

## Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

State Survey Results 2015



"to build capacity through a Community of Practice (CoP) across and within States to create policies, practices and systems to better assist and support families that include a member with intellectual and developmental disabilities (I/DD) across the lifespan"

Project Objectives	Outcomes
1. To develop and refine a model framework for supporting families that addresses the needs of families with a family member with I/DD across the lifespan and supports states to develop and sustain exemplary family support practices.	State and national consensus on a national framework and agenda for improving support for families with children with I/DD
2 .To develop and facilitate a multi-level Community of Practice designed to build capacity within states and the nation to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan.	Enhanced State policies, practices, and sustainable systems that result in improved supports to families
3. To capture and share lessons learned and products to develop, implement and sustain exemplary practices to support families and systems.	Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems



- Online survey was distributed to the State Team CoP email list of approximately 56 people
- Thirty-eight people completed the survey
- Within states the number of respondents ranged from 10 to 3
- Sections included Demographics, System Drivers, and LifeCourse Principles
- Lichert scale response choices for each item included:
  - Not at all
  - Minimally
  - Partially
  - Extensively
  - Don't know



- Policies & Directives
- Leadership
- Voice of Self-Advocates and Families
- Framing & Communications
- Training & Technical Assistance
- Collaboration & Partnerships
- Infrastructure
- Space for Innovation
- Quality & Outcome Data



#### Individuals & Families...

- Receive information to make informed decisions about the supports they choose, including privately or publicly-funded or others part of typical community activities
- Person or family-centered that respect cultural, ethnic, economic, and spiritual differences
- Design and direct the supports they receive to the extent possible
- Receive supports that change as their needs change, they age through the life cycle or roles change
- Receive combinations of supports that are privately or publicly-funded or involve natural supports
- Have access to and receive health related services they need



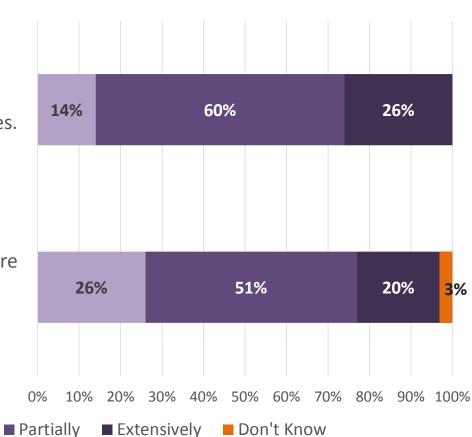
#### Individuals & Families...

- Access everyday technology, as well as specialized technology and environmental adaptations to meet their needs
- Access community supports available to any other citizen, including supports offered by community serving organizations, houses of worship, and community businesses
- Offer support to one another within "peer support" or exchange networks or human service cooperatives
- Are satisfactorily involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them
- The provision of supports results in the achievement of valued outcomes identified by individuals and families

## Policies & Directives To what extent are policies and directives in place to support families?

Strategic goals have been established to develop and implement supports to families.

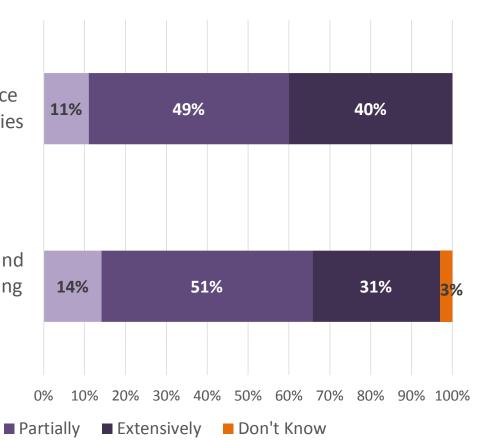
Policies and directives are in place that are consistent with the strategic goals for supporting families.



## Leadership To waht extent is there support from leaders to focus on supporting families.

Systems level leaders endorse and advance policies and practices for supporting families

Local community agency leaders endorse and advance policies and practices for supporting families



## Voice of Self Advocates and Families To what extent are individuals and families involved in activities to shape policies to support families.

Individuals with disabilities and family members are included in activities.

■ Not at all ■ Minimally

11% 57% 31% 9% 54% 37% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

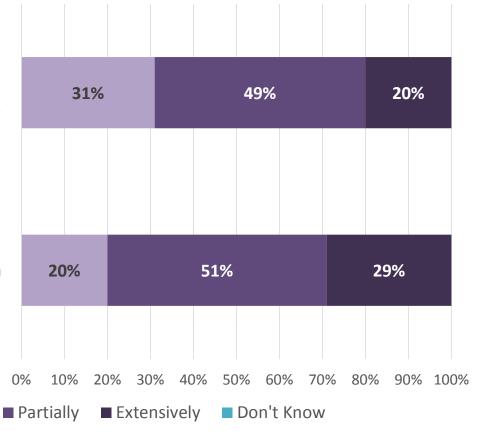
■ Partially ■ Extensively ■ Don't Know

Their input is valued and included in decisions and outcomes.

## Framing & Communications To what extent are stakeholders informed about policies and practices for supporting families.

An overall, cohesive message regarding families has been developed and utilized.

Information describing the LifeCourse framework reaches key target audiences in effective ways

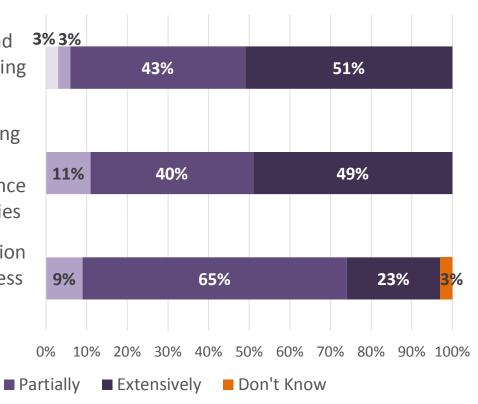


## Collaboration & Partnerships To what extent does your CoP team collaborate and partner to ensure better outcomes for individuals and families.

The CoP team collaborates to advance and establish policies and practices for supporting families

The CoP team actively builds new or existing partnerships with other agencies, organizations, and the community to advance policies and practices for supporting families

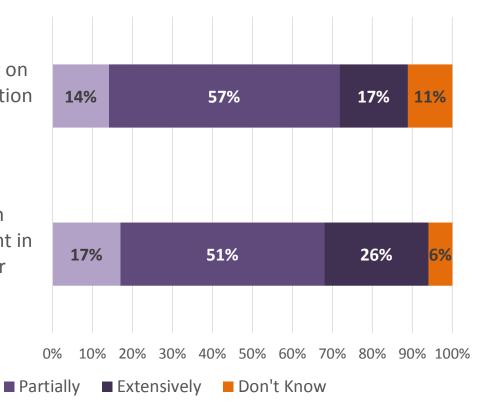
Systems level leaders endorse collaboration and cross training with a focus on seamless transition



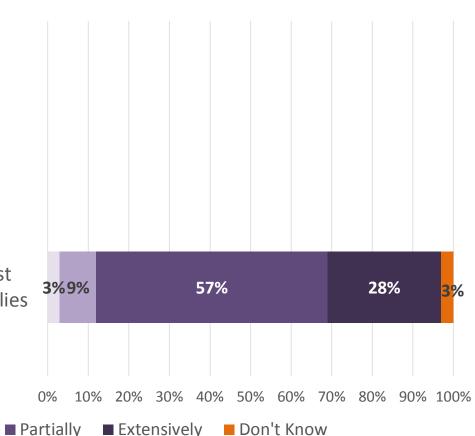
# Training & Technical Assistance To what extent does your CoP team participate in shared learning/professional development related to supporting families.

Community partners receive training on strategies to promote self-determination among people with IDD.

Community partners receive training on strategies for promoting family involvement in planning and providing supports to their family member.



### Space for Innovation To what extent does your CoP team create space for innovation to occur



There are opportunities to create and test innovative approaches for supporting families

### Infrastructure

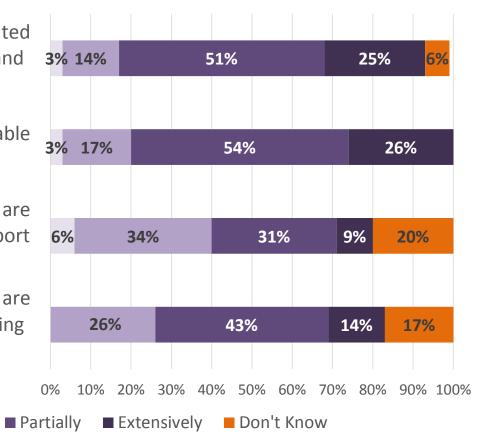
### To what extent is the necessary infrastructure being developed to support families.

At the systems level, staff have designated responsibilities to facilitate, develop, and coordinate supports to families

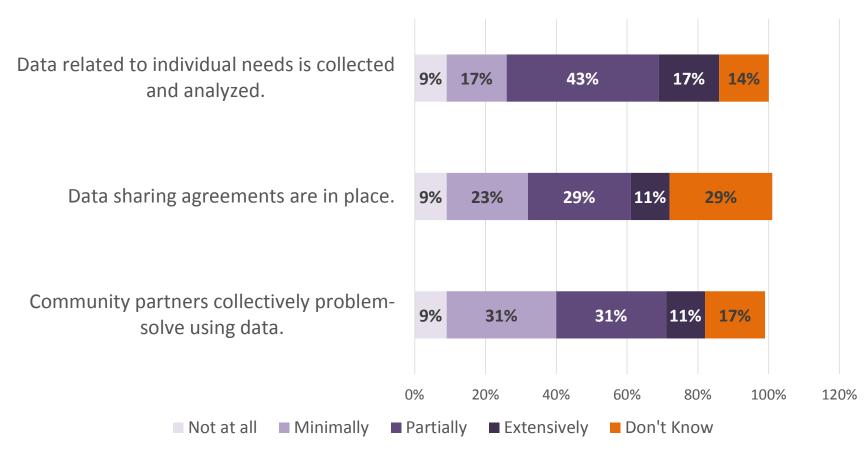
A range of services consistent with is available to support families.

Rates of reimbursement for services are ample to support practices that support families.

Case managers/service coordinators are prepared for facilitate service planning meetings.



## Quality Assurance and Outcome Data To what extent does your CoP team use individual and community data to inform supports to families.



### Reflections on State Performance Related to LifeCourse Principles

Individuals and families receive information so they can make informed decisions about the supports they choose, including...

Individuals and families receive person and/or family centered supports that respect cultural, ethnic, economic, and spiritual...

Individuals and families design and direct the supports they receive to the extent possible.

Individuals and families receive supports that change as their needs change, they age through the life cycle or roles change.

Individuals and families receive combinations of supports that are publicly or privately funded or involve natural supports.

Individuals have access to and receive the health related services they need.

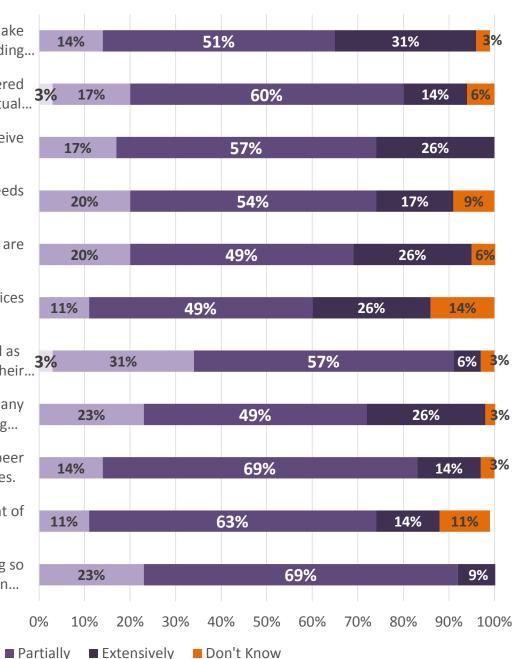
Individuals and families access to everyday technology, as well as specialized technology and environmental adaptions to meet their...

Individuals and families access community supports available to any other citizen, including supports offered by community serving...

Individuals and families offer support to one another within "peer support" or exchange networks or human service cooperatives.

The provision of services and supports result in the achievement of valued outcomes identified by individuals and families.

Individuals and families are satisfactorily involved in policy making so that they influence planning, policy, implementation, evaluation...





- Experiences with completing the survey
- Anything missing?