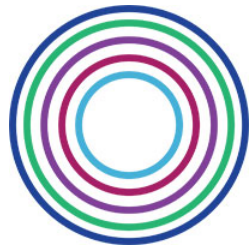




**Community of Practice  
for Supporting Families of Individuals  
with Intellectual & Developmental Disabilities**

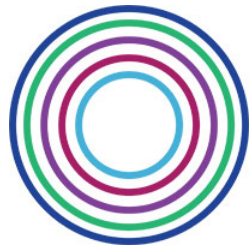
State Survey Results  
2015



# Project Intentions

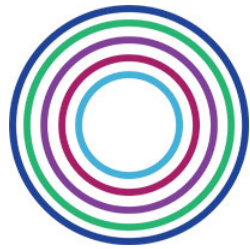
*“to build capacity through a Community of Practice (CoP) across and within States to create policies, practices and systems to better assist and support families that include a member with intellectual and developmental disabilities (I/DD) across the lifespan”*

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



## Overview

- 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



# System Drivers

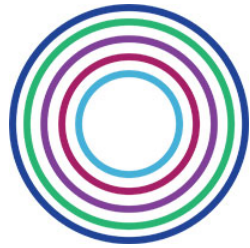
- Policies & Directives
- Leadership
- Voice of Self-Advocates and Families
- Framing & Communications
- Training & Technical Assistance
- Collaboration & Partnerships
- Infrastructure
- Space for Innovation
- Quality & Outcome Data



# LifeCourse Principles

## 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



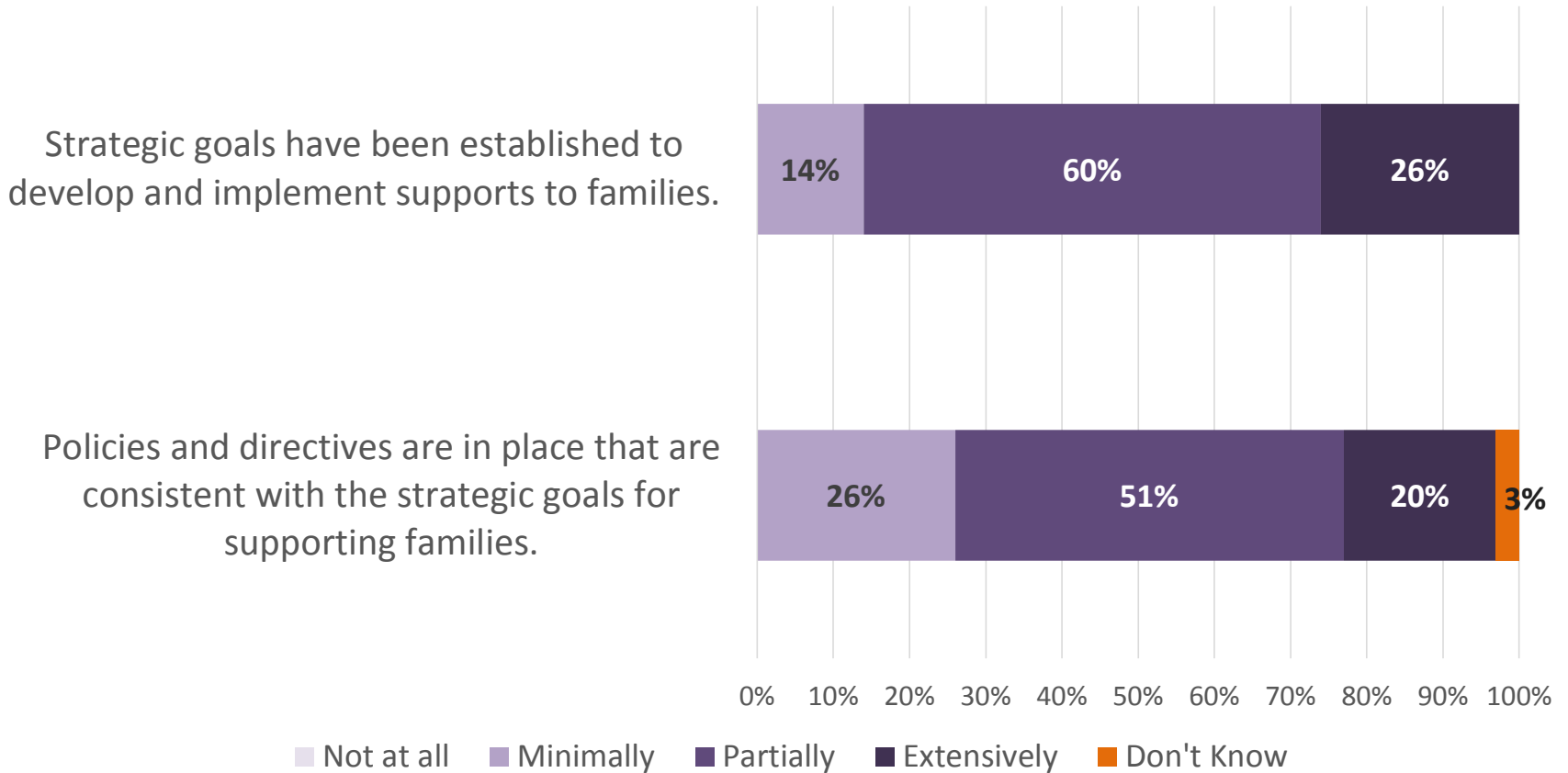
# LifeCourse Principles

## 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

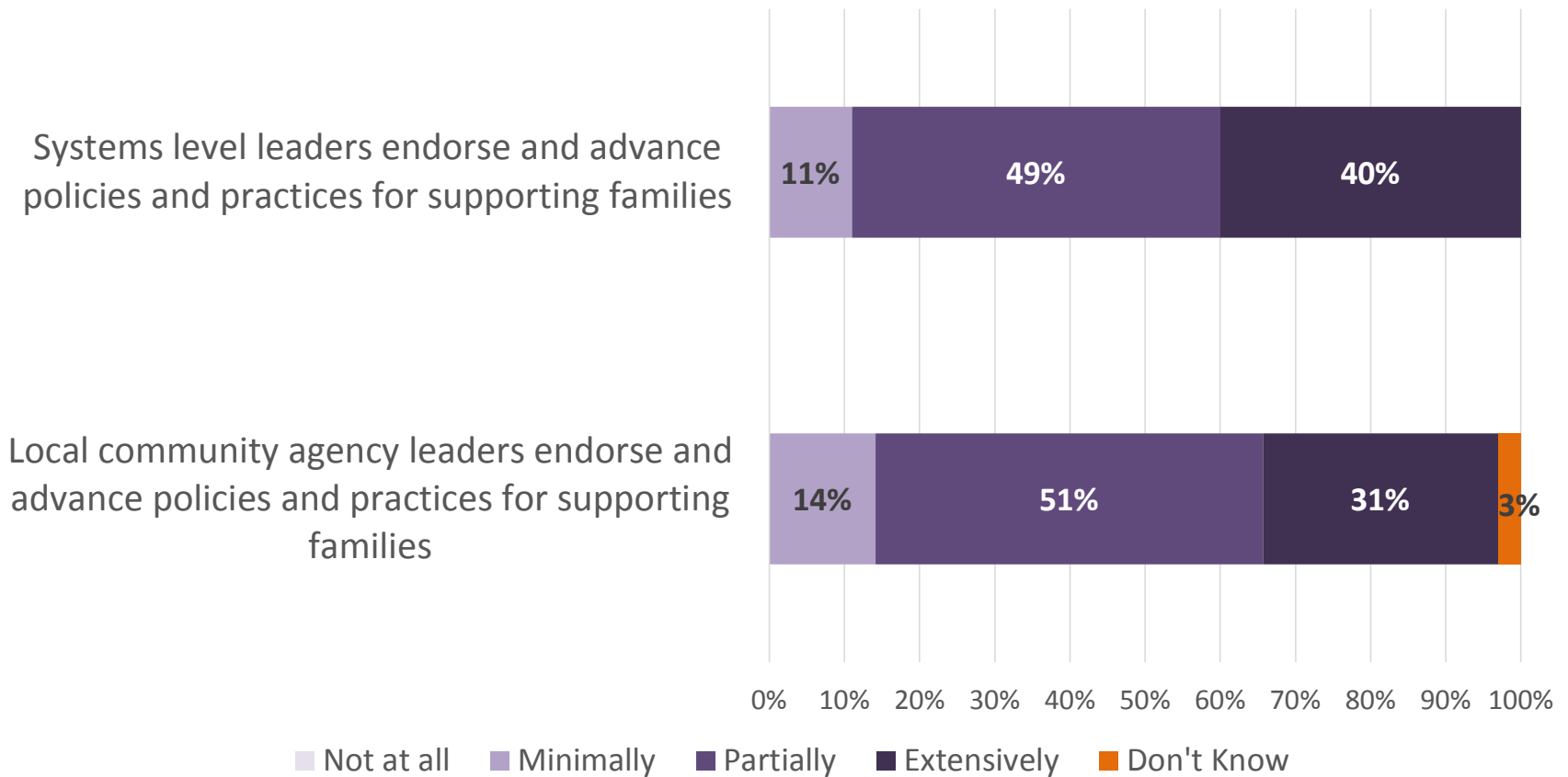
# Policies & Directives

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



## Leadership

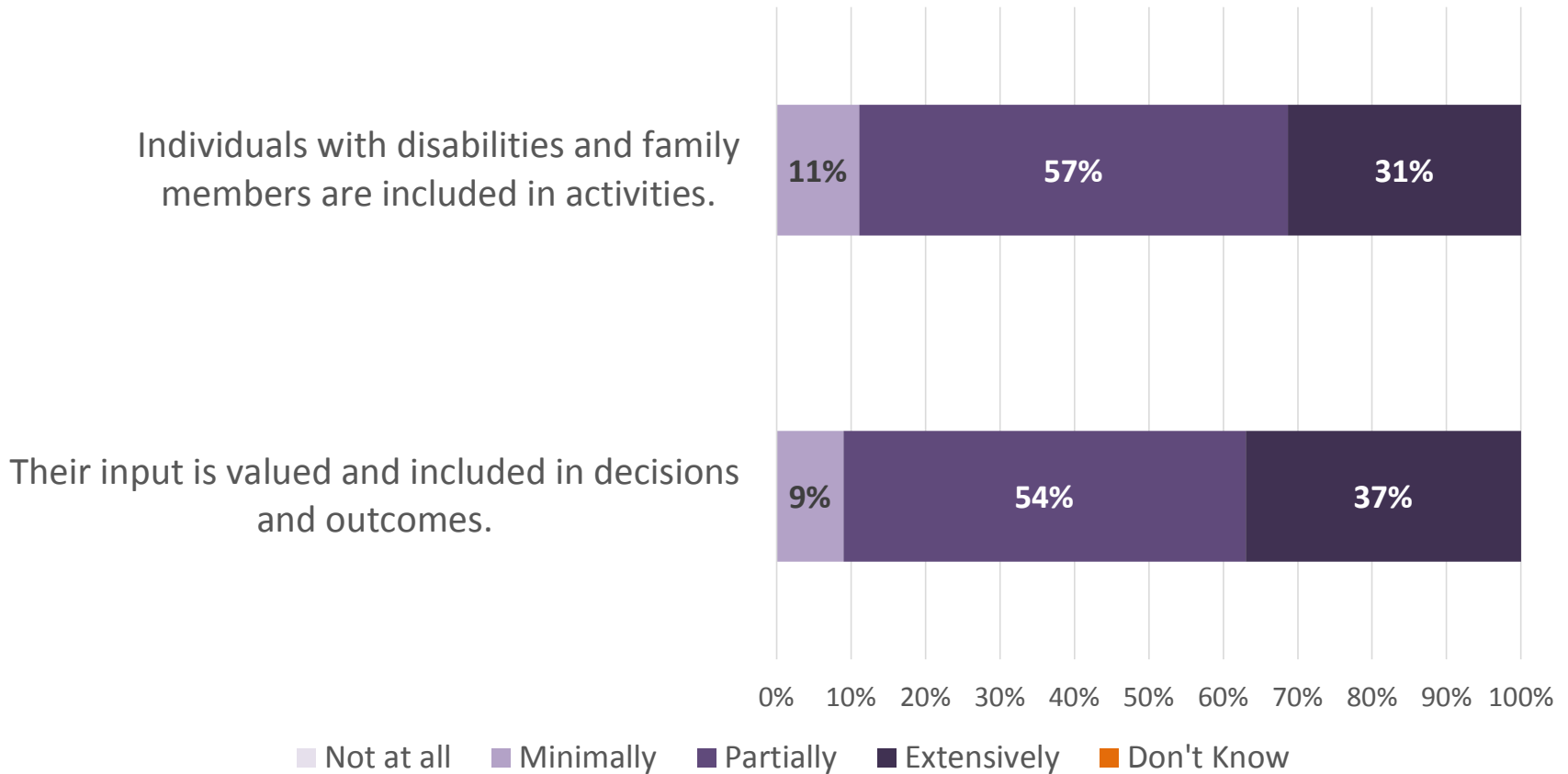
To what extent is there support from leaders to focus on supporting families.





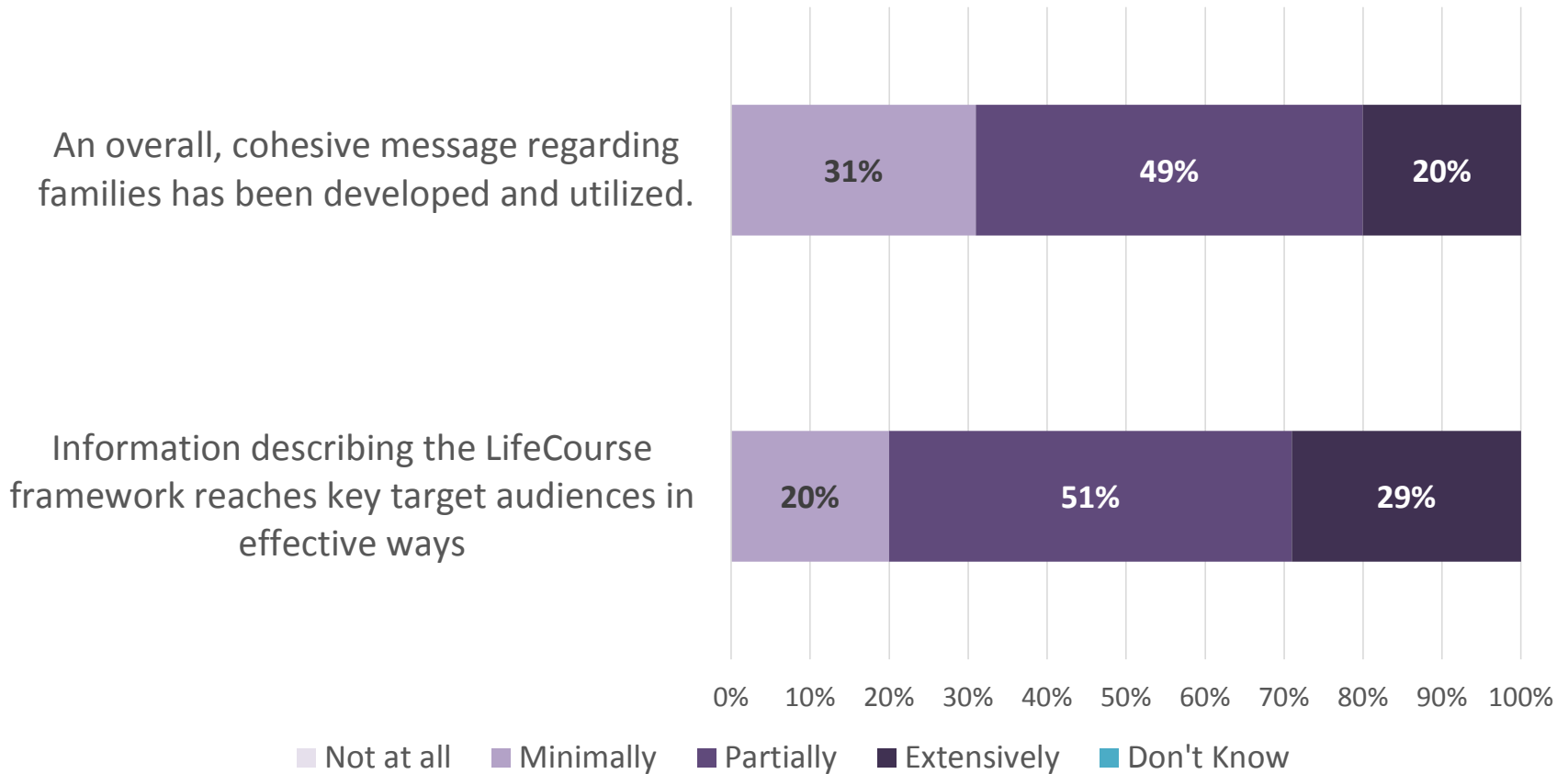
## Voice of Self Advocates and Families

To what extent are individuals and families involved in activities to shape policies to support families.



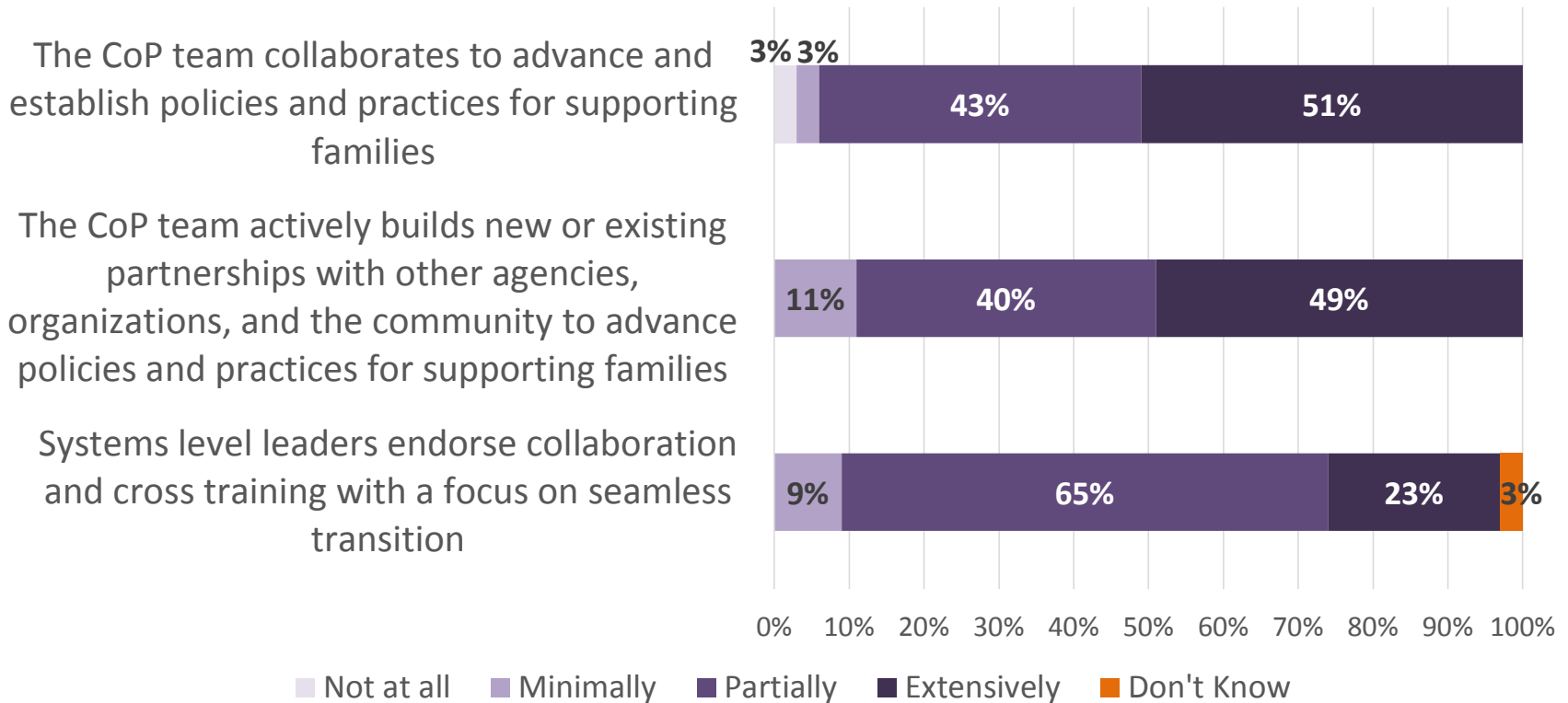
## Framing & Communications

To what extent are stakeholders informed about policies and practices for supporting families.



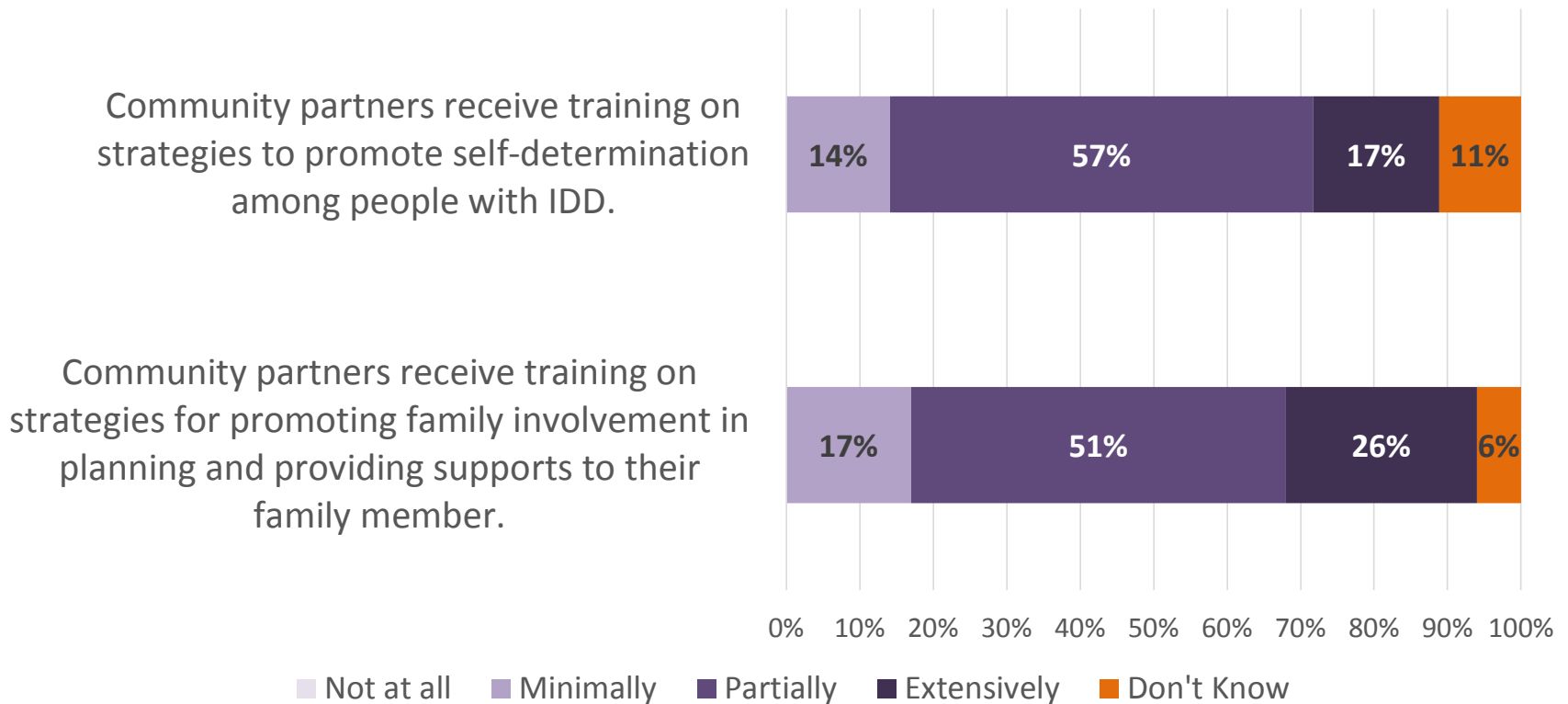
## Collaboration & Partnerships

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



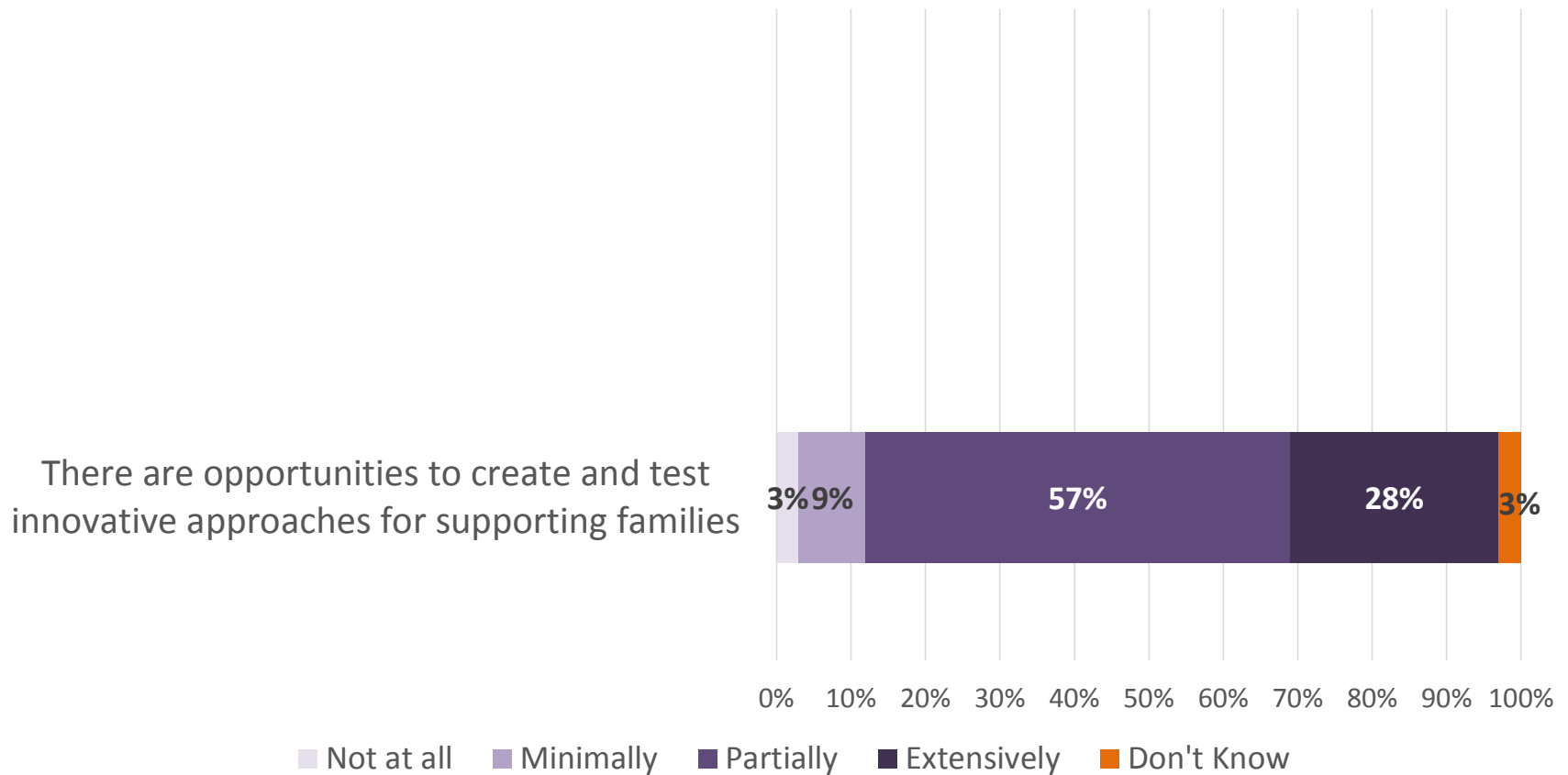
## Training & Technical Assistance

To what extent does your CoP team participate in shared learning/professional development related to supporting families.



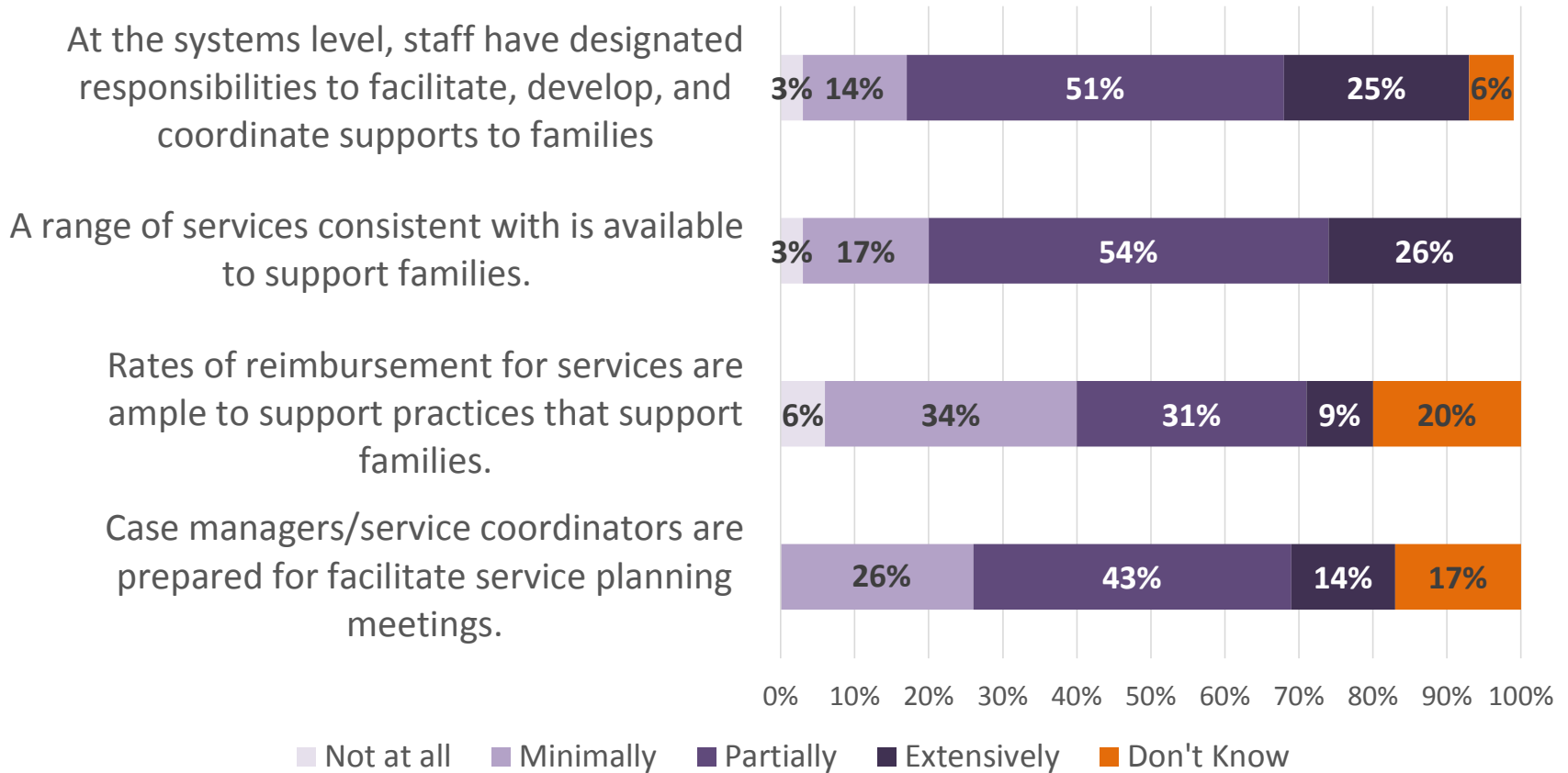
## Space for Innovation

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



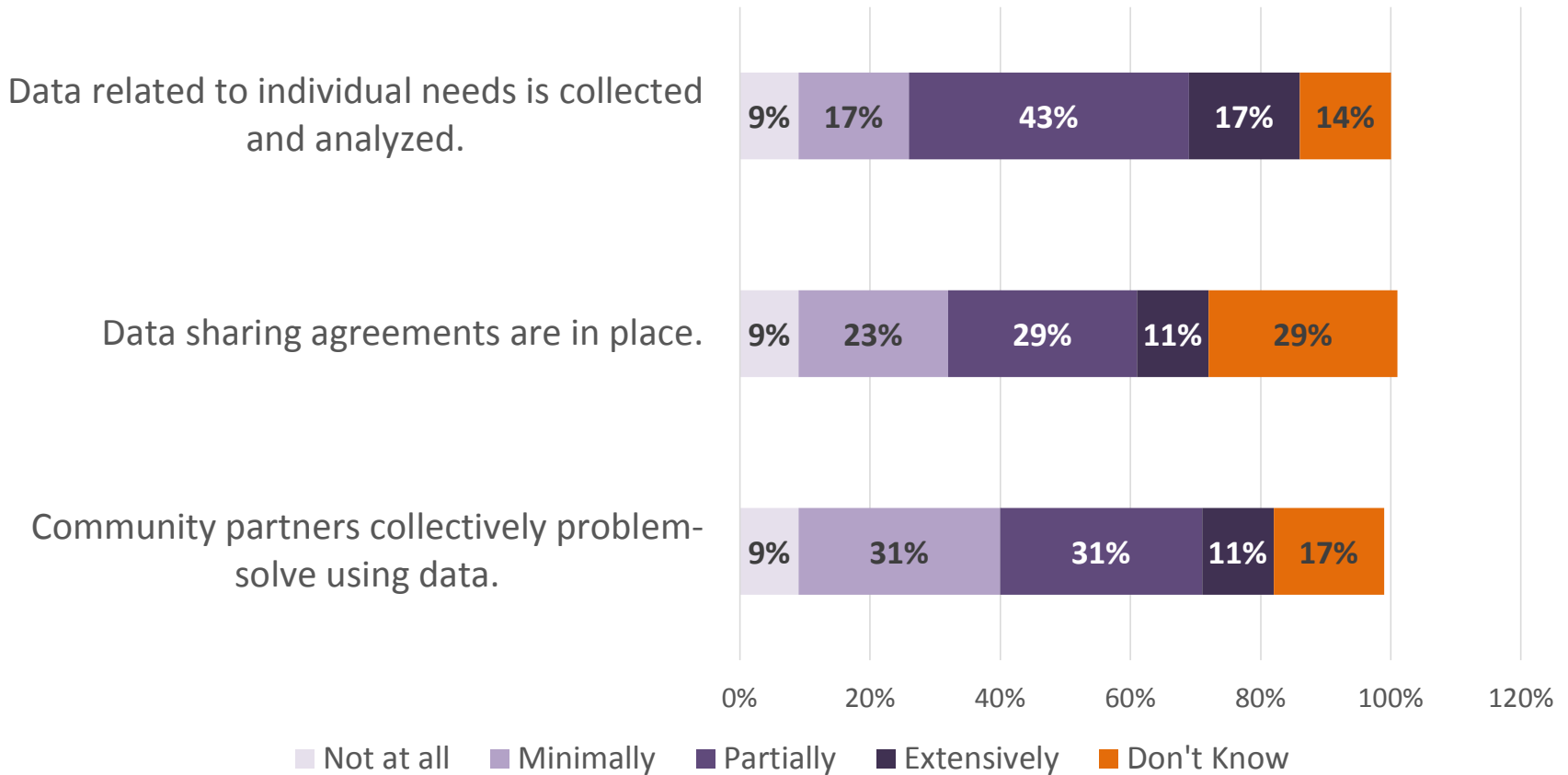
# Infrastructure

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

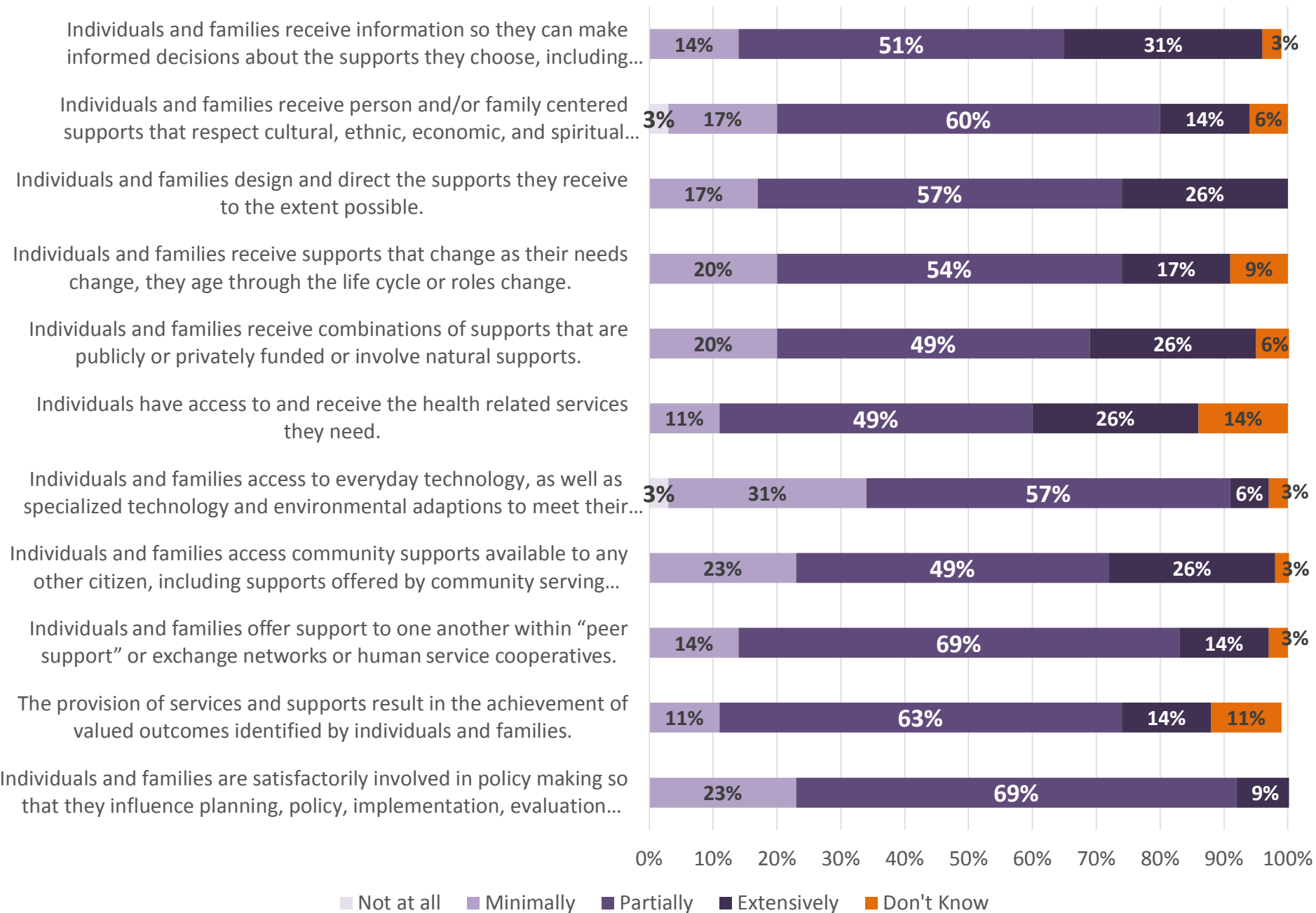


# Quality Assurance and Outcome Data

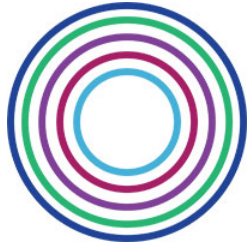
To what extent does your CoP team use individual and community data to inform supports to families.



# Reflections on State Performance Related to LifeCourse Principles







- Experiences with completing the survey
- Anything missing?