

BRINGING EMPLOYMENT FIRST TO SCALE

Support Coordination Strategies that Impact Employment Outcomes and Services for Individuals Served by State Intellectual/Developmental Disabilities Agencies

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Key Findings
from the RRTC
on Advancing
Employment

Read this brief to learn about how states are implementing support coordination strategies that embed employment as a priority into service planning and implementation.

Introduction

In concert with the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) identified potential topical areas for policy white papers that influence employment outcomes and services for individuals served by state intellectual/developmental disabilities (I/DD) agencies. This is the third white paper in a series of five.

To determine priority topics for the white papers, discussions were held with ICI and NASDDDS leadership, advisory team members, and self-advocates identifying potential topics aligned with the high-performing states model for increasing employment. The high-performing states model draws from extensive research in states that achieve strong employment outcomes with systems change initiatives. The seven key elements essential to improving and achieving employment success that guide the structure of the model are:

1. Leadership
2. Strategic Goals and Operating Policies
3. Financing and Contracting Methods
4. Training and Technical Assistance
5. Interagency Collaboration
6. Services and Service Innovation
7. Employment Performance Measurement and Outcome Data

SERIES OVERVIEW: This series provides an in-depth analysis of priority and emerging practices and policies implemented by state-system collaborations. Other papers have addressed what states have learned from the implementation of the Centers for Medicare and Medicaid (CMS) 2011 guidance on prevocational services and employment, and multi-system collaboration that supports individuals across the life course. This paper addresses state I/DD agency development of guidance and strategy to embed employment as a priority for support coordination/case management in service plan development, implementation and follow-up.

Case managers, often called support coordinators, are pivotal in the service system supporting people with I/DD and their families to have meaningful lives in the community, which includes access to community integrated employment. Support coordinators balance this priority, along with ensuring individual health and wellbeing and completing the administrative duties associated with Medicaid requirements. Further, as employment practices and service structures evolve, case managers will need additional skills and knowledge around employment service delivery across multiple systems as part of their repertoire.

This white paper analyzes the importance and complexity of support coordination and identifies policy considerations and strategies for public I/DD systems to assist support coordinators (and teams) to embed employment as a priority in service plan development, implementation, and follow-up. Support coordination and planning processes of three states (Missouri, Pennsylvania, and Washington, D.C.) are highlighted.

Figure 1: Higher Performing States Framework



The Essential Role of Support Coordinators

Case managers, often called support coordinators, are pivotal in the service system. They have essential roles regarding health and well-being of people with I/DD and ensuring that individuals have good lives that result in the outcomes they set for themselves. They are an agent of the individual (first) and family. Individual and families rely on support coordination to help them build and sustain their lives¹.

As an agent of the state, support coordinators are the front line on monitoring, quality compliance, outcomes, and safety, acting as the “eyes and ears” for the system (and for the person). They play essential roles in upholding key Medicaid requirements. Support coordinators have central responsibility for completing the paperwork that ensures resources (for example, Medicaid funds) for the supports people need.

How states organize support coordination systems varies. Systems reflect state and local history, such as the use of state employees as support coordinators, or county-based services or contracted case management. State systems reflect shifts in best practices, and recent Centers for Medicare and Medicaid Services (CMS) regulations emphasize conflict-free case management, which requires that service coordination be separate from service provision. Systems change also brings participant-directed services, with states separating “traditional” case management functions from supports where people direct their own services.

Case managers have essential functions such as evaluation or re-evaluation of level of care (depending on the Medicaid system in a state); assessment/reassessment of the need for waiver services; development and/or review of the service plan; coordination of services; linking individuals to other federal, state, and local programs; monitoring the implementation of the service plan and participant health and welfare; addressing any concerns in service provision; and assisting individuals to access needed supports, regardless of the funding source.

Support coordination is offered through a variety of funding structures, such as through Home and Community Based Services (HCBS) waivers, Medicaid State Plan targeted case management, Medicaid administrative funds and, with less frequency, state general funds. All 50 states and the District of Columbia use Medicaid in one form or another to finance case management for people with I/DD. Many states use a combination of Medicaid financing options for different populations and purposes within their states.

Connecting with families

Beyond the core functions of case managers, they are also typically the ones that individuals with I/DD and their families develop relationships with and rely on as the key person to help understand and navigate the system. Case managers help individuals understand choices to make informed decisions. They are problem solvers and listeners, and walk with people with disabilities and their families over time.

“But how case managers engage with individuals and families is critical to setting expectations about the services system and the opportunities--and limitations--within the system².” This is especially true in assisting individuals to obtain community integrated employment. Support coordinators need the opportunity, information, and skills to work with families of young children with disabilities to encourage the early expectations of employment and build upon those expectations along the path to adulthood. Support coordinators need the knowledge, along with individuals and families, about what they, the community, and service systems can all do throughout the school and adult years for individuals to achieve their employment and career goals.

With these multiple responsibilities, support coordinators must balance priorities. From minor modifications to large transformation, one part of the change process for I/DD agencies is openly recognizing this need for balance, and continuously working with directly support coordinators on practices, tools, and resources.

¹Cooper, R. 2006. Medicaid and Case Management for People with Developmental Disabilities: Options, Practices, and Issues (Second Edition). NASDDDS.

² ibid.

Policy consideration: Support coordinators from Missouri, Pennsylvania, and Washington, D.C expressed appreciation for having the opportunity to present ideas and input on what might be helpful in streamlining processes.

- Some shared that small focus groups added to the exploration of ideas and allowed for honest conversations with leadership when suggestions were not fiscally or otherwise feasible. Understanding the “why” was helpful.
- Focus groups discussed what could be done differently, offering a better understanding of why some responsibilities are needed and tested assumptions about whether a longstanding practice needed to be kept, or could be stopped to free up time.
- Small process changes were encouraged, piloted, and evaluated together with leadership.

Increased Opportunities and Responsibilities for Case Managers: Employment

The CMS final rule, signed in 2014, emphasizes the importance of support coordinators in empowering people to live good lives in the community, including obtaining community integrated employment.

The rule centers on requirements of the settings where individuals live and/or spend their days. It establishes a definition of home and community-based settings based on the experiences of individuals, as well as the physical characteristics and location of these settings. The rule’s intent is to ensure that people have full access to community life.

While person-centered planning has been considered a process by which people with I/DD explore and voice their interests, preferences, and vision for a fulfilling life in the community, the rule underscores the importance of settings providing access to “seek employment and work in competitive integrated settings.”

Shaping a process for fulfilling the CMS rule

There is no model way to organize a system. States continue to analyze structures and policies, modify and build on best practices, and implement changes in concert with the stakeholder community. These changes can be the springboard to increase community integrated employment for youth and adults with I/DD.

Many states have strong practices in person-centered planning, with policy and/or guidance on how teams, facilitated by the support coordinator, address employment conversations, learn together about a person’s interest in working, explore possibilities and potential barriers, and document specific steps and services to achieve integrated employment outcomes. These have emerged from employment initiatives in and across states, recognizing that both the skills of and the support for the support coordinator are fundamental to the development and implementation of person-centered plans with decisive goals and outcomes for the path to community integrated employment.

Addressing integrated employment takes intentionality. The intricacies of communication, explaining opportunities and choices, and facilitating difficult conversations with individuals, families, providers, and other team members are substantial responsibilities. How services are funded, authorized and woven in and across other supports, including residential supports, adds to the complexity of needs addressed by support coordinators.

Specific language in the CMS rule regarding the person-centered planning process and person-centered service plan:

“The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports.”

“The state must ensure that the setting chosen by the individual is integrated in, supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS”

A shared responsibility

The responsibility for employment needs to be shared across the service system, I/DD leadership, providers, individuals, families, and community members, as well as the individuals themselves. In employment initiatives across the country, state I/DD systems are changing funding models, services and service definitions, policies, and systemic planning to increase community integrated employment. As a part of these initiatives, states are increasing their focus on person-centered policies and practices, and developing guidance to assist support coordinators to emphasize and encourage competitive integrated employment.

Conversations and Planning Tools: State Approaches to Support Coordination

National Core Indicators Adult Consumer Survey 2015–2016

Of the 47% of individuals expressing a desire to work, 70% did not have employment as a goal in their service plan.

A growing number of states are using tools and facilitated conversation guides for support coordinators to help individuals with I/DD, along with their families, to pursue employment and careers. There are similarities in the tools and practices, but each state has customized them.

As noted in the National Core Indicators Adult Consumer Survey, only 30% of respondents wanting a job have employment listed as a goal in their plan. States are implementing guidelines and policies to facilitate conversations that lead to employment goals in support plans, with outcomes and steps to success. While the responsibility for successful implementation rests with the entire team, the practices give support coordinators tangible and meaningful steps to work with individuals and their teams.

The LifeCourse Framework

The National Community of Practice for Supporting Families of Individuals with I/DD across the LifeSpan (CoP), originally funded by the Administration on Intellectual/Developmental Disabilities (AIDD) for six states and now expanded to 17 states, works across and within states and a national project team to create policies, practices, and systems to support families that include a member with I/DD across the lifespan.

The LifeCourse Framework (often referred to as Supporting Families Framework) applies to the role of support coordinators in their endeavors to enhance community life and to collaborate with individuals and families to plan for jobs. The 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 to make that vision a reality, and identify how to find or develop supports. It can provide a clear and creative approach to planning, building on personal strengths and relationships, and identifying services and supports in the system and within the community, including employment.

Employment is included in the framework with tools across the lifespan from childhood into retirement. Families and their teams can start at any age, but there are benefits to building early expectations of a life that includes having friends, close relationships with family members and others, and a job. The LifeCourse Framework is composed of several domains: daily living and employment, community living, safety and security, healthy lifestyles, social and spirituality, and citizenship and advocacy. Each domain emphasizes what a person can do as part of everyday life.

With an understanding of the framework, there are tools for use, including for support coordinators for thinking and planning. Charting the LifeCourse: Daily Life and Employment is a resource for families, individuals with I/DD, support coordinators, and others to foster a positive employment trajectory. It provides practical suggestions and ideas, with exploratory questions for infancy, school age, transition, adulthood, retirement, and aging.



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

www.lifecoursetools.com/principles/

Missouri's approach: Implementing LifeCourse

The Missouri Division of Developmental Disabilities has incorporated the LifeCourse Framework, inclusive of employment into the state Individual Support Plan (ISP) <http://dmh.mo.gov/dd/manuals/docs/ispguidenew.pdf> and into quality measures. The Missouri ISP is organized by domains within the framework. The employment domain includes career-planning steps, outlined by an individual's age, and links to tools to assist in guiding conversations.

Another Missouri effort is a partnership with the CoP Supporting Families Across the LifeSpan and Missouri Show-Me-Careers. The Show-Me-Careers project was funded by the Administration for Community Living with a goal to increase employment for youth and young adults with developmental disabilities. The two projects worked together to develop an employment guide, which includes developing an employment profile, mapping supports, and a unique career planning exploration sheet that matches people's interests and gifts with examples of jobs. For example, there are potential jobs listed for "Doers," "Thinkers," "Creators," "Helpers," "Persuaders," and "Organizers."

Policy Consideration: *Supporting Families Across the LifeSpan provides a framework, tools, and ideas to assist families, individuals, and support coordinators in building early expectations for employment and a structure to use across ages and stages. States that are part of the community of practice may wish to review the Missouri initiatives for applicability in charting the employment person-centered planning processes. Even if a state is not part of the CoP, consideration should be given to exploring components that align with their employment initiatives and practices.*

Pennsylvania's approach: Guidance for employment conversations

In August 2015, Pennsylvania's Office of Developmental Programs (ODP) held a workgroup focused on how support coordinators engage individuals and their families about community-based employment, as well as strategies and resources. The goal was to bring employment "front and center" into the Individual Service Plan (ISP).

The workgroup was composed of representatives of support coordination organizations, a person receiving services, providers, and representatives from the Regional and Administrative Entity. The group concluded there are several employment-related resource materials available to support coordinators, including an ISP manual, an employment supplement, and an employment manual. Even with these, it was determined that support coordinators needed further guidance in how to engage in conversations with people and their team to increase integrated employment for people with I/DD.

Pennsylvania worked with the State Employment Leadership Network (SELN) to develop "Guidance for Conversations about Employment." It includes "conversation starters" for support coordinators to use when planning employment, exploring barriers, and seeking solutions.

To promote buy-in and successful implementation, the workgroup further concluded it was important not to create additional mandatory paperwork or forms that support coordinators needed to complete. ODP stopped use of the employment supplement and manual in late 2015, instead offering new guidance and incorporation of employment information into the general ISP process.

The guidance is not mandatory. It is a set of sequential questions designed for support coordinators to facilitate discussions about employment at any point in the process including during ISP meetings, while conducting a monitoring visit, or anytime the team meets.

OPD developed a user-friendly way to guide conversations. Compiled into a four-page form with questions and ideas, the guidance is conversational in manner, designed to learn more about the person and to create an environment to assist the person and the team to move towards integrated employment.

There are three primary pathways: one that centers on people who are not working and express they do not want to work, another to use when a person is not working and wants a job, and a pathway for people who are already working. Each pathway is composed of guided questions and ideas for the team, next steps, ISP documentation, and applicable services.

These guiding questions provide a platform for a person to reflect on their current situation, address worries, and identify interests. Based on this information, the team's next steps are reflected in ISP discussions and development, keying in on the person's interests, and identifying and addressing barriers through action planning. There are suggestions of services to assist an individual to discover their talents, such as through volunteering.

Somewhat unique to PA's process in the exploratory guidance is sharing success stories with the individual and team, weaving in ideas to help the person build networks and looking at supports the person may need while not working.

In releasing the guidance, state leadership communicated clearly and broadly to the field about the importance of employment by outlining ODP's principles, e.g., "achieving employment and community inclusive outcomes are the cornerstones of ODP policies and practices," and underscoring "that employment practices must ensure individuals receive information about employment opportunities and that prevocational, vocational, adult training and community supports should promote progress towards a pathway to employment."

Of particular note relevant to assisting support

coordinators to do their jobs is ODP's message to everyone that touches the lives of people served by the system. "While support coordinators will be facilitating the conversation with the individual and their team, all team members, including service providers, have a key role in talking about employment with individuals they support." This type of statement helps give support coordinators the authority and confidence needed to implement change.

These strong statements from state leadership provide support coordinators with a heightened understanding of the agency's vision and beliefs. This communication also bolsters the awareness of system stakeholders as to why support coordinators are using the guidance.

***Policy Consideration:** Public I/DD agencies should clearly articulate the role and importance of support coordinators to the community to provide the context for employment conversations during discovery and person-centered planning as part of the employment outreach strategies.*

DC's approach: Assessing a person's interests and progress towards employment

The theme of exploratory questions and pathways continues with a modified approach in the District of Columbia. The District's Division of Disability Services is composed of both vocational rehabilitation services and the Developmental Disabilities Administration (DDA). The District has invested significant effort into increasing the number of people with I/DD entering community integrated employment, has a mayoral executive order for Employment First, participates in the Employment Learning Community (a national effort to support states in improving systems and services), and has launched a customized employment community of practice, as well as a secondary transition community of practice.

The District is an active member of the State Employment Leadership Network (SELN). In partnership with the SELN, the DDA developed a process and accompanying tool to assess an individual's interests and their progress towards employment. The assessment is conducted at intake and as part of the ISP. When it is completed as part of the ISP, there is also a mandatory employment goal.

The assessment process has talking points for support coordinators to use in raising expectations that all people must have the opportunity to work. Similar to PA, the District explains the importance and expectations of work, and outlines the reasons that having a job increases overall quality of life. There is honest information front and center that articulates people's concerns, including fear of loss of benefits, and the need for other supports to wrap around employment. The process includes accompanying statements explaining the help available to address those fears.

There are three potential paths to employment, with similarities to Pennsylvania's three paths, but the pathway questions and next steps have some differences. The DC assessment guidelines offer questions, documentation, and tools to use in the person-centered planning process depending on the pathway and action planning. The DC follow up actions are more structured than that of Pennsylvania's, with mandatory ISP documentation regarding a person's satisfaction, current job aspirations and related goals such as travel skills, benefits planning and career advancement.

Of note is the action plan for individuals working part-time to determine the status for wraparound supports. Discussions about missing friends at the workshop or families not having the consistent hours of support that a workshop or day program provides are hard, but important. Once addressed, these concerns can pave the way to more meaningful opportunities.

The DDS guidance emphasizes that most people get jobs through people they know, so outreach to other community resources and networks is helpful. The guidance still outlines referrals to vocational rehabilitation and other relevant services, but the addition of explaining how relationships contribute to finding jobs is a unique way to target related goals and action steps.

DDS focuses on data and measurement, requiring that the person's desired employment outcome be documented with action steps leading to a job in the next 12 months and how progress and success can be measured.

Policy Consideration: *As states transform services and supports to support people in community integrated employment, there is a natural focus on transition-aged youth. Youth and young adults have not yet been in other day settings, often have high expectations for employment, and increasingly have had job related experiences and exploration during their high school years. Partnerships with the schools, the developmental disabilities agency, and vocational rehabilitation have grown stronger, and the Workforce Innovation and Opportunity Act further anchors work expectations for youth and young adults.*

Yet in the midst of multiple changes, there have not been as many readily available strategies related to people with I/DD who wish to retire. Residential funding models can be barriers to people retiring (as they have been for people who work part time or atypical work hours). As states rebase rates and staffing models that more easily accommodate non-traditional work schedules, the focus on being able to retire is an important part of planning. Support coordinators' ability to explore retirement options and develop relationships and interests is needed. The District's prompts and guidance are a consideration to include in other states' planning processes.

<http://dds.dc.gov/sites/default/files/dc/sites/dds/publication/attachments/Assessing%20Employment.pdf>

Policy Consideration: *States must decide between mandatory and optional conversational processes, tools and guides. In Pennsylvania's case, the state agency made the decision to weave the conversational tools and guidance into the ISP, but did not make all guidance mandatory, or prescribe the order or specific use of the guidance questions. ODP worked to ensure this resource would not create additional forms. Some manuals were discontinued to infuse information directly into the ISP without staff needing to review multiple manuals. Support coordinators are allowed and encouraged to use the guidance any time the team meets. Alternatively, DC mandates some tools and processes, as do some other states implementing a "pathway to employment" through conversational guides, tools, and processes.*

Conclusion: Overarching Policy Considerations

Support coordinators are integral to assisting individuals with I/DD to obtain and keep community integrated employment. Their jobs are complex, with multiple responsibilities. Support coordinators engage in high-quality, person-centered planning that keeps the full focus on the person. But how case managers engage with individuals and families is critical to setting expectations about the services system, including both its opportunities and limitations. The person-centered planning and settings components of the HCBS rule provide a strong foundation for support coordinators to further meaningful conversations with individuals, families, and teams.

Support coordinators across the country often express the difficulties of “carrying the ball” on policy changes when working at the individual team level. Despite case managers’ facilitation skills and knowledge, conversations that encourage the move to employment from congregate or unpaid services are complex. Support coordinators have reported feeling alone during the planning process in certain situations. For example, when all other team members express fear or disagreement with the idea of employment, support coordinators have expressed challenges with championing employment as an essential part of community life.

This paper highlights the following strategies that states are using to enable support coordinators to prioritize employment:

1. State leadership’s clearly stated commitment to employment as the first and preferred outcome for people with I/DD in a manner that stresses the importance of the person-centered planning process gives support coordinators a head start in facilitating positive conversations. Some of the tools state agency leaders use are widely distributing materials, bringing stakeholders into the planning process, and holding leadership meetings with other state agencies, providers, and family and self-advocacy groups.
2. States are finding new ways to improve the person-centered planning process that involve Pathways to Employment, which offer guidance, questions, and action steps for support coordinators to use with teams in three primary scenarios:
 - a. The person is not working and does not express interest in working at the current time.
 - b. The person is not working but would like to have a job.
 - c. The person is working and improvements could be made.

3. States have variation as to what parts of the pathway are mandatory, how it is documented, and how it is implemented. Careful consideration should be given as to when and how processes are made mandatory, or when more flexibility would be beneficial. There is no one way to determine how the pathway is developed and implemented in a state, but developing guidance with a stakeholder group, analyzing what can be done to embed the pathway into the person-centered planning process without creating additional paperwork, and looking at how pathway guidance assists during different life stages are all promising practices.

Within this context:

- » States are developing questions and guidelines that are conversational in nature.
- » The pathways direct aspirations for work and careers, and invite honest conversations about concerns and difficulties to find potential solutions to getting a job.
- » States are looking at the ages and stages of individuals supported and gearing policies and practices that relate to different age groups, from birth to retirement.
- » At least one state has embedded the Community of Practice for Supporting Families Across the LifeSpan into action planning and the ISP. Other states are in the exploratory or planning stages.
- » The importance of early expectations is being reinforced.
- » Increased recognition is being given to the need for wrap-around supports for people who are not working or are working part time.
- » Some states are addressing retirement and how individuals can stay engaged, learn new things, and meet new people.
- » Leadership’s commitment and communicating the role of support coordinators in the planning process is critical.

With these ideas, approaches, and guidelines come opportunities for individuals with I/DD to explore various routes to employment, leading to satisfying jobs and careers.

Resources

HCBS Rule

<https://www.medicaid.gov/medicaid/hcbs/guidance/hcbs-final-regulation/index.html>

LifeCourse Employment Guide

www.lifecoursetools.com/wp-content/uploads/EMPLOYMENT-GUIDE-FINAL.pdf

Missouri ISP and Career Planning

<https://dmh.mo.gov/dd/manuals/docs/ispguidenew.pdf>

<http://dmh.mo.gov/dd/docs/careerplanningispquestions.pdf>

PA Conversational Guidance Tool

www.paautism.org/desktopmodules/asert-api/api/item/ItemDetailFileDownload/3865/Pathway%20to%20Employment%20Guidance%20for%20Conversations%20and%20Conversation%20Guide%20030-16.pdf

DC Pathway Tool

<https://dds.dc.gov/sites/default/files/dc/sites/dds/publication/attachments/Pathways%20to%20Employment%20and%20Community%20Integration%20Benchmarks.pdf>

Building Capacity for Support Coordinators

http://static.smallworldlabs.com/umass/content/seln/docs/seln_odp-pa-sc-handout_6-5-15-online-event2.pdf

APPENDIX 1

State Variations on the Pathways to Employment and Guided Conversations

More states are developing and using guided conversations, pathways to employment, and/or LifeCourse to assist support coordinators to work with individuals, families, and teams to support employment. States may wish to explore the resources from the brief descriptions below.

New Jersey has formally implemented that state's Pathway to Employment. This change is being implemented at the same time as new waiver services are offered and the rate system has been rebased. There are mandatory processes for the support coordinator to follow with the individual, family, and team, and outcomes related to an individual's "path to employment" are to be listed in the person's service plan after the facilitated discussion and determination of which path the person is on. The pathways follow those of Pennsylvania and the District of Columbia. New Jersey's process is structured, with mandatory processes. As with the other states, roll out and implementation is new and continuing.

The Massachusetts Department of Developmental Services has guidance and services related to different employment pathways, as well as addressing meaningful time in the community when a person is not working. The Massachusetts Blueprint for Success sets ambitious goals to accomplish over a 4-year period, including to no longer fund sheltered workshops. In partnership with the Institute for Community Inclusion at the University of Massachusetts Boston, multiple resources are available for stakeholders, including support coordinators. MA is a state that has invested heavily in technical assistance and training.

www.mass.gov/eohhs/docs/dmr/bfueprint-for-success.pdf

www.employmentfirstma.org

In January 2016, Iowa developed Guidebook: A Resource for Community Based Case Managers, Care Managers, Service Coordinators and Integrated Health Home Coordinators. The Iowa Department of Human Services worked with stakeholders to provide a guidebook with information, tools, and resources to help support coordinators "do the best possible job of assisting transition-age youth and working-age adults with disabilities they support to work." The guidebook describes Employment First, provides an overview of the agencies involved with employment, gives a roadmap to prevocational services, and offers ideas on assisting people on waiting lists to pursue employment. The guidance explores frequently asked questions by people with disabilities, families, providers, and talking points for the support coordinator to consider. <http://www.ivrs.iowa.gov/cesframeset.html>

APPENDIX 2

LifeCourse Description

The National Community of Practice for Supporting Families of Individuals with I/DD Across the LifeSpan (CoP) is entering the final year of federal funding from the Administration for Intellectual and Developmental Disabilities (AIDD), with 17 states participating. The COP works across and within states to create policies, practices, and systems to assist and support families that include a member with I/DD across the lifespan.

Participating states have improved cultural considerations in supporting families, guided and influenced policymakers, and helped shape waivers and other Medicaid authorities to focus on supporting families and individuals throughout the lifespan. NASDDDS, along with the University of Missouri Kansas City Institute for Human Development, partner to support states, work to impact national policies, develop products and tools, and provide technical assistance.

The LifeCourse Framework (often referred to as the Supporting Families Framework) has significant applicability to the role of support coordinators in their endeavors to enhance community life and to partner with individuals and families to plan for good jobs. It 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 to achieve this vision, identify how to find or develop supports, and discover what it takes to live the lives they want to live.

The LifeCourse Framework can provide a clear and creative approach to planning, identifying services and supports in the system and within the community, including employment. The framework and accompanying tools cross the lifespan, with considerations for children birth to three, across life stages into retirement/aging, inclusive of employment. Families and their teams can start at any age, but there are benefits to building early expectations of a good life, with friends, family, and a career.

The LifeCourse Framework is composed of several domains: daily living and employment, community living, safety and security, healthy lifestyles, social and spirituality, and citizenship and advocacy. Each domain emphasizes what a person can do as part of everyday life.

The CoP for Supporting Families Across the LifeSpan uses tools to assist families and those that support them, such as support coordinators, to plan for a connected and fulfilling life for the family member with a disability, from birth to retirement age. One such tool is a booklet that centers on the daily life and employment domain. *Charting the LifeCourse: Daily Life and Employment* is a resource for families, individuals with I/DD, support coordinators and others to use to foster a positive employment trajectory.

Charting the LifeCourse: Daily Life and Employment takes people on a journey through education, employment, and individual and family life at each life stage. All the questions and ideas are written in the voice of the person with I/DD, even for young children. For infants and toddlers, questions include, “Do you recognize and respond to my signs, signals, babbling, gestures, and words? Are you playing with me and helping me to find ways to learn about and explore my environment?”

Employment is addressed even at this age, and families can bounce off ideas with support coordinators and others. A few employment questions for infancy and toddlerhood include, “Are you worried about how a diagnosis might affect my future? Do you have a vision or plan in mind for me when I get older that will support my growth and development now?”

The Early Childhood stage employment questions include, “Are you keeping a vision in mind for my future as I learn and grow? Do you view me as being able to do what other children do, even if I need extra help

to do so? Do I have chores or responsibilities at home like cleaning my room or picking up my toys?” Other important questions in early childhood are, “Are you giving me opportunities to make choices (between two or three options)? Do I have the opportunity to make mistakes and are you helping me learn from my mistakes?”

The School Age life stage probes employment through asking, “Do you ask me what I want to be when I grow up? Am I learning about lots of different jobs from my family, teachers and others? Do I have responsibilities at home such as daily chores?”

At the Transition Stage, the possibilities of postsecondary education, college, and work are discussed, along with employment questions such as, “Does my transition plan include work or volunteer experience, and practicing how to look for, get, and keep a job? Does my transition plan balance work experience, social skills and academics according to my needs, desires, and abilities? Are you helping me understand that doing my best at school and being responsible will help me get a job I like someday? Am I learning about the different roles people have in life and how they are interrelated?”

In Adulthood, education is emphasized on finding ways to continue learning at the job, volunteering, in the community, or with friends and if there are other interests the person would like to explore. Employment questions probe: “What will I do during the day now that I am an adult? What are the things I really like or want to do? Can I find a job or volunteer opportunity that matches my passion or interests? Would I prefer to have a full-time job, part-time job, or volunteer? Where can I learn or improve my employment skills? Can I turn an interest of mine into a way to earn income/start my own business?”

Aging has its own areas of emphasis, with questions about learning a new skill, keeping busy or earning money in retirement, senior classes, hobbies, medical and health information, and funds or support available when income changes. Employment questions at this life stage: “Can I afford to retire? What will I do to keep busy if I retire? Do I have funds or support to replace my income when I retire?”

www.lifecoursetools.com/wp-content/uploads/EMPLOYMENT-GUIDE-FINAL.pdf

ThinkWork!



The Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities.

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