Supporting Families Community of Practice Evaluation
Preliminary Reporting Tool Findings – March 26, 2019

States participating in the Supporting Families Community of Practice (CoP) evaluation completed an online reporting tool between February 4, 2019 and February 22, 2019 to provide information on CoP structure and members, use of the Charting the LifeCourse (CtLC) framework, and improvements made to family supports. Information regarding changes made to policies, programs and services, and initiatives, as well as the impact or anticipated impact of these changes was also captured. As of March 1, 2019, all 16 participating states submitted their respective reporting tools. This document summarizes preliminary findings from state responses to closed-ended questions. The evaluation team is in the process of coding the qualitative data by value cycle and will present complete reporting tool findings at the Annual CoP Meeting in Kansas City, Missouri on April 30, 2019.

Summary of Closed-Ended Responses

CoP Structure and Members

For evaluation purposes, the evaluation team stratified the 16 participating states into three groups based on their stage of development:

- Group One contains the six original CoP states: Connecticut, Missouri (mentor state), Oklahoma, Tennessee, Washington State, and the District of Columbia

- Group Two include states with previous exposure to the CoP and CtLC framework before joining the expansion state cohort: Maryland, Ohio, Pennsylvania, and South Dakota

- Group Three consists of states with little or no exposure to the CoP and CtLC framework before joining the expansion state cohort: Alabama, Delaware, Hawaii, Indiana, Kansas, and Oregon

Thirteen (13) states reported that they rely on individuals other than the CoP point(s) of contact for leadership, administration, and/or oversight of the CoP, while the remaining three states (South Dakota, Oregon, and Alabama) do not.

Most states reported that they included State Agency professionals (12), DD Council professionals (12), family members (11), and self-advocates (10) in their CoP leadership team within the last year. This is more frequently observed among Group 1 states. Other roles not provided as response options include education, higher education, and special education professionals.

Figure 1. Role of individuals who participated in CoP leadership
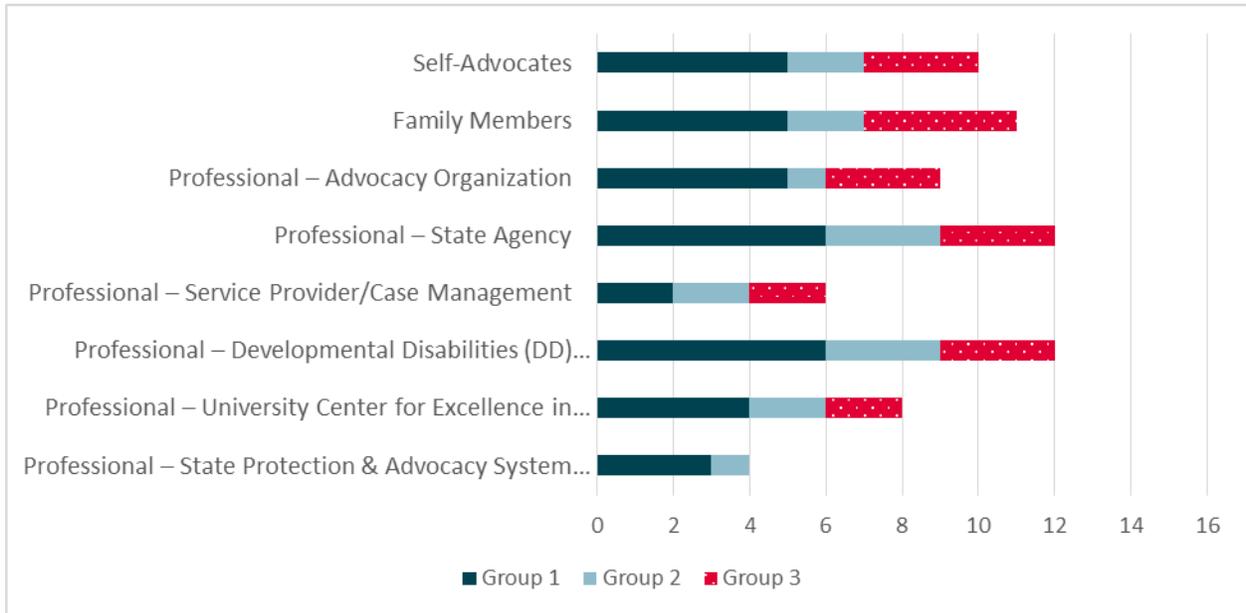
Ten (10) states reported that three or more individuals comprise the CoP leadership team in their state, while six (6) states reported only 1-2 individuals.

The most common activities performed by CoP leadership within the last year include building/maintaining relationships (15), developing/facilitating training (14), facilitating cross-agency/organizational meetings (12), facilitating networking (12), supporting communication (12), and initiating partnerships (12). Alabama reported N/A.

**Figure 2. Activities performed by CoP leadership**
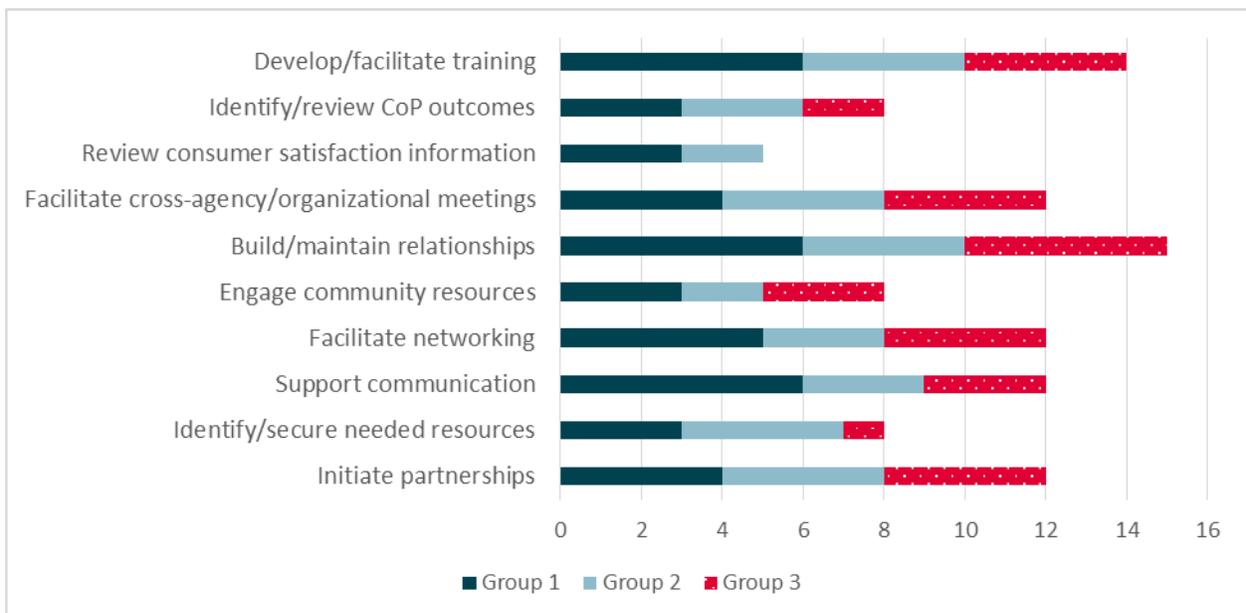
Individuals with I/DD are mostly engaged in CoP leadership as active CoP members (10) and advisors on policy development (8). Their engagement is more frequently observed among Group 1 states. Tennessee and Ohio reported N/A.

Figure 3. I/DD individuals engaged in CoP leadership
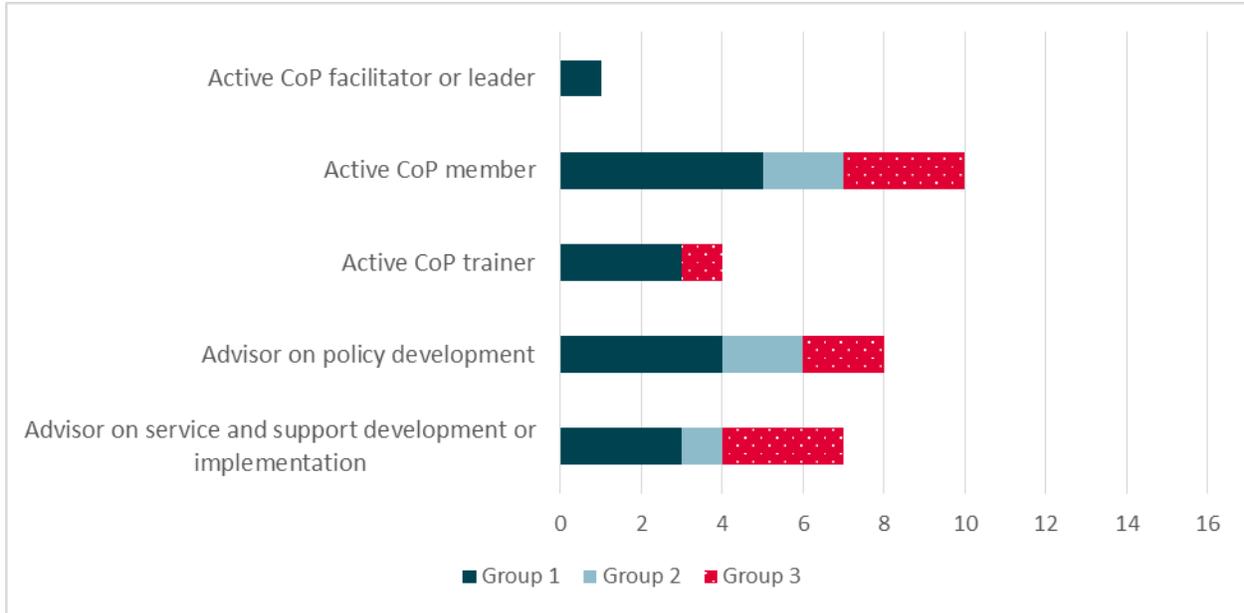
Family members are mostly engaged in CoP leadership as active CoP members (14), advisors on policy development (13), advisors on service and support development or implementation (11), and active CoP trainers (10). Tennessee reported N/A.

Figure 4. Family members engaged in CoP leadership
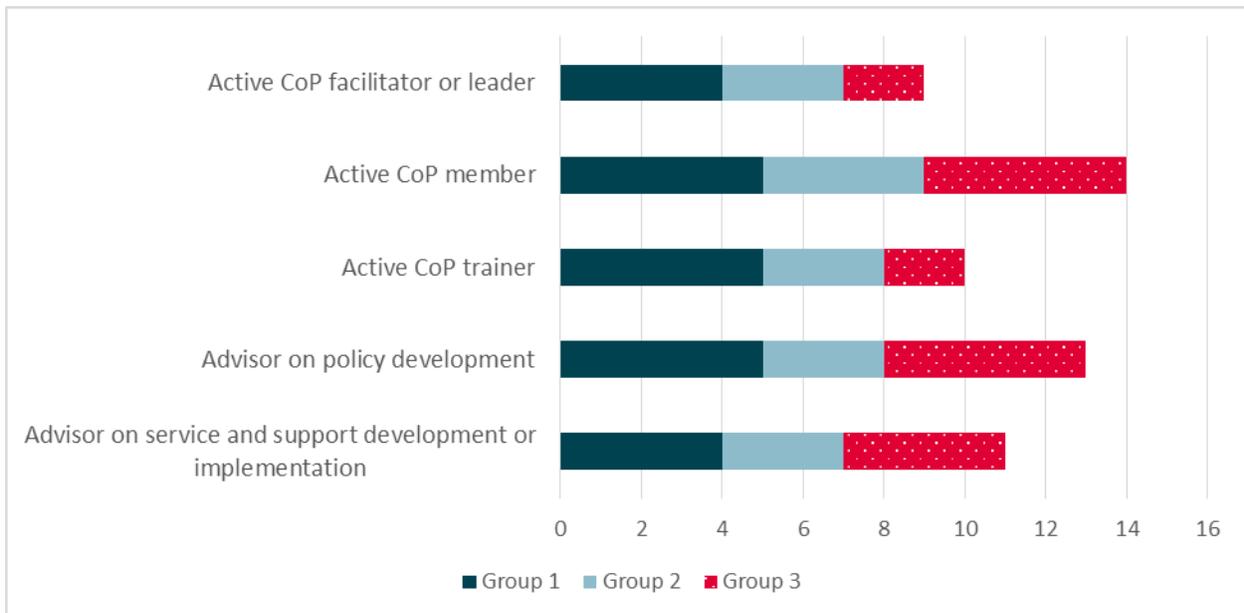
Improvements to Family Supports

The most frequently observed improvements/changes related to family supports within the last year include increased family member knowledge on how to better support their loved one(s) (15), increased family member skills to navigate and access services (14), enhanced family member ability to advocate for services and policy change (13), increased family-to-family support (13), increased self-advocacy (11), and increased use of non-disability community support (10). Tennessee reported N/A.
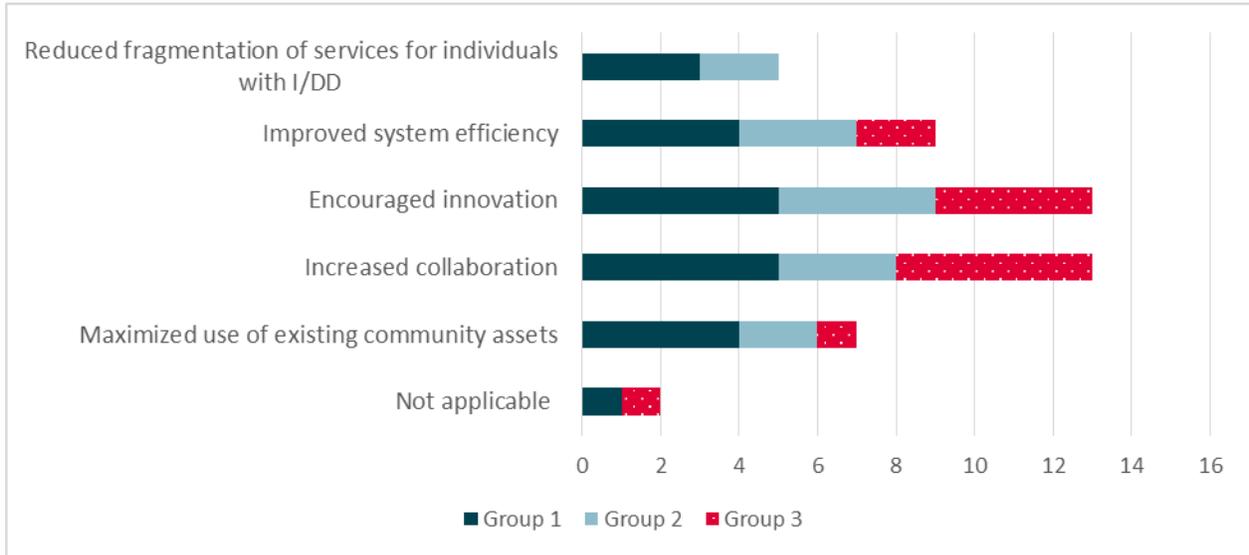
Figure 5. Improvements/changes related to family supports
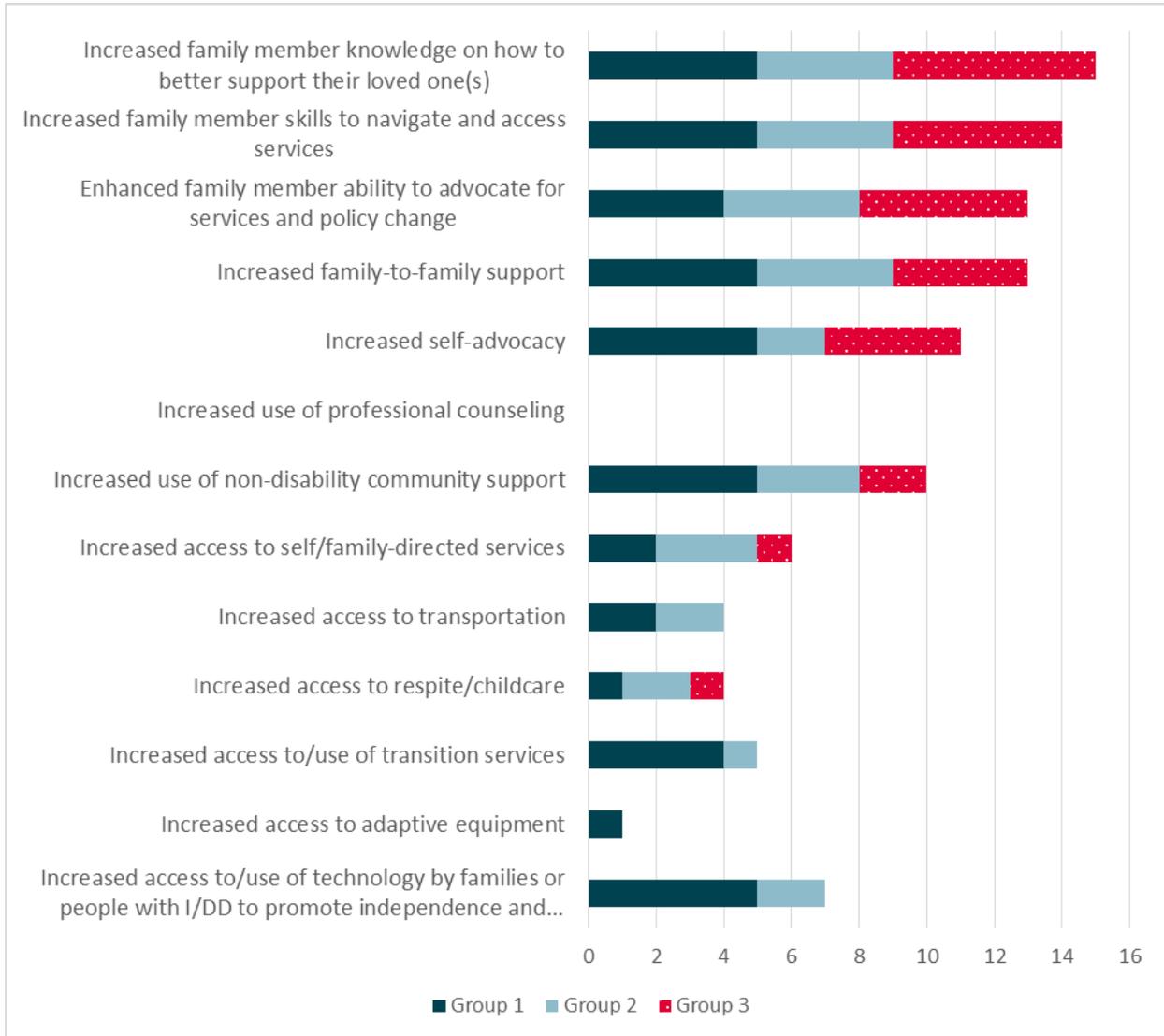
Impact of Partnerships

The most frequently observed improvements/changes influenced by partnerships within the last year include encouraged innovation (13), increased collaboration (13), and improved system efficiency (9). Tennessee reported N/A.

Figure 6. Improvements/changes influenced by partnerships

Impact of Changes to Policies

A smaller number of states reported improvements/changes to state policy influenced by CoP activities within the last year. The most frequently observed improvements/changes include encouraged innovation (9) and increased collaboration (7). Tennessee reported N/A, in addition to half of Group 3 states (Alabama, Indiana, and Kansas).
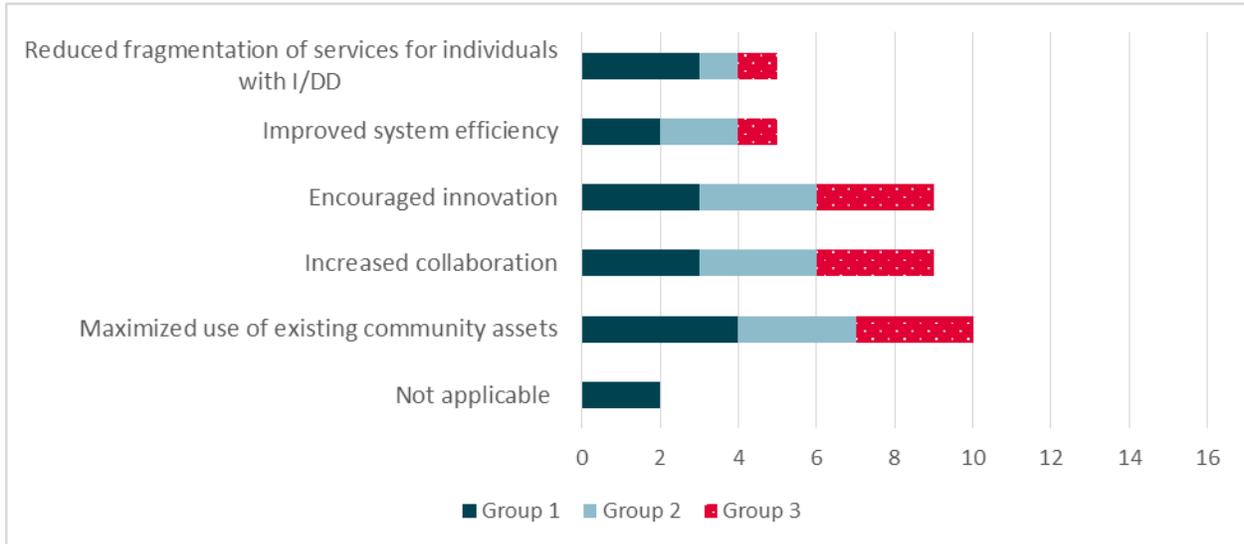
Figure 7. Improvements/changes to state policy
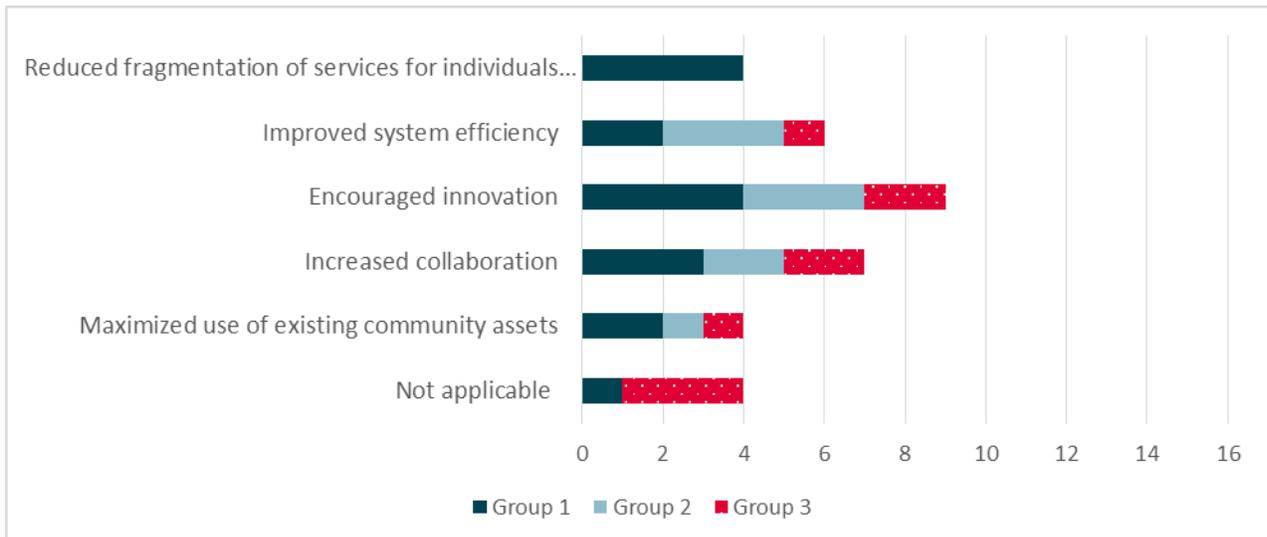
Impact of Changes to Programs and Services

The most frequently observed improvements/changes to programs and services within the last year include maximized use of existing community assets (10), encouraged innovation (9), and increased collaboration (9). Two Group 1 states reported N/A (Tennessee and Oklahoma).

Figure 8. Improvements/changes to programs and services

Impact of Changes to Initiatives

Less than half of states reported improvements/changes to initiatives within the last year. The most frequently observed improvements/changes include maximized use of existing community assets (7), encouraged innovation (7), and increased collaboration (7). Tennessee and Maryland reported N/A.

Figure 9. Improvements/changes to initiatives
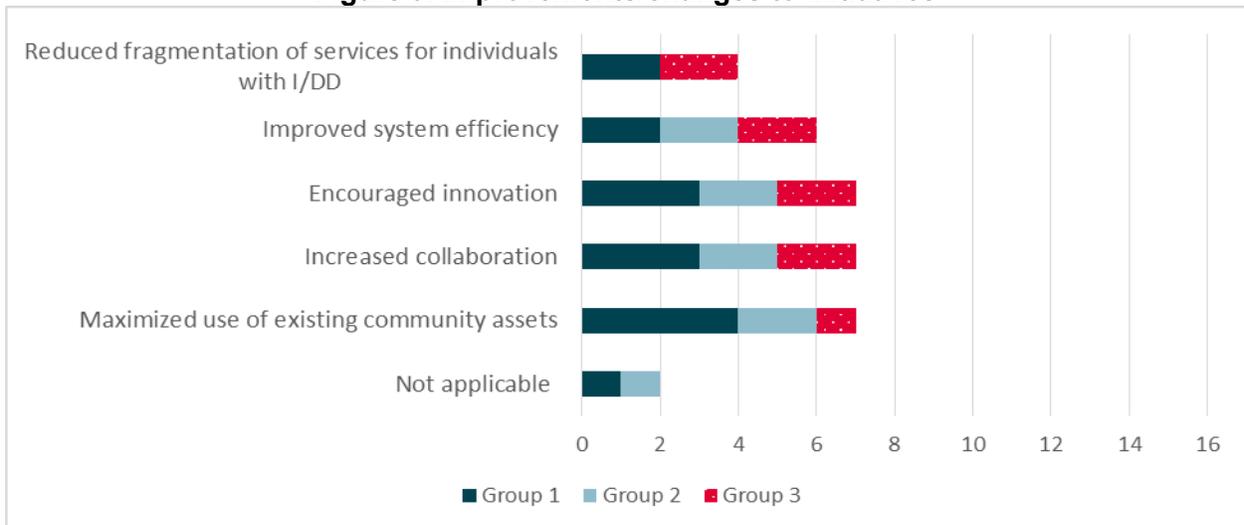
Progress towards AIDD Priority Areas

The most frequently observed AIDD priority areas in which states progressed towards within the last year include better supporting families of individuals with I/DD (12), individuals with I/DD and their families' ability to access home and community-based services and supports that are self-directed and ensure opportunity for full and meaningful community participation (11), and increasing systems' focus on community integration at all levels and stages of service from information and referral, needs assessments, service matching, and service provision (10). Oklahoma and Kansas reported N/A.

**Figure 10. Progress towards AIDD priority areas**
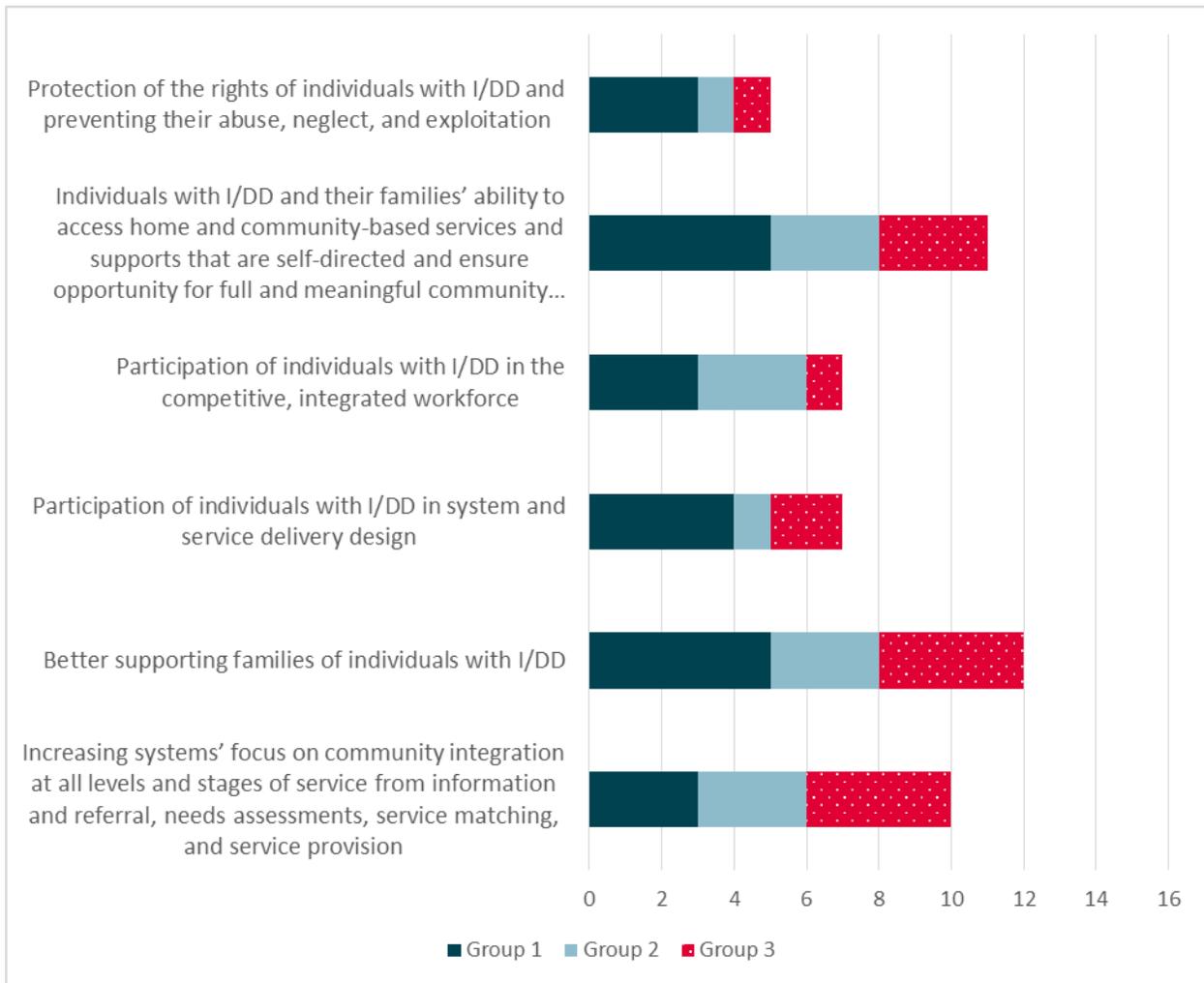
Most states (11) are in progress to meet the goals they identified for each selected AIDD priority area (if any), while only the District of Columbia reported that they achieved their identified goal.

Use and Effect of CtLC Framework

The most frequently observed improvements/changes influenced by the CtLC framework within the last year include professional development of those who use the CtLC framework in their work (12) and improved connections between agencies serving individuals with I/DD and their caregivers/families (8).

Figure 11. Improvements/changes influenced by the CtLC framework
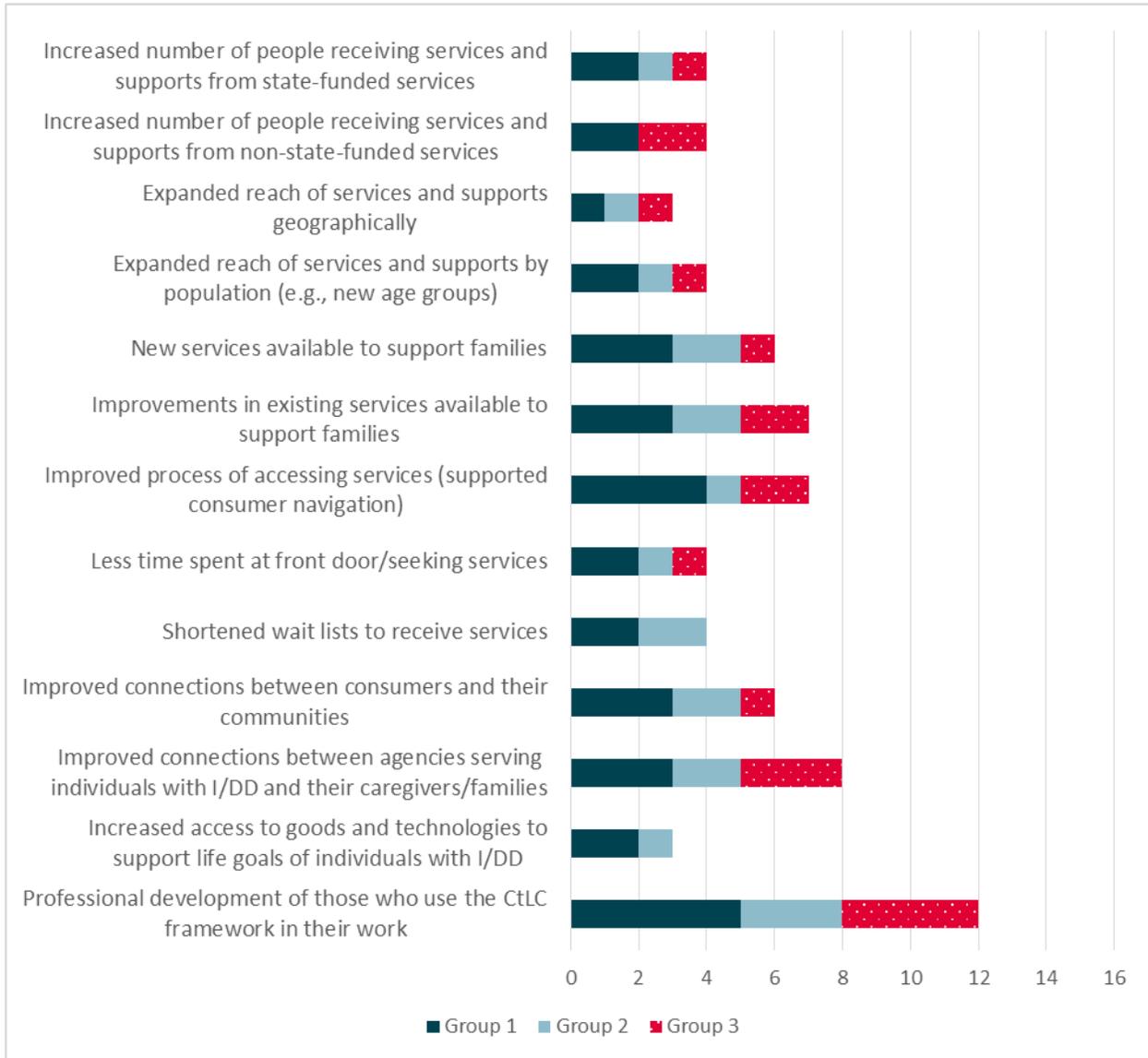
Half of states (8) reported that the CtLC framework had a medium influence on the improvements/changes observed in their state. Four states reported high influences, while three states reported low influences.

Questions Specific to Group 1 States (CT, DC, MO, OK, TN, WA)

Of the six Group 1 states, the most frequently observed actions taken within the last year to support sustainability of the CoP include increased use or application of the CtLC framework or tools (5), strengthened or formed new partnerships (4), and increased involvement of families and self-advocates (4).

Figure 12. Actions taken to support sustainability of CoP among Group 1 states

Questions Specific to Group 2 States (MD, OH, PA, SD)

Of the four Group 2 states, only half of them adopted practices from other participants in the national CoP. Those adopted practices include practices related to CoP structure (e.g., organizational structure, meeting schedule) (1), and practices related to engagement with families and/or self-advocates (2). Only one Group 2 state indicated that other participants in the national CoP adopted practices from their state. Specifically, the Pennsylvania CoP shared their PA Family Network and strategies to support families with the Maryland CoP as they build their Family Leadership Collaborative. No specific practices have been adopted yet.

Additionally, Group 2 states identified the following as objectives their state CoP intended to achieve by joining the national CoP: enhance support to families (4), increase engagement of family members and self-advocates in service delivery and/or policy development (4), increase partnerships and collaboration (4), increase use of CtLC tools and framework (4), improve formal service and support program for people with I/DD (3), and improve informal supports for people with I/DD (2).

Figure 13. Intended objectives of joining the national CoP among Group 2 states
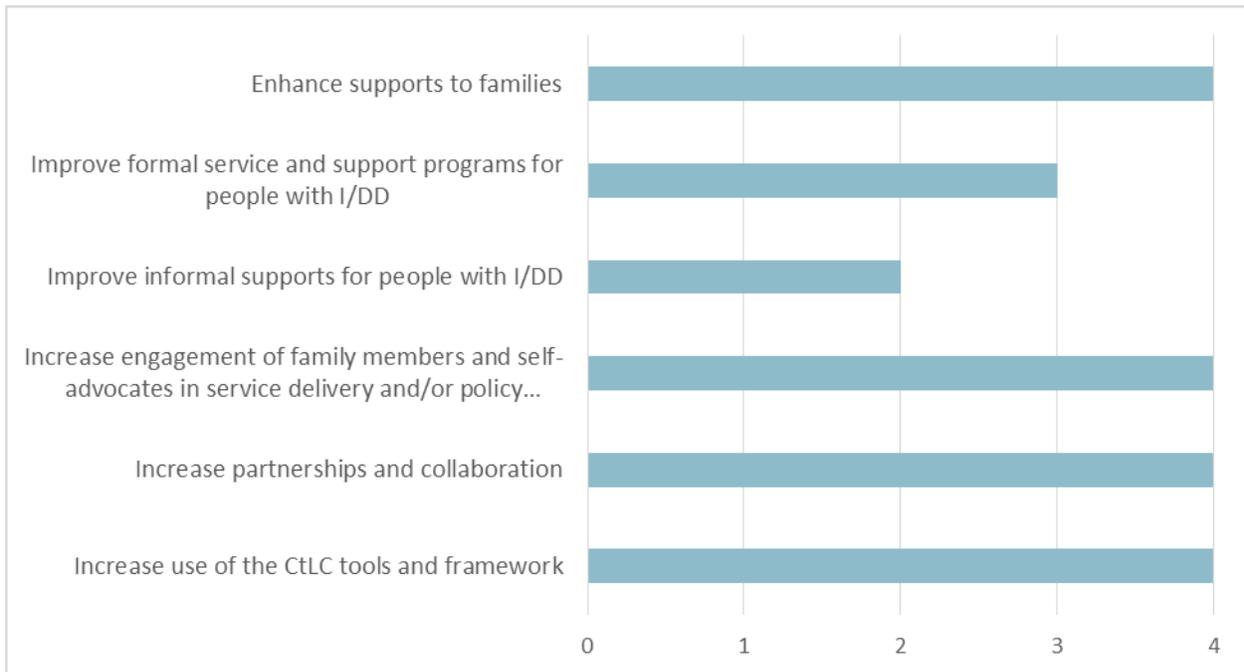
Lastly, three Group 2 states indicated that having previous exposure to the CtLC framework (before joining the expansion state cohort) had a medium influence on their ability to achieve outcomes. Only one Group 2 state (Maryland) indicated a high influence.

Questions Specific to Group 3 States (AL, DE, HI, IN, KS, OR)

Among the six Group 3 states, half of them indicated that the opportunity to engage with other states through the national CoP did not affect their ability (low influence) to achieve or progress toward goals within the last year. Two states indicated a medium influence, while only one state (Indiana) indicated that engaging with other states was essential in achieving or progressing toward state CoP goals within the last year. Additionally, half of Group 3 states reported that their state CoP activities are partially aligned with the CtLC framework as a national framework for supporting families, while one state (Indiana) reported full alignment and another state (Hawaii) reported little or no alignment.

Lastly, the most frequently observed contextual factors that influenced the success of state CoP's include existing experience with person-centered approaches (6), existing partnerships (5), meaningful engagement with families and self-advocates (4), and dedicated CoP leadership (4).

Figure 14. Contextual factors influencing CoP success among Group 3 states