Looking Toward the Future



Strategic Planning Leadership Group

The SPLG engaged the statewide developmental disabilities community in processes to help set strategic direction, and improve Ohio's developmental disabilities service system during the next ten years.

> **Final Report** December 2014



Ohio Department of Developmental Disabilities

John R. Kasich, Governor John L. Martin, Director



Table of Contents

Director's Letter	3-4
Final Report – Planning Process	5-7
Benchmarks	8-11
More Resources, SPLG Membership	11-12

December 2014

A Letter to Stakeholders and Participants in Ohio's Developmental Disabilities Community:

It is my privilege to present the Final Report of the Ohio Department of Developmental Disabilities (DODD) Strategic Planning Leadership Group (SPLG). This report is the culmination of efforts by the Group's members and other stakeholders who advised and informed their efforts, and is a testament to their collective commitment to improve services for Ohio's citizens with developmental disabilities. We greatly appreciate their gift of time, and their dedication to this process.

SPLG members represent diverse roles and perspectives from across the statewide service system, bringing energy to the process of benchmarking and creating recommendations. Their recommendations emphasize involvement of individuals served - and their families - in directing services and defining the quality of services, as well as strengthening collaborative planning within geographic regions to meet peoples' needs. The recommendations also call for the development of methods for sustainable, data-based decision-making and policy development, and address how services may be more easily accessed and effectively planned.

Twenty-four representatives from 14 stakeholder organizations, along with representatives from the Ohio Office of Medicaid and DODD comprised the SPLG. Stakeholder organizations represented in this process include the Ohio Association of County Boards of DD, Ohio Superintendents of County Boards of DD, The Arc of Ohio, People First, The Ohio League, Advocacy and Protective Services, Inc., Ohio Self Determination Association, The Autism Society, Down Syndrome Association, Ohio Developmental Disability Council, Ohio SIBS, Ohio Waiver Network, Values and Faith Alliance, Ohio Provider Resource Association, and Ohio Health Care Association.

The Group met monthly from November 2013 – November 2014 to examine trends and issues, conduct in-depth analyses of data, and learn about best practices pertaining to issues of central importance to the system of services for people with disabilities.

In addition, four Open Forums offered opportunities for the SPLG to invite people with disabilities, families, services providers and County Board staff from across Ohio to hear presentations from recognized national leaders. Open Forum topics focused on the federal Centers for Medicare and Medicaid Services (CMS) rule, Work Opportunities, Community Living, and Listening to People/Family Supports. After listening to the national experts, Forum participants engaged in Café Conversations allowing small groups to process the ideas and information from leading experts, and generate feedback for the SPLG to consider as it developed benchmarks.

Two key events occurred during the planning year that impacted the work of the SPLG. (1) CMS published new rules for Home and Community Based Services (HCBS), and (2) Disability Rights Ohio sent Governor Kasich, DODD Director John Martin, and key members of Governor John Kasich's administration a letter outlining a series of findings, and proposing remedial actions. The SPLG considered these two events as it continued the planning process.

(continued on next page)

After a careful synthesis of nine months of study and conversation, the SPLG used the final three sessions to generate 24 Ten-Year Benchmarks. This report summarizes highlights of the planning process, and shares the Benchmarks organized into three groups addressing key areas of study.

While the Committee's work involved extensive analysis of the issues, and provides recommendations addressing many areas, it would be disingenuous to present the report without acknowledging that some daunting challenges are ahead for the developmental disabilities services system in Ohio, as well as for such services across the nation. We believe, however, that we have gathered some strength and some consensus through the work of the Strategic Leadership Planning Group, which will help us to move forward more effectively.

Using the Group's recommendations as a guide, the Department will continue its focus on communitybased services and supports, and its collaboration with the individuals, families, and other stakeholders throughout Ohio's developmental disabilities community. We greatly appreciate the work accomplished by this important stakeholder group, as it leads us forward to a more sustainable system, and ultimately to better lives for Ohioans with developmental disabilities.

Sincerely,

John L. Martin, Director Ohio Department of Developmental Disabilities



Representative members of the Strategic Leadership Planning Group. See the complete listing of members at the end of this report.

Director's Office, DODD, 30 East Broad Street, 12th Floor, Columbus, OH 43215-3414



Self Advocate Diana Mairose (standing) adds her thoughts during a brainstorming session. Self advocates were active participants in the SPLG process, and provided valuable insights from their perspectives as service recipients.

FINAL REPORT - The Planning Process

A. Trends and Forces

In its initial organizing session the SPLG reviewed trends and forces that are likely to significantly impact the future of people with disabilities and systems that support them. Director John Martin set the stage for consideration of trends and issues by noting:

"Forces and trends inside and outside our system are unsettled and active." Mindful of this environment, these trends and forces were discussed in the opening SPLG Session:

- Health care reform and the connection to support services: Recognition at the federal level that the systems of long-term care and supports (waivers, Intermediate Care Facilities (ICFs) impact health care costs and usage. An assumption is made that reform in one system— health care is impacted by reform in the other long-term care and supports. Historically, each of these systems has ignored the other.
- Federal budget problems and entitlement cost control.
- Movement away from institutional services delivery models.
- An active Department of Justice, armed with the Olmstead decision and the Americans with Disabilities Act (ADA)
- Workforce Issues: A shrinking workforce, regulations, and pay rates for people providing services in the DD and Aging arena are each creating much discussion at the national level, with significant implications to state service delivery systems. New Department of Labor (DOL) regulations could significantly impact our current system.
- **Changing Demographics:** The nature of whom we serve is shifting, as certain types of disabilities (Autism, Co-Occurring Mental Health Issues, etc.) increase at significant rates, while other types of disabilities remains stable. Like our entire population, individuals with disabilities continue to get older, as do their caregivers. These changing demographics cause an impact on waiting lists, type of service provided, and available service dollars.
- Families, providers, unions, legislators, County Boards, DODD, all experience both opportunity and concern as legacy programs are changed.
- Scarce resources could create tension and control issues as Families, Self-Advocates, Providers, County Boards and DODD have different priorities.



B. Key Strategic Issues

After discussion of these trends and forces, the Group committed to in-depth examination of the following issues:

- Aging of people with disabilities and their caregivers
- Waiting List
- Work Opportunities
- Legacy Programs
- Creative Options for Community Living
- Listening to People/ Family Supports
- Outcome-based Planning
- Workforce Development

C. Monthly Meetings

These topics became the focus of monthly SPLG meetings. As each topic was considered, members addressed these questions:

- What does the data tell us about this issue?
- What's changing about this issue?
- How have SPLG members experienced this issue?
- What threats and challenges does the issue raise?
- What opportunities does this issue present?
- What do we hope to see in 10 years about this issue?

D. Open Forums

Open Forums allowed for engagement of national experts on these four topics (link to presentation):

- The CMS Rule
- Work Opportunities
- Community Living
- Listening to People/Family Supports



These presentations offered opportunities for the broad audience of SPLG members and other interested stakeholders to hear provider organizations, government leaders in other states, and recognized family/advocacy experts.

E. Arriving at the 24 Final Benchmarks

After considering each of the issues in depth, the Group reserved the final three sessions for reaching consensus about Ten-Year Benchmarks. *Benchmarks required a 'yes' vote by 75 percent of the group in order to be adopted.* And, while DODD staff participated in discussions, they did not participate in voting. The benchmarks address three key areas: (1) The experiences of people with disabilities and their families; (2) service delivery; and, (3) infrastructure development. Separating these recommendations by functionality offers more clarity in understanding why the benchmarks matter in the statewide system, and to whom they might matter most. It also allows for more detailed principles or action steps to be defined.



Self Advocate Tami Grogg (left) and People First of Ohio Executive Director Sadie Hunter take a break during presentations on residential options.

The 24 Benchmarks

Ten benchmarks address the experiences of people with disabilities and families:

1. People with disabilities experience person-centered services and supports and achieve outcomes that matter.

Principles/action steps associated with this benchmark:

- i. Offer training in person-centered thinking and practices to people served, families, and organizations.
- ii. Develop a Community of Practice focused on day supports that are based on research and best practice.
- iii. Offer training that focuses on the application of person-centered practices and developing outcomes that matter for people who are aging into their senior years (including the retirement process).
- iv. Offer people information to chart a positive life course.
- 2. People and families have a resource that provides information about services and offers a way to view and share information with and from others.

Principles/action steps associated with this benchmark:

- i. Include more than ICF and waiver services in this resource.
- ii. Provide ways for families to access local information.
- iii. Include 'Angie's List'- like features.
- 3. People who receive services and their families are working together to meet their wants and needs through creative, family-led efforts.
- 4. We have agreed upon, easy-to-understand words to describe important concepts related to services and supports.

- 5. People who receive services and their family members are asked what would be helpful, and resources are aligned to minimize emergencies and maintain people in their current home, when that is the person's choice.
- 6. The Early Intervention (EI) System is family-focused and uses evidence-based practices.
- 7. Transition-age students have multiple opportunities and experiences to explore work and education.
- 8. Young people and adults have opportunities to speak up, express preferences, and be a part of informed decision-making.
- 9. 90 percent of individuals newly-enrolled in waiver services are planned enrollments, not emergencies.
- **10.** People who receive services and their aging caregivers, along with other family members, are supported by highly-trained facilitators to engage in planning for future needs.

Six benchmarks address service delivery:

- 1. 25 percent of all DD waiver recipients live in host homes, using technology and creative strategies for recruiting, matching, and providing supports for success.
- 2. The number of quality, affordable, and accessible housing units in safe neighborhoods is increased by 25 percent.
 - Principle associated with this benchmark:
 - i. DODD will work with Ohio Housing Finance Authority (OHFA) and stakeholders to encourage collaboration to identify, track, and grow the stock of affordable and accessible housing.
- **3.** People with disabilities have subsidies and resources necessary to live in the community. Principle associated with this benchmark:
 - i. DODD will make these subsidies available.
- 4. Collaborative efforts provide improved educational outcomes in integrated settings.
- 5. The number of people employed is 50 percent of adults served.

Principle associated with this benchmark:

i. Hours worked per week range from one to 40, with an aggregate average of 20 hours per week. Individuals choose activities for the remainder of the day with as much community involvement as possible.

6. County Boards identify individuals with Intellectual and Developmental Disabilities (IDD) who are living in nursing facilities, engage in the Pre-Admission Review and Resident Screening

(PASSR) process, assess and coordinate services, and work with DODD to suspend the waiver (if applicable) until the person can return to their home.

Eight Benchmarks Address Infrastructure:

1. Nursing Services are available in all waivers.

Principle associated with this benchmark:

- Nursing services will be funded by the state. Addition of nursing services will not impact ODDP range or caps on services. Delegation continues to be used. Smooth intersection between personal care and nursing.
- 2. All Direct Support Professionals (DSPs) have the opportunity to engage in training and development to improve competencies and support career development.

Principle associated with this benchmark:

- i. DSP's and people served participate in design of curriculum.
- 3. All DSPs earn a livable wage (200 percent of the poverty level) for all services provided to people with disabilities.

Principle associated with this benchmark:

- i. Will require rate increase for waiver services. Wages should be equitable across service types (waiver/ICF). Will require increase to funding ranges and caps. Assurance that rate increase goes to DSP.
- 4. No one is living in Developmental Centers; community supports are adequate and funded.

5. The total number of ICF beds is reduced by 50 percent, to 2800 beds.

- a. Principles associated with this benchmark:
 - i. Waivers are adequately funded.
 - ii. Providers and County Board staff are offered training that builds capacity to serve these individuals.
 - iii. Adequate affordable and accessible housing is available to support these people to live in community settings.
- 6. 1500 people will leave ICF facilities of 16 beds or larger and move to community homes. The average setting size of these community homes is four beds or fewer.
 - a. Principle associated with this benchmark:
 - i. People with disabilities and their families have opportunities to engage in education that leads to improved capacity to offer informed consent.
- 7. The Waiting List is addressed by offering 500 new Level One, 600 new SELF and 100 new IO new waivers each year:
 - a. Principles associated with this benchmark:
 - i. Continue current rate of new waiver development for people not on the waiting list.

ii. Offer education about the Self Empowered Life Funding (SELF) waiver to families, people with disabilities, providers and County Board staff.

8. A comprehensive DD waiver is available.

These 24 benchmarks provide a vision and a direction for our service delivery system. Moving in the direction of these benchmarks represents some significant changes. Our job as leaders is to manage these changes in responsible, planful, ways that honor the choices and listen to the voices of those affected by these changes. I appreciate the incredible time commitment, and the open, honest dialogue this group engaged in on this year-long journey, facilitated by the skilled leadership of Jo Krippenstapel. While the team's formal responsibilities end with the issuance of this report, I look forward to benefiting from their continued insight as we work at implementation, and answering the many questions this report raises. This is a significant point in the lives of people with disabilities in Ohio.

-DODD Director, John Martin

More Resources

Additional information about the Strategic Leadership Planning Group and its meetings was reported in many issues of the DODD *Pipeline* publication. All articles may be found online at <u>DODD Pipeline</u>. In addition, updates on this and related subjects may be found online at <u>DODD.Ohio.Gov/OurFuture</u>.

Please see the next page for the SPLG membership Roster

SPLG Membership Roster

We are extremely grateful for the participation of the 24 members involved in the SPLG efforts and thank them for their work in this important process.

OACBDD/OSCBDD	Steve Oster, Alice Pavey, Willie Jones, Dee Zeffiro-Krenisky
Arc of Ohio	Gary Tonks, Judy Murray
People First	Sadie Hunter, Tami Grogg
The Ohio League	Neil Castilow
Ohio Self Determination Association	Sharon Travis, Diana Mairose
Autism Association	Pat Cloppert
Down Syndrome Association	Marge Barnheiser
APSI	Karla Rinto
Ohio Developmental Disabilities Council	Carolyn Knight
Ohio SIBS	Barb Sapharas
Ohio Waiver Network	Kathy Phillips
Ohio Provider Resource Association	Mark Davis, Jorji Milliken
Ohio Health Care Association	Pete Van Runkle, Marilyn Weber
Values and Faith Alliance	Vicki Obee-Hilty, Deb Lyle
Ohio Department of Medicaid	Icilda Dickerson

NOTE: The following DODD staff offered information and participated in discussions as requested by the SPLG, but did not participate in the benchmarking process: Patrick Stephan, Lori Horvath, Kate Haller, Monty Kerr, Zach Haughawout, Ann Rengert, Ginnie Whisman, and Toni Wallace. Facilitator for the SPLG was Jo Krippenstapel.

End Report