2025 Developmental Disabilities Legislative Symposium

June 2025

Shifting to Home and Community-Based Settings: Integrated Services for People with Complex Needs

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Integrated Services for People with Complex Needs

Over the past five decades, there has been a strong movement towards supporting people with intellectual and developmental disabilities (I/DD) within home and community-based settings. This has resulted in a shift in all states from congregate settings (including intermediate care facilities) to home and community-based services. While most support this effort, transitioning those with more complex needs has proven to be a challenge.

In this session, Dr. Christopher Baglio will discuss the history behind intermediate care facilities and common barriers that may limit a state's ability to transition some people into more integrated settings. This will be followed by a discussion of financial, policy and programmatic strategies to overcome these challenges, building a proactive plan that can help states avoid the pressure of litigation and settlement agreements while supporting people with I/DD to live their best life.

Particular attention will be paid to those with intellectual and developmental disabilities who have more complex needs, such as those with behavioral health conditions and/or forensic involvement.

Key words: Intellectual and developmental disability, dual diagnosis, discharge planning, transition services, care continuum, crisis services, intensive treatment program, intermediate care facility, home and community-based services.

Presentation Outline

June 12, 11:00am to 12:00pm

I. Shifting from Intermediate Care Facilities (ICF) to the Community

I. ICF vs. HCBS

II. National Trends

III. ADA and Olmstead

II. Community Placement Challenges

III. Strategies to Support Community Placement

I. Effective Transition Planning

II. Enhanced Care Continuum

III. Intensive Treatment Programs

IV. Facility Modernization

Intermediate Care Facilities (ICF) vs. Home and Community-Based Services (HCBS)

Historic model for individuals with intellectual and other developmental disabilities (I/DD) was institutional, providing total care within congregate settings. Since the 1980s there has been a strong shift to HCBS with Alaska, Michigan, Montana, and Oregon no longer operating ICF/IIDs (as of 2020).

Setting

- Always includes residential services
- Minimum size is 4-beds, some have hundreds (thousands in the past)
- Many include day/vocational, recreation and ancillary services on the same grounds
- Most are privately owned and operated, with several states no longer operating ICFs

Intended Benefits

- Bundled services, wrap around with coordinated care for those with more complex needs
- Additional federal expectations around rules and regulations, oversight
- 24-hour supervision and care

Authority/Funding

- ICF/IID program established in 1971; Social Security Act (SSA), Section 1905(d)
- Federal financial participation (FFP) in “institutions” that provide “active treatment” for individuals with intellectual disabilities or related conditions
- FMAP impacted by state per capita income (minimum of 50% and a maximum of 83%)

Observed Challenges

- Congregate care, privacy concerns
- Restrictive environments, less choice and more control
- Concerns around quality of care, prevalence of abuse and neglect (increased risk factors)

Eligibility

- Need for active treatment (AT) services, “aggressive, consistent implementation of a program of specialized and generic training, treatment and health services”
- States may not limit access to ICF/ID services, or make it subject to waiting lists (they can for HCBS)

Intermediate Care Facilities (ICF) vs. **Home and Community-Based Services (HCBS)**

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Setting

- Can include in-home residential (own home or a family home)
- Host home or shared living (providers' home or shared living arrangement)
- Residential habilitation in provider setting (can include continuous home, host home, shared living)
- Specialized residential habilitation (specialized services in provider setting)

Intended Benefits

- Integrated care within the community, positive outcomes and better lives
- Freedom of choice, including choice of different service providers, roommates, etc.
- Promotes independence and often more cost-effective

Authority/Funding

- 1981 Section 1915(c) of the Social Security Act (SSA) established HCBS.
- 1915(i), 1915(j), 1915(k), 1915(b), 1115 Demonstration
- States can request waivers for individuals who would otherwise receive services in an ICF/IID.
- FMAP is like ICF/IIDs, but can be more with other programs (e.g., MFP)

Observed Challenges

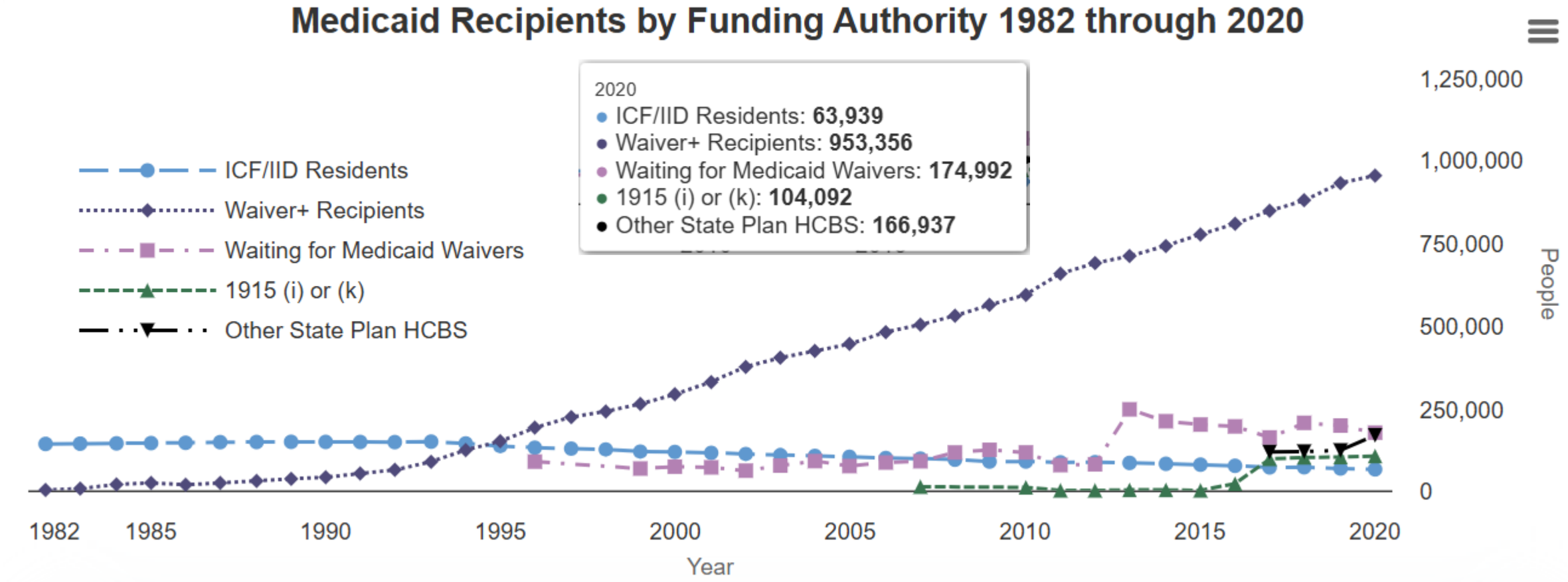
- Access and availability of service, particularly for complex needs (waiting lists, provider capacity)
- May not have same access to specialized care, potential for hospitalization
- Coordination of care is more complex

Eligibility

- Meet both financial and medical/functional eligibility requirements
- Functional eligibility associated with institutional level of care (LOC)
- Program specific requirements, based on waivers

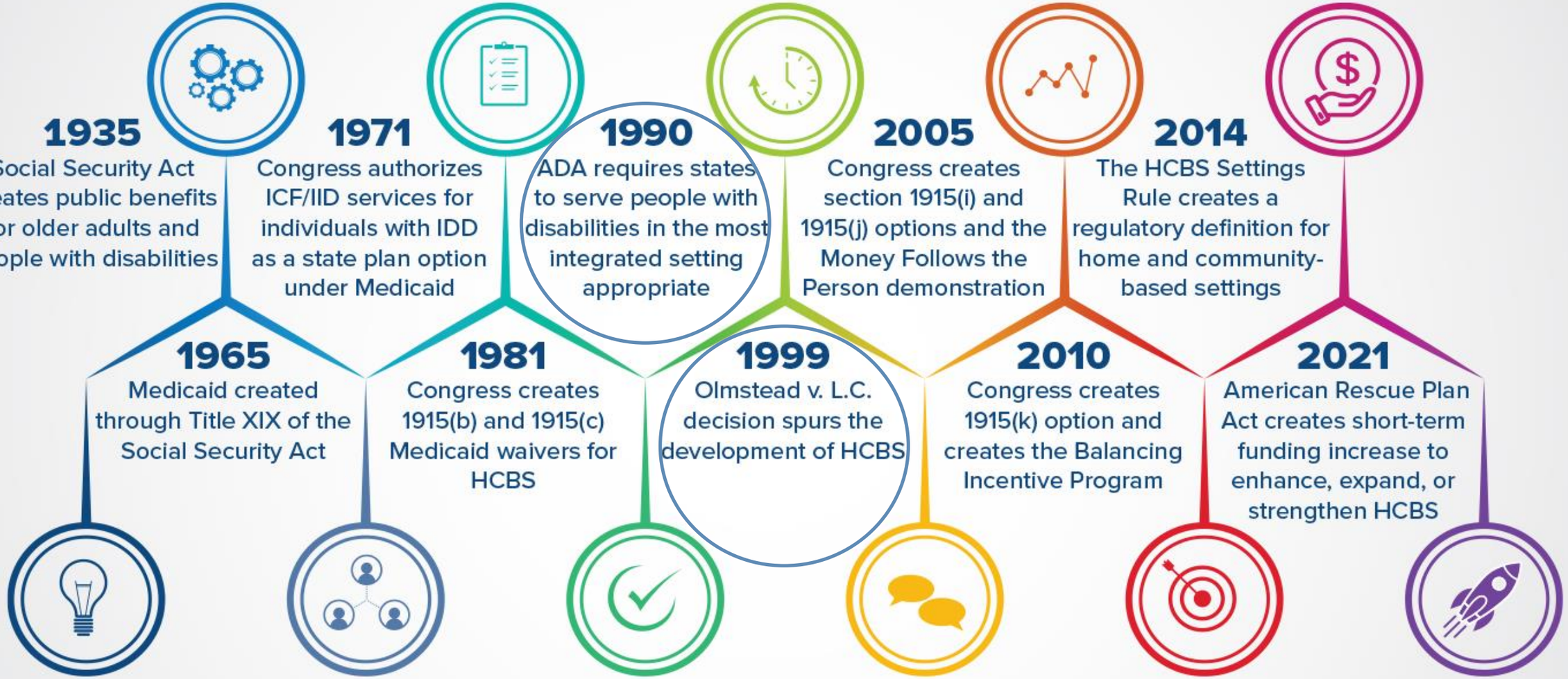
Shift From Intermediate Care Facilities to Home and Community-Based Settings

Following creation of the Medicaid HCBS waivers in 1981, there has been a steady increase in people with intellectual and developmental disabilities accessing services through those programs. This has resulted in a reduction in ICF/IID participation and an increase in HCBS waiver waiting lists.



Residential Information Systems Project (2020). Medicaid Recipients by Funding Authority 1982 through 2020. Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: https://risp.umn.edu.

NAMD Issue Brief (2024) | **Why did they do it that way?**
Home and Community-Based Services



Sources:

- Medicaid Services for People with Intellectual or Developmental Disabilities: Evolution of Addressing Service Needs and Preferences, Health Management Associates report to MACPAC
- Long-Term Care in the United States: A Timeline, KFF
- Long-Term Services and Supports Rebalancing Toolkit, CMS

Levers for Community Integration

Americans with Disabilities Act (ADA) – 1990

The ADA prohibits discrimination against people with disabilities in everyday activities – guaranteeing they have the same opportunities as everyone else for employment, the purchase of goods and services, and to participate in state and local government programs.

- Title I (Employment)
  - Covers employers in the private sector, state and local governments, and labor unions.
  - It prohibits discrimination against such individuals and requires employers to provide such individuals reasonable accommodations.
- Titla II (Public Services)
  - **Subtitle A:** State and local governments must provide people with disabilities an equal opportunity to benefit from all their programs, services, and activities.

Olmstead | U.S. Supreme Court Decision – 1999

Landmark Supreme Court decision enforces the protections of the ADA and ensures access to community-based disability services.

- The unjustified segregation of people with disabilities is a form of unlawful discrimination under the ADA (Title II).
- The U.S. Department of HHS Office of Civil Rights (OCR) supports the Olmstead decision and promotes community living through enforcement of the ADA and other key civil rights laws.
- Key provisions of the Olmstead decision is that people with disabilities have the right to receive state funded support and services in the community rather than institutions.

Olmstead Decision | **Enforcement and Litigation**

The U.S. Department of Justice, Civil Rights Division, enforces the integration mandate of the U.S. Department of Health & Human Services (HHS), Office of Civil Rights, regulation implementing Title II of the ADA. Olmstead litigation primarily focuses on the unnecessary institutionalization of individuals with disabilities.

Step 1: Initiation & Inquiry
- DOJ receives complaints or identifies civil rights concerns.

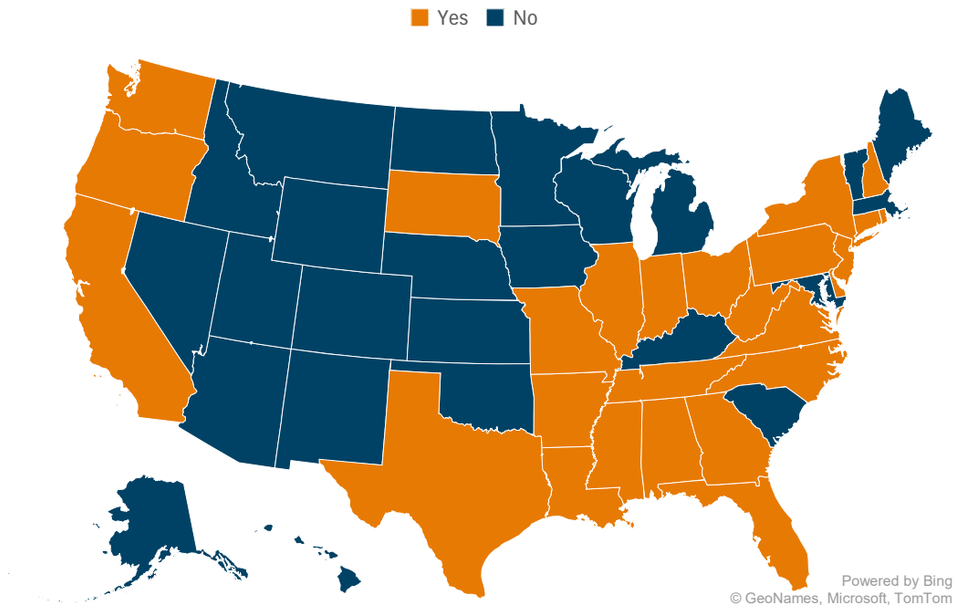
Step 2: Investigation & Fact-Finding
- On-site visits, interviews, and expert assessments.

Step 3: Findings Letter
- DOJ issues a findings letter detailing violations.

Step 4: Negotiation & Settlement
- DOJ negotiates reforms
  - Settlement or consent decree.

Step 5: Enforcement & Compliance Monitoring
- If non-compliant, DOJ may file a lawsuit.
- DOJ monitors reforms.

Olmstead Litigation (DOJ) by State



Recent Example: USDOJ has opened an investigation into Illinois' treatment of people with developmental disabilities, examining whether the state provides adequate resources for community living and protects residents from harm in public institutions. Choate, Mabley, and Shapiro Center.

Factors that Make Community Placement Challenging

While there is broad support for moving individuals from Intermediate Care Facilities (ICFs) into the community, there are several factors that can make community placement challenging. These are a few.

Factor	Sample Challenges
Complex Needs	Individuals in ICFs often have severe intellectual and developmental disabilities (I/DD) and complex medical and behavioral needs. This **requires specialized care that may be difficult to replicate in community settings**.
Funding and Resources	Securing adequate funding for community-based services can be difficult. Additionally, there can be a lack of resources, **including insufficient funding for community services and workforce shortages (waiting lists).**
Insufficient Community Alternatives	**A lack of readily available and adequately equipped community-based alternatives may exist.** These include appropriate housing and support programs to meet the diverse needs of individuals.
Lack of Planning and Leadership	**Effective planning, strong leadership, and coordination between different agencies and stakeholders** are crucial for successful deinstitutionalization. Insufficient planning and accountability can hinder the process.
Family and Caregiver Concerns	Families may have concerns about the **safety and well-being** of their loved ones in community settings and **may not fully understand the available support options**. They may also be resistant to the transition due to feelings of guilt or fear of the unknown (also **history of trauma and failed placements**).
Attitudinal and Social Barriers	**Stigma and negative attitudes towards individuals with I/DD** within the community can lead to resistance and hinder successful integration.
Workforce Challenges	**Workforce shortages, low pay, and lack of adequate training for direct support staff** can impact the quality of care and contribute to difficulties in community placement.

Factors that Facilitate Community Placement

There are several strategies that can address key barriers to placing individuals from intermediate care facilities (ICFs) into the community. These are a few.

Sample Strategies

Factor

- Expand accessible and affordable **housing options**.
- Develop and invest in varied and robust **home and community-based services (HCBS)** infrastructure.
- Improve **transportation** options.

Enhancing Community Resources

- Strengthen the **direct support professional (DSP) workforce**.
- Advocate for **fair compensation, training, and professional development** (possibly certification).

Addressing Workforce Challenges

- Advocate for policies that prioritize **community living** (includes employment options).
- Eliminate Medicaid's **institutional bias** and ensure full implementation of the **HCBS Settings Rule**.
- Provide **financial assistance** for transition costs.

Improving Funding and Policy

- Conduct **awareness programs**, educating the public about the importance of inclusion and diversity.
- Promote **self-advocacy.**
- Challenge discrimination and push for **inclusive policies** in all aspects of community life.

Combating Stigma and Promoting Inclusion

- Implement true **person-centered planning** (individual's goals, preferences, and needs).
- Improve **coordination** of services.

Individualized Planning and Coordination

- **Empower individuals with I/DD** to make choices about their lives and control their services and supports.
- **Foster independence** through providing opportunities to develop skills, manage finances, and participate in the community.

Promote Self-Determination

- Provide families with **information and support.**
- **Involve families** in transition planning.

Fostering Family Engagement

Strategies to Improve Community Placement | **Effective Transition Planning**

Facilitating a transition from an Intermediate Care Facility (ICF), or other congregate setting, to community living for individuals with I/DD requires a multifaceted approach that addresses their physical, social, emotional, and cognitive needs.

Action Steps

Factor

Early and Comprehensive Discharge Planning

- **Start early**, soon after admission (highlight the intended temporary nature of the placement).
- Identify individual needs and interests (**CtLC Vision Tool**).
- Develop a **clinical management plan** (focusing on reasons for admission).
- **Highlight the person**, help build their story.

Person-Centered Approach

- **Involve the individual and family** (ensure their choices, preferences, and needs are respected).
- Listen to their needs and goals (vision of a good life, **CtLC Life Trajectory**).
- Provide **clear information**, use plain language to increase participation.

Community Integration

- Promote **community participation,** including social clubs, recreational programs, employment, etc.
- **Address barriers** to community participation, including transportation.

Programmatic Support

- **Mirror the environment** the person is moving to (or targeting for transition).
- **Reduce restrictions**, some things cannot be implemented in community settings.
- Plan for **training of community staff.**
- Include **incentives** to placement (financial incentives, transition support).

Pre-Transition Support

- Use a **matching process**.
- Conduct **pre-transition visits** (activity, day, dinner, overnights).

Post-Discharge Support

- Designate a team for **wraparound support.**
- Make **follow-up phone calls** to the person within 24-72 hours of discharge to check in and address concerns.
- Develop a **follow-up visit schedule** (e.g., weekly, monthly, quarterly).

Charting the LifeCourse (CtLC) | **Vision Tool**

Life Domain	Description	My Vision for My Future	Priority
Daily Life & Employment	What do I think I will do or want to do during the day in my adult life? What kind of job or career would I like?		
Community Living	Where would I like to live in my adult life? Will I live alone or with someone else?		
Social & Spirituality	How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?		
Advocacy & Engagement	What kind of valued roles and responsibilities do I or will I have, and how can I have control of how my own live is lived?		

CtLC's Vision Tool can be used to identify preferences, set priorities and facilitate matching with community providers.

Life Domain	Description
Healthy Living	How will I live a healthy lifestyle and manage health care supports in my adult life?
Safety & Security	How will I stay safe from financial, emotional, physical or sexual harm in my adult life?
Supports for Family	How do I want my family to still be involved and engaged in my adult life?
Supports and Services	What support will I need to live as independently as possible in my adult life, and where will my supports come from?

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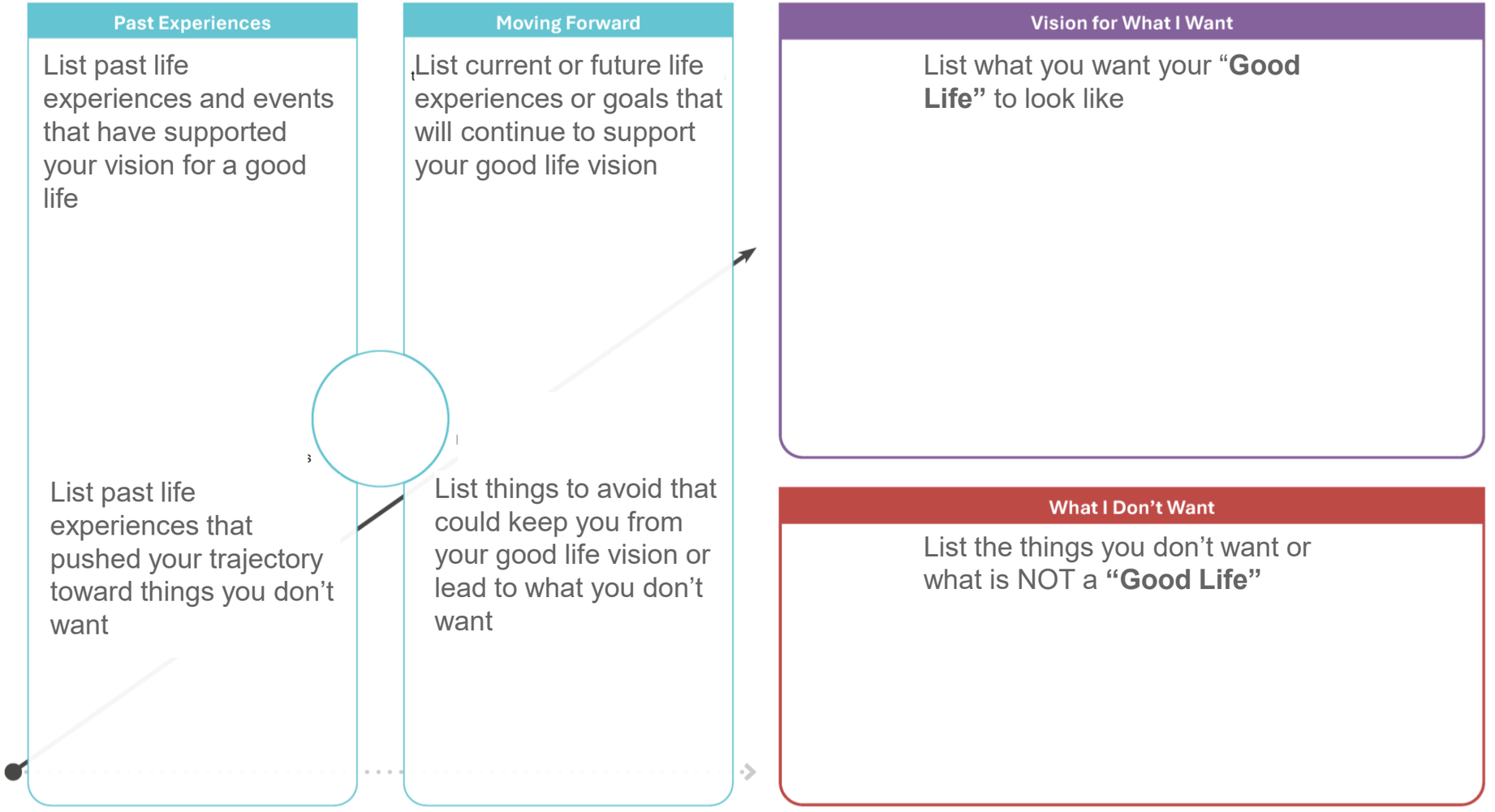
Charting the LifeCourse (CtLC) | **Planning a Path Forward**



- Envision your "Good Life" and identify the steps or experiences needed to get there
- Sometimes easier to start with "What I Don't Want"
- Highlights the past life experiences that are leading or moving you away from your vision
- Provides space for current goals and things to avoid moving forward

Strategies to Improve Community Placement | **Enhanced Care Continuum**

Goal: The safely support people in their homes, with out-of-home options that are short-term and used only when needed. Designed correctly, people will be less likely to be placed out of their home, including in hospital, jails or out-of-state placements. Considerations: Qualifications, workforce, cost/funding, training, referral/tracking and eligibility.

Build Provider Capacity

- Education, outreach, and training.
- Enhanced rates/budgets based on level of service, both quality and quantity (e.g., acuity-based rates, value-based payments).

Crisis Response

- 988, hotline, intake.
- Onsite mobile response. Regional teams of clinicians (behavior analysis, mental health, medical).
- In-Home Response. Assessment, treatment planning, training, and direct support.

Crisis Stabilization Services

- Out-of-Home Stabilization.
- 30, 60, 90 days.
- Longer term stabilization available up to 18 months.

Post Crisis Transition and Monitoring

- Follow along services, weekly, monthly

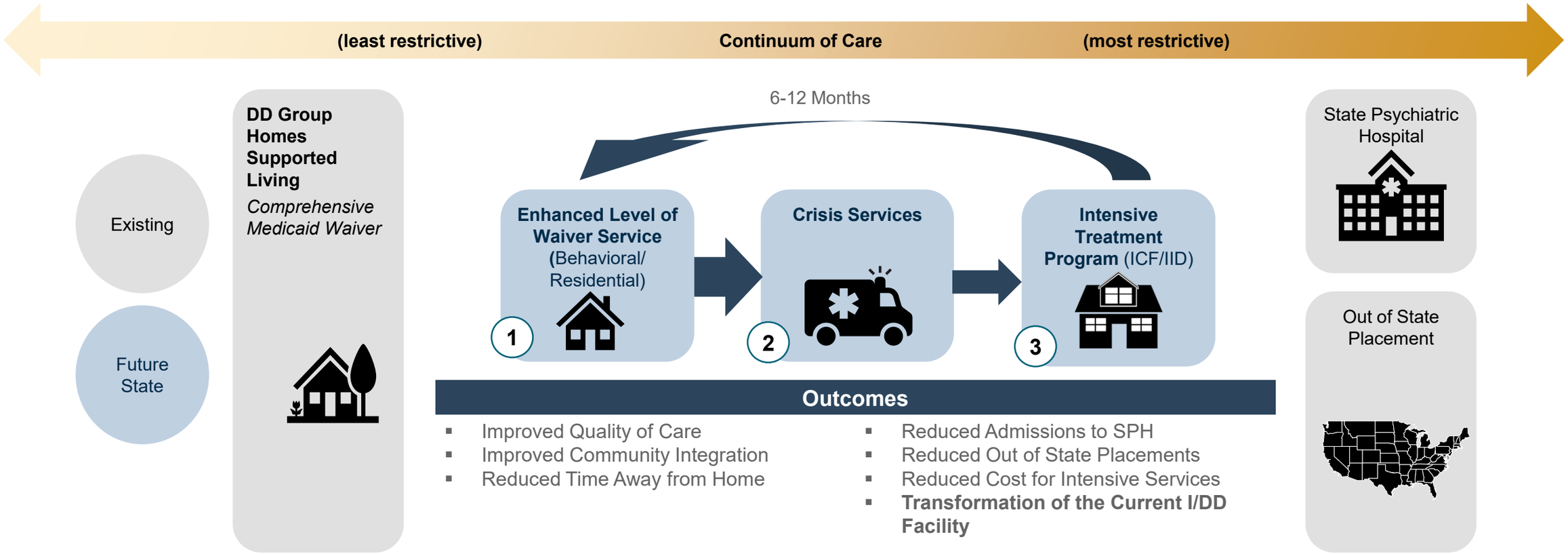
Supporting People with Complex Needs | **State Model**

All states have an obligation to support individuals within the least restrictive and most integrated setting. To meet this obligation and support the Department's vision for individuals with I/DD who have complex needs, [State] needs to introduce three new services, which are common in other states: (1) Acuity based Medicaid Waiver services and associated rates; (2) Crisis services; and (3) An Intensive Treatment Program.

	1 Enhanced Level of Service Behavioral/Residential	2 Crisis Services	3 Intensive Treatment Program
INTENDED OUTCOMES	▪ Individuals with complex needs (like those at state facility) would be better served in the community.	▪ Assist providers and families in preventing, deescalating, and intervening in instances in which individuals with I/DD are likely to go into crisis and be placed out of their home.	▪ Support individuals who cannot be safely served within an HCBS environment. ▪ Stabilization and transition back into more integrated settings.
DETAILS	▪ Higher reimbursement rates for exceptional behavioral and residential needs so that providers can deliver enhanced level of care. ▪ Transition support teams (programming and positive behavioral plans) that help providers make the transition from facility successful.	▪ Prevention, intervention, and crisis support. ▪ Training and support for providers and families to prevent crisis. ▪ Direct professional staff support in the individual's current placement. ▪ Through provision of temporary crisis support, out of home placements and admission to more restrictive settings will be reduced. ▪ National Center for START Services®.	▪ 6-to-12-month, short-term stays ▪ Active and intensive treatment ▪ Small, home-like cottages (2-4 beds) ▪ Step up from community for intensive support ▪ Transition back to community ▪ Potential model: Kennedy-Krieger ▪ Seek academic partnerships

Supporting People with Complex Needs | **State Model**

The goal is to support all individuals with I/DD within the community, even those with complex needs. To achieve this outcome, the service delivery system requires sufficient capacity to wrap services around those individuals who are either at risk of being placed outside of their home, or have been removed from a home, placed into a more restrictive and less integrated setting.



Supporting People with Complex Needs | **Intensive Treatment Program**

Components obtained through review of similar services in other states. These are not all encompassing but provide key components that need to be considered when implementing short-term stabilization or another enhanced service program (e.g., intensive treatment program).

Settings

- Homelike settings, fewer participants in each setting, ability to fade restrictions (e.g., egress, perimeter), also consider hardening some aspects.

Services

- Intensive clinical services (trauma informed care, applied behavior analysis, psychiatric services, OT/PT, speech, dietary and others needed).

Population

- Based on state needs, likely adult with ability to support both men and women.

Length of Stay

- Shorter term placement (30-90 days), mechanism to extend, option to transfer to alternate setting.

Admission Criteria

- Eligibility criteria (very clear and linked to discharge criteria), mechanism for referrals, no-reject policy, etc.

Discharge Criteria

- Stabilization definition (and agreement at admission), criteria that triggers transition, no-eject policy, etc.

Post Transition Follow

- Follow along contact after transition to alternate setting, type and duration (weekly, monthly, quarterly, annual).

Provider Qualifications

- Limit to select providers, expectations above standard levels, staffing (e.g., BCBA, RBT, NADD-DSP).

Training Requirements

- Enhanced level of training (program and provider staff), behavior drills, integrity checks.

Payment Model

- State program (e.g., ICF/IID), HCBS provider – full state funded, Medicaid waiver.

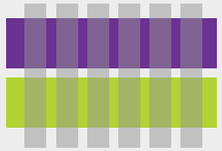
Sample Programs

- ICF Intensive Treatment Programs (OK), NADD Certified Facilities (MO), Enhanced Behavioral Support Homes (CA), Neurobehavioral Units (MD), Crisis Stabilization Centers (START), blended BH/DD settings (MS).

Strategies to Improve Community Placement | **Facility Program Modernization**

Assessing the broader care continuum and the critical part that the facility plays in providing individuals with I/DD and the most complex needs access to critical care is the core work that needs to occur. This allows development of a strategic plan that will serve as a guide to modernize facility-based services in support of more integrated care.

Understand Who is Served. Develop "All Triangles" for impacted communities.



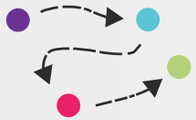
Deepen Understanding of Impacted Communities. Break down impacted communities (including BH).

Identify Market Factors and Impact. Factors that impact demand and access to services both at facility and across the broader service delivery system.

Understand What Supports and Services Exist. Map and organize supports and services (i.e., care continuum for I/DD and BH).

Understand State and Federal Structures. Leverage national facility and community experience to define baseline operational and service environment.

Build Relationships and Facilitate Dialogue. Utilize baseline understanding to engage and include the perspective of impacted stakeholders (and communities)



Identify the Needs of Facility Population. For each identified segment of the population at Facility, develop detailed understanding of service and support needs.

Facility Operations and Programming. Discover Facility's current structure and operation through completing observations, interviews, and review of records.

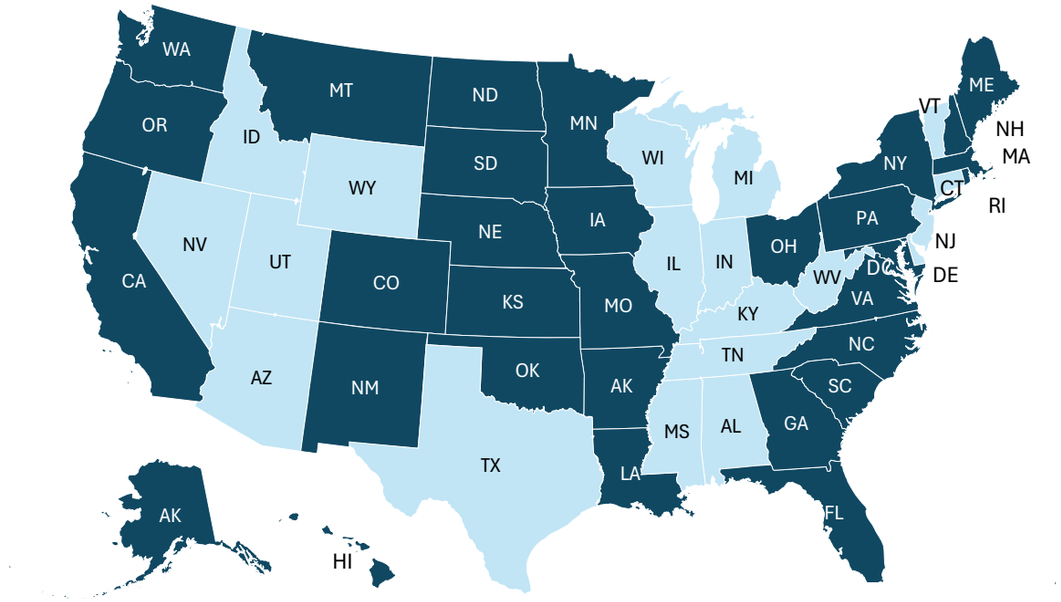
Strategic Planning. Establish plan with 5, 10, and 15+ year trajectory that includes a model for facility modernization and establishes its place in the care continuum.

- *Specialized Services*
- *Shorter Term Placements*
- *In Support of Community Services*
- *Convert Beds to Respite/Stabilization*

About Us

Among other areas, Alvarez & Marsal (A&M) specializes in Public Health and Human Services (PHHS) consulting, helping state agencies assess, stabilize, and transform programs related to medical and behavioral healthcare. A&M assists with improving Medicaid, Intellectual and Developmental Disabilities (I/DD), Medicaid Long-Term Services and Supports (MLTSS), Behavioral Health, and Child Welfare operations.

Recent A&M Engagements with Health and Human Services (HHS) Agencies



= Current or recent A&M Public Sector engagements

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Dr. Christopher Baglio is a Managing Director with Alvarez & Marsal Public Sector Services. He partners with state and local agencies, transforming service delivery systems to achieve meaningful outcomes for individuals with complex needs.

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