



the spark initiative

A creative catalyst for change

A Focus on Helping Individuals Live a Self-Directed Life

Optum-developed SPARK Initiative brings together leaders in government, non-profit, and private sectors to discuss solutions to better support people with intellectual and developmental disabilities.

For the more than four and a half million Americans* living with intellectual and/or developmental disabilities (I/DD), the ability to make their own choices and live independently is high on their list of desires – yet among the most challenging in our current health and human services environment.

Fragmented delivery systems, pre-conceived stereotypes, funding issues, social stigmas, insufficient community supports and training, and lack of coordination in areas that affect lifestyle and well-being – such as education, housing, and employment – all of these are obstacles that individuals with I/DD face as they attempt to live more self-directed and fulfilling lives.

So how can government agencies, advocates, providers, the health system, and other stakeholders work in a collaborative fashion to help these individuals live the lives they choose?

Some 25 of these stakeholders – all experts in the I/DD area – recently gathered in Eden Prairie, Minnesota, to begin the discussion about the challenges facing Americans with disabilities, the problems with the system that serves them, and a potential direction for solutions. The group convened as part of the Optum “SPARK Initiative” – developed by the health services company to “spark” new thinking on major national health and human services issues.

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changes in the service delivery system. The session was developed in partnership with an advisory committee that included subject matter experts Donna Meltzer, CEO of the National Association of Councils on Developmental Disabilities (NACDD), a national non-profit organization that supports the nation's 56 governor-appointed Developmental Disabilities Councils; and Christina Dupuch, Chief Operating Officer for Vaya Health of North Carolina and former Implementation Director of the Executive Leadership Team for North Carolina's Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MH/DD/SAS).

The two-day forum that launched this SPARK Initiative is just the beginning, noted Dan Ohler, Vice President of State and Local Programs at Optum. "This was all about pulling out all of the big issues and getting them on the table," he said, "and among the biggest is how people with disabilities can have access to the tools and programs to make more informed decisions." Added Christina Dupuch: "Stigma still exists for people of the I/DD community. SPARK is an opportunity to continue to address this reality and make sure all people are recognized as true citizens and fully capable of realizing their goals like any other American can. 'Stand up, show up and speak up' -- that's what Spark is about. Our passion is the power to help individuals with disabilities become a greater part of our communities."

The forum was timely, since Americans with developmental disabilities are caught in something of a crossroads – a desire to live independently conflicting with a service system that that is fragmented and not necessarily person-centered or self-directed.

On the one hand, evolving federal and state programs, such as Medicaid's Home and Community Based Services (HCBS) waiver programs, envision that Americans with disabilities have the right to live independently in their own communities, making their own decisions with support from an integrated web of services. On the other hand, reality continues to lag behind this ambitious vision and states continue to struggle to move forward from a legacy system that has been based on congregate settings. CMS's Home and Community Based Settings Rule has opened up dialogue in each state as to how we define community and has launched - at times contentious- debate around what constitutes community living.

Moreover, social stigmas and paternalistic thinking have limited the scope of decision-making for people with I/DD. Segregated programs built around special schools and workshops have limited their choices for education, employment, and economic advancement. Though these approaches are now largely discredited, there are limited options to replace them and a lack of funding to develop alternatives, and where there are promising demonstrations there are challenges to scale the approach broadly.

It was these issues that drove the SPARK discussion.

Four Work Groups

Early in the forum, participants were challenged to recall and share a bad decision from their own lives, and then asked whether they had "grown" as a result of the experience. Nearly all agreed that bad decisions can be an engine for personal growth. Yet, the forum discussion noted that people with disabilities are often denied the freedom to make decisions deemed "bad" by others, such as their guardians, or by providers or attorneys expected to serve the individual's best interests. In short, the system, not the individual, is making decisions.

"It is a leap of faith for some to believe that individuals with I/DD can and should be the primary decision-making authority for their own life," said Donna Meltzer, "but it's time that we take that leap and flip the dialogue so that individuals are controlling and directing their lives and not systems.

2017 Spark participating organizations:

Human Services Research Institute (HSRI)
 University of MN – RTC/CL
 Vaya Health
 Community Resource Associates
 National Association of Councils on Development Disabilities (NACDD)
 American Network of Community Options and Resources (ANCOR)
 Human Services Research Institute
 The Arc of Arizona
 U.S. Department of Health & Human Services/Administration for Community Living
 Michigan Department of Health and Human Services, The Behavioral Health and Developmental Disabilities Administration (BHDDA)
 Hope House Foundation
 American Association on Intellectual & Developmental Disabilities
 The Council on Quality and Leadership
 OPEN MINDS
 University of Delaware – The National Leadership Consortium on Development Disabilities (NLCDD)
 The Arc of the United States
 Rehabilitation and Community Providers Association of Pennsylvania
 National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD)
 National Association for Rural Mental Health (NARMH)
 People First of Nevada
 Alliance Behavioral Healthcare
 National Council of Behavioral Health/Community Services Group
 The Institute for Community Inclusion at University of Massachusetts Boston
 Quality Trust for Individuals with Disabilities

Ultimately, the day and a half session led to the formation of four work groups:

- A group tasked with defining a “Shared Framework,” that explores what self-determination should look like for people with disabilities. The group will consider such questions as: What does informed decision-making look like? How can individuals get information about options so they can make the best decisions?
- Another group will tackle the challenge of how to educate stakeholders in a newly designed service system; in short, how to best teach service providers, guardians, employers, educator, and others who interact with disabled Americans how to interact with them in ways that enable greater self-determination and independence.
- A third group will survey providers and other support personnel to identify barriers that stand in the way of so-called “person-directed services,” and then consider how these obstacles can be eliminated through changes to providers services.
- The fourth group will address outcomes and performance by making recommendations that help policy-makers develop more flexible funding mechanisms, and suggesting new tools for disabled individuals to make it easier for them to direct funds according to their needs.

“It’s going to be a huge task,” Dan Ohler explained. “Ultimately, the work groups will be looking at everything throughout the life stages of individuals with disabilities, and at the various people, roles, services, and supports they will be interacting with.”

“SPARK’s investment in the products developed by the 4 workgroups is incredible,” said Meltzer. “Having the support and backing of capable staff to bring the stakeholders thoughts and ideas to life will help move our ideas from sketched-out thoughts to serious framework papers and recommendations. This is how you quickly move the needle on problem solving.”

To learn more about the SPARK initiative for I/DD services, please contact **Dan Ohler** at **ohler@optum.com**.

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