- Online search engines
- Social Media
- Videoconferencing and calling software (Skype, Facetime)
- Online Banking and Tax Software
- Community education on technology use

PUBLIC-PRIVATE PARTNERSHIPS
- Assistive technology and accessible mainstream technology
- Information and referral
- Problem-solving and life navigation

ELIGIBILITY SPECIFIC SUPPORTS
- Services based on a developmental disability diagnosis

TECHNOLOGY

1. 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.
2. President's Committe for People with Intellectual Disabilities. Report to the President—Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities. 2015.
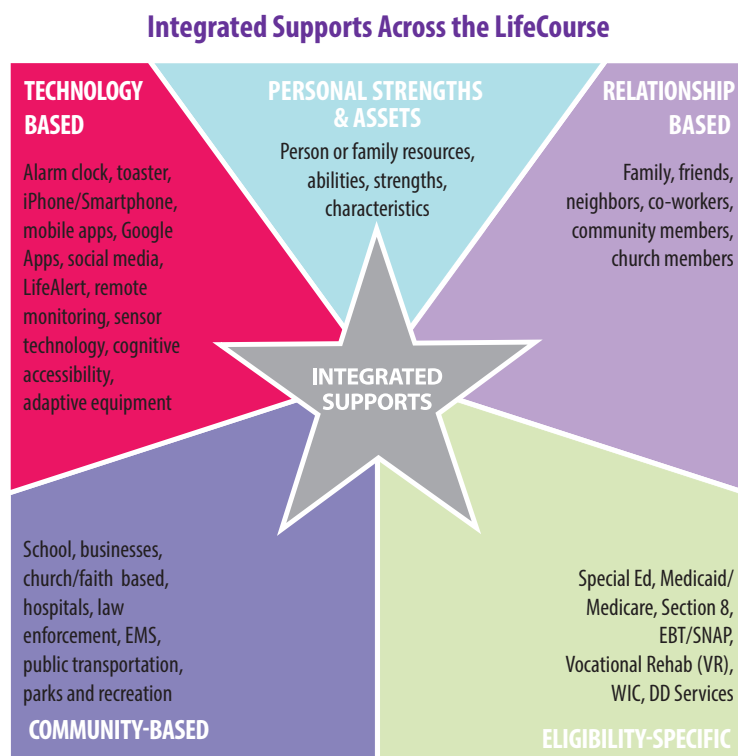
TECHNOLOGY AND SUPPORTING FAMILIES

Across the country, the Community of Practice is working to help individuals and families as well as organizations and policymakers understand that we ALL access a variety of supports to make it through our daily lives.

A visual representation of the Integrated Supports principle from the LifeCourse framework, the Integrated Supports Star, is being used across the country to have this conversation and help reframe the way people think about services and supports for individuals with I/DD and their families. In the past, the disability services field has had a tendency to put of all of our focus on the green region of the star.
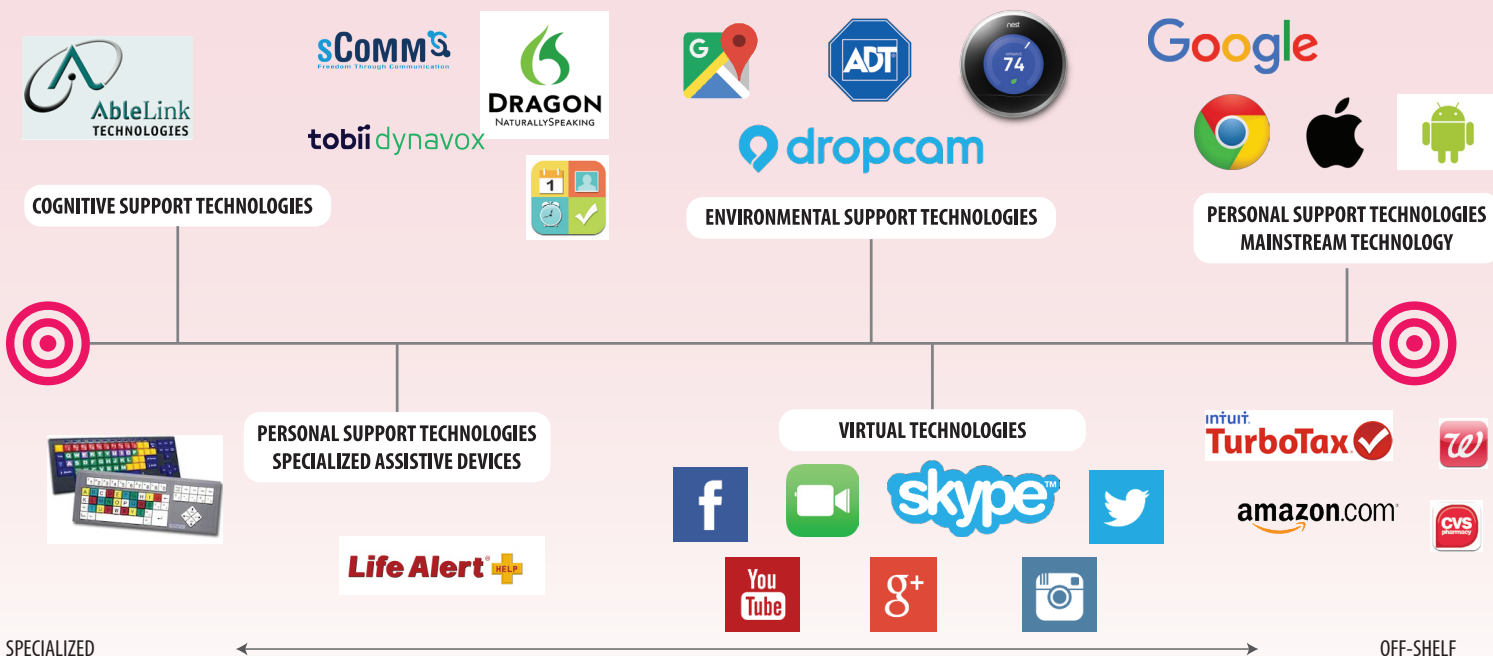
Integrated supports means looking at not only the services for which we may be eligible, but also our own **personal assets and strengths**, the **relationships** in our lives, and resources that are publicly available to everyone in the **community**. **Eligibility-specific supports** are those that we might be eligible for because of ability or disability, income, life situations (Example: a family might qualify for EBT/SNAP assistance with food because of their income, a person might be able to apply for an accessible parking placard because of a disability diagnosis).

Technology, loosely defined, is the creation and use of devices that allow us to interrelate with society and the environment. They may be as simple as a light switch or as complicated as computer networks that fill entire rooms. The disability service field often immediately thinks of assistive technology or adaptive equipment, but the world is changing and we often now seek mainstream technology first when addressing the barriers faced by people with disabilities. Today, we are all using technology to help us manage our daily routines, social obligations, work affairs, and more. ◎

Integrated Supports Across the LifeCourse

TECHNOLOGY BASED
Alarm clock, toaster, iPhone/Smartphone, mobile apps, Google Apps, social media, LifeAlert, remote monitoring, sensor technology, cognitive accessibility, adaptive equipment

PERSONAL STRENGTHS & ASSETS
Person or family resources, abilities, strengths, characteristics

RELATIONSHIP BASED
Family, friends, neighbors, co-workers, community members, church members

INTEGRATED SUPPORTS

School, businesses, church/faith based, hospitals, law enforcement, EMS, public transportation, parks and recreation
COMMUNITY-BASED

Special Ed, Medicaid/ Medicare, Section 8, EBT/SNAP, Vocational Rehab (VR), WIC, DD Services
ELIGIBILITY-SPECIFIC

TODAY'S TECHNOLOGY SPECTRUM

COGNITIVE SUPPORT TECHNOLOGIES

ENVIRONMENTAL SUPPORT TECHNOLOGIES

PERSONAL SUPPORT TECHNOLOGIES
MAINSTREAM TECHNOLOGY

PERSONAL SUPPORT TECHNOLOGIES
SPECIALIZED ASSISTIVE DEVICES

VIRTUAL TECHNOLOGIES

SPECIALIZED ⟷ OFF-SHELF

Adapted from: President's Committe for People with Intellectual Disabilities. Report to the President—Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities. 2015.

TIM

Tim and his brother use hydrotherapy to help them stay healthy. The family's primary concern was their caregivers' safety getting Tim and his brother in and out of their hydrotherapy tub. Their family was unsure what technology options were available and consulted with other families, OT's and Assistive Technology (AT) Specialists with their local State AT Program. Ultimately, they decided on a lift, but the cost was more than family budget allowed. They worked with the state AT program to find a program to fund the equipment. Tim and his brother are now able to stick to their therapy regiment and family care givers aren't fearful of injury to themselves or to either of the boys. ◎

AARON

Aaron is approaching adulthood and his family's goal was increasing his level of independence when it came to daily living skills. His dad researched online resources and consulted with staff at his local State Assistive Technology Program. They were able to design technology that worked for Aaron using technology he already owned. The result was Aaron was able to do more for himself independently and his dad had more time to focus on other family members and himself. ◎

SANDRA

Sandra's family's primary concern was safety and security—Sandra was opening the door for everyone who appeared and would leave her apartment with the door wide open. They worked together with their AT program to identified the issue and review options. They ultimately pursued off-the-shelf solution using DropCam, so now her mother can see who is at the door or if Sandra has left without securing her home. ◎

BEN

Ben is 25 years old and lives at home with his parents. Up until very recently, he had very little experience being by himself. Through the use of his iPad, accessing apps to keep him occupied as well as FaceTime, an iPad/Apple iOS app to communicate with people he trusts, he is able to stay alone for up to an hour. Before, he had never even stayed five minutes alone. Using technology increased his personal assets & strengths, but it also benefitted his caregivers. Now Ben's mother is able to go for walks, an activity she enjoys and will help her stay healthy, and both parents are able to get back and forth from work, because they know that Ben will be okay to stay by himself. ◎

SUPPORT AND FUNDING FOR TECHNOLOGY

STATE ASSISTIVE TECHNOLOGY ACT PROGRAMS

Each U.S. State and territory has a State Assistive Technology (AT) Program. The programs offer services and conduct activities in two broad areas: educating individuals and families about technology and helping them secure the actual equipment they need. Programs offer information and assistance, public awareness, training, technical assistance, outreach and professional development to promote knowledge and understanding of how to apply at in various sectors of society. Programs also offer device demonstrations, short-term device loans, device reuse and state financing. These services are designed to provide users the opportunity to "try before you buy" as well as acquisition of solid technology solutions at an affordable price.

To find your state's AT program, visit the Association of Assistive Tech Act Programs at **ataporg.org** ◎

FUNDING FOR TECHNOLOGY

One of the major concerns when it comes to obtaining the equipment needed by an individual or family is funding.

Funding is not only needed for purchasing the equipment, but also for maintaining it and keeping it in working order, as well as the training needed to use it to the maximum potential.

While paying for technology can seem challenging and overwhelming, numerous potential funding sources are available.

Common sources:
- Federal and state programs
- Special education programs
- Public and private insurance
- Supplemental Security Income (SSI)/ Supplemental Security Disability Income (SSDI) Work Incentives
- Vocational Rehabilitation Agencies
- Employers
- Disability Non-Profits
- Philanthropic Groups
- State Assistive Technology Programs
- Crowdfunding
- Special Needs Trusts

The families featured in the webinar used creative combinations of funding to obtain the technology they needed. To get more information on funding sources for technology, connect with your state AT Program! ◎

OBTAINING TECHNOLOGY THROUGH ELIGIBILITY-SPECIFIC SOURCES

Here are some examples of work incentives and other programs that can be used to generate cash flow to pay for technology:

Impairment Related Work Expenses/Blind Work Expenses (IRWE): If a person is an SSI recipient and they are working at all, they can use their expenses like technology, that aid in work, as a reduction of their countable income calculation, thus restoring those SSI dollars as cash flow.

Plan to Achieve Self Sufficiency (PASS) Account: SSI recipients may save cash earned in a separate account protected from being counted as income or resources by SSI and purchase equipment from this account.

Property Essential to Self-Support (PESS): Excludes valuable items that are being used to support oneself from being counted as an asset. This is applicable to an individual as well as to parents of a minor child.

Student Earned Income Credit (SEIC): SSI recipients under age 22 and regularly attending school, up to $1,780 of earned income per month is not counted when SSI payment amounts are calculated. The maximum yearly exclusion is $7,180.

Achieving a Better Life Experience (ABLE Act) accounts (available early 2016): The ABLE Act will allow people to take miscellaneous income and save it without it effecting their SSI calculations. When they are ready to buy the technology, they will have the funds saved.

Each state has a **Work Incentives Planning and Assistance (WIPA)** office that can educate individuals and families about SSI/SSDI work incentives. Locate yours at **www.chooseworkttw.net**

# TECHNOLOGY IN THE COMMUNITY OF PRACTICE STATES

CONNECTICUT (CT)

Good Life Assistive Technology Campaign At a Glance

The Connecticut CoP Technology committee has been collaborating to begin hosting a series of regional technology-focused workshops for self-advocates, families, providers, state DD agency staff, and other interested community members. Topics of the workshops will include a basic overview of AT, communication, teamwork (TYZE), organization, and more. The team will administer surveys to collect data on the learning and satisfaction of attendees.

Employment iPad Pilot At a Glance

The CT Council on Developmental Disabilities, funded a one-year project to see how iPads may help people with IDD obtain, and keep jobs. Three agencies provided nineteen hours of iPad training over the course of eight months. Through the project, they conducted AT evals of fourteen individuals with I/DD to help match them with apps that could assist them. Technical assistance was provided to agencies and individuals throughout the process. The pilot project collected data through surveys, pre/post tests, and exit interviews to measure its impact.
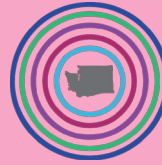
WASHINGTON (WA)

### SMART Living Project At a Glance

The Washington State CoP team is excited to embark on a new pilot project to research how technology can help individuals with disabilities and older families enhance their quality of life by increasing their independence and ability to live in their own home in the community. The project is a partnership between the Arc of WA State, the WA Developmental Disabilities Council, and the WA Developmental Disabilities Administration.

All individuals must complete a person-centered plan using mylifeplan.guide or a similar tool. The project will help them identify the right equipment for them then receive assistance in obtaining the device(s), training on how to use it/them, and nine months of ongoing technical consultation and assistance.

MYLIFEPLAN.GUIDE At a Glance

My Life Plan was recently launched in Washington state. It is a free online tool to help individuals with disabilities and their family member identify interests, strengths and needs at all stages and areas of life. Try it out online at **mylifeplan.guide.**

LEVELING THE PLAYING FIELD: IMPROVING TECHNOLOGY ACCESS AND DESIGN FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Report to the President

Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities
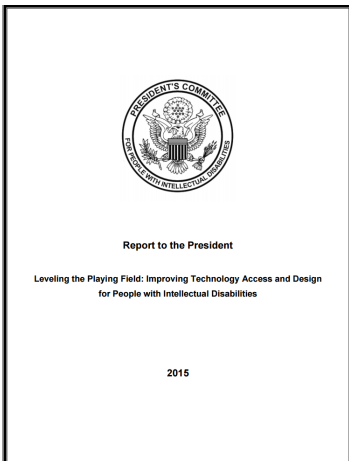
2015

Recently the President's Committee for People with Intellectual Disabilities (PCPID) published its 2015 Report to the President titled *Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities*. The report describes the critical and increasing role of technology in enabling individuals with I/DD to have greater control over their own lives and to experience the full benefits of citizenship.

The primary goals of the report's recommendations are:
- To make technology more usable, or cognitively accessible, for people with I/DD through increased federal research, and by incentivizing product developers in the tech industry to create technology that expands the independence and participation of people with I/DD in everyday living situations
- To strengthen federal policies to ensure that people with I/DD have equal access to everyday technology
- To increase the availability, quality and affordability of cognitive support technologies through policies, practices, development, and research.

The report contains federal policy recommendations, with immediate priority given to the focus areas of elementary, secondary, and post-secondary education; community living; employment and economic well-being; and health and wellness. View the report online at **supportstofamilies.org.**

Watch the archived *Innovations* webinar, **Technology & Strategies for Supporting Families**, to hear about even more resources to help you explore technology!

The LifeCourse Framework
REFRAMING OUR THINKING TO ENHANCE SUPPORTS TO FAMILIES

The LifeCourse framework was developed by families 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 or may 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 person 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.
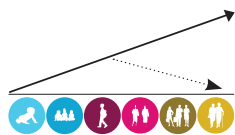
LIFECOURSE FRAMEWORK/PRINCIPLES

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.

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

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.

Learn more about the series at supportstofamilies.org

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

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HSRI Human Services Research Institute