

Feature Issue

Person-Centered Positive Supports and People with Intellectual and Developmental Disabilities

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# Impact

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## From the Editors

*"She treats me like a human being."*

*Caroline Chavez says these seven words changed her life. Reflecting on her years as a direct care provider she tells this story in this issue of Impact:*

*"One of the guys never addressed staff by name, ever... One day, out of the blue, he addressed me by name. My stunned co-workers asked him why. "She treats me like a human being."*

*Person-centered positive supports are about empowering people with disabilities to live lives that fully reflect their individuality and their humanity. They're about using evidence-based positive practices in the service of the needs, values, and goals of the person receiving the support. And they're about promoting quality of life for people in ways that are meaningful to them.*

*This Impact issue examines the use of person-centered positive supports with people who have intellectual and developmental disabilities. It educates about the issues, guiding principles, and choices that must be examined in policy and practice. It profiles exemplary strategies for delivery of services. And it shares personal stories of the difference that person-centered positive supports make for individuals.*

*It's our hope that this Impact will help ensure that all people with disabilities have access to quality services and supports that empower them to live the lives of their choosing.*

## About the Cover:

Phyllis Kolden (*right*) shares a hug and conversation with her support facilitator, Rebecca White. Phyllis talks about her journey from a childhood in an institution to marriage, parenthood, and an active life as a senior citizen in the article, "A Smiling Phyllis Kolden" on [page 22](#).



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*Evan Nodvin spoke about the importance of employment in his life at the 2016 Disability Policy Seminar in Washington, D.C.*

*Photo courtesy of the Association of University Centers on Disabilities.*

## The **Revolution** (Re)Starts Now: Federal Policies Driving Toward Person-Centered, Individualized and Inclusive Practices

*by Alison Barkoff*

When my brother Evan was born with Down syndrome almost 40 years ago, my family was told that the best option available for him, and “for the sake of the entire family,” was to place him in an institution. At that time, institutionalization was the only publicly-funded option, and most Americans like Evan were segregated from the rest of society. Fortunately, new laws, policies and advocacy were developing. These included the first anti-discrimination law protecting people with disabilities, the statutory right to a public education for all students with disabilities, legal challenges to abuse and neglect in institutions, and the first federal funding for community services. A revolution had begun, in which people with disabilities and their families began demanding the right to be included in their communities.

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A REVOLUTION HAD BEGUN,  
IN WHICH PEOPLE WITH  
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|||||

A “rival image” to institutional life began to emerge, and expectations rose significantly over the ensuing decades. People

with disabilities, supported by their families, pursued the right to live in their own homes, have real jobs, and be “of the community” and not just visitors in it. Yet most states’ disability service systems have not evolved to meet these changing expectations and desires. These systems largely continue to segregate people with disabilities in congregate programs focused on group activities and schedules rather than on individuals’ own goals and interests. But change is once again in the air. New federal policies are creating a modern vision for the full and authentic inclusion of people with disabilities in society. A new revolution has begun.

### **Enforcement of the Americans with Disabilities Act and the *Olmstead* Decision**

The “integration mandate” of the Americans with Disabilities Act, affirmed by the Supreme Court’s 1999 decision in *Olmstead v. L.C.*, prohibits needless segregation of people with disabilities and gives them a civil right to live, work, and be full members of their communities. In the last several years – in large part due to the Obama Administration’s prioritization of *Olmstead* enforcement – advocacy based on the integration mandate has expanded from challenges to unjustified placement

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of people in state-operated institutions to the creation of robust, community-based alternatives for adults and children in or at risk of entering a wide range of segregated settings, including private institutions, nursing homes, board and care homes, congregate day settings like sheltered

have set legal precedents and created models of the community services necessary to help people with disabilities fully participate in community life, including Medicaid waivers (often restructured to focus on more individualized services), residential supports and rental subsidies

family supports. *Olmstead* and the integration mandate have become a powerful weapon in the fight for real integration and inclusion of people with disabilities.

## **New Federal Rules Defining "Community" for Home and Community Based Services**

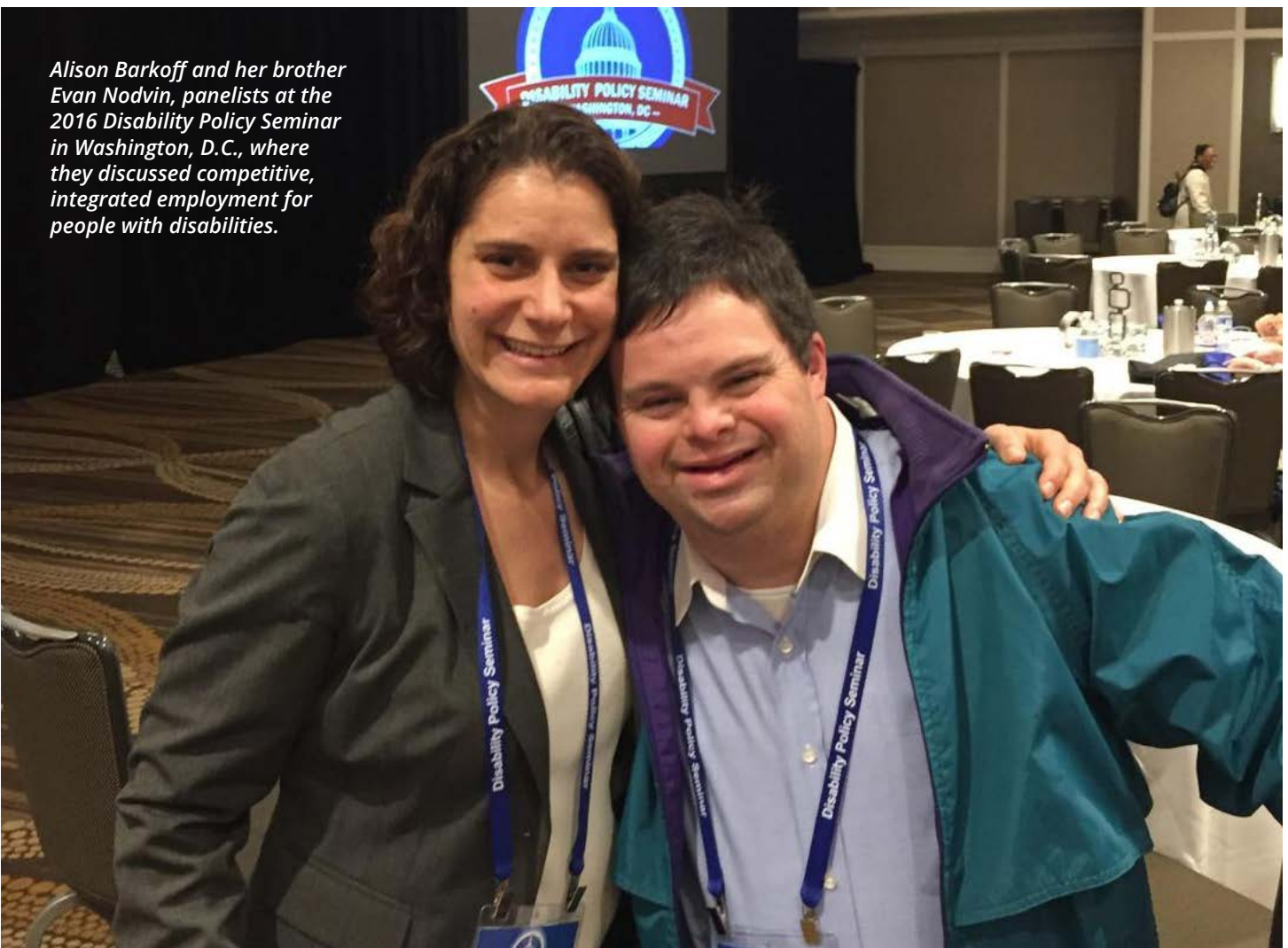
DOZENS OF *OLMSTEAD* CASES IN THE LAST SEVERAL YEARS HAVE SET LEGAL PRECEDENTS AND CREATED MODELS OF THE COMMUNITY SERVICES NECESSARY TO HELP PEOPLE WITH DISABILITIES FULLY PARTICIPATE IN COMMUNITY LIFE, INCLUDING MEDICAID WAIVERS (OFTEN RESTRUCTURED TO FOCUS ON MORE INDIVIDUALIZED SERVICES), RESIDENTIAL SUPPORTS AND RENTAL SUBSIDIES TO HELP PEOPLE LIVE IN THEIR OWN HOMES OR APARTMENTS, A RANGE OF COMMUNITY-BASED CRISIS SERVICES, SUPPORTED EMPLOYMENT, AND FAMILY SUPPORTS.

Building off momentum created by *Olmstead* enforcement and new opportunities for federal funding created by the Affordable Care Act, the federal government recently issued rules defining the characteristics of "community" settings that can be funded as Medicaid Home and Community Based Services (HCBS) (Medicaid Program, State Plan Home and Community Based Services, 2014). The goal of these rules is to ensure that all individuals receiving HCBS have full access to the benefits of community living. They require that HCBS settings be integrated in and facilitate access to the broader community, and give people in

workshops and day habilitation, and segregated schools and classrooms. Dozens of *Olmstead* cases in the last several years

to help people live in their own homes or apartments, a range of community-based crisis services, supported employment, and

*Alison Barkoff and her brother Evan Nodvin, panelists at the 2016 Disability Policy Seminar in Washington, D.C., where they discussed competitive, integrated employment for people with disabilities.*



*Photo courtesy of the Association of University Centers on Disabilities.*

those settings control over life choices and daily activities, privacy, a choice of settings and service providers, and opportunities for competitive integrated employment. States – with the input of stakeholders – are starting to plan and implement changes necessary to comply by March 2019.

The HCBS settings rules carry great promise for moving state systems toward more integrated, individualized, and person-centered services. They are forcing us to seriously evaluate whether common service models and settings really provide people with disabilities access to the community, choice and control over their daily lives, and opportunities to interact with people without disabilities. And they are giving us the opportunity to consider what we want our modern disability service systems to look like.

spending their days in segregated day programs like sheltered workshops (where they are paid subminimum wage) or facility-based day habilitation. But “real jobs for real pay” is a rallying cry in this new revolution and is a goal supported by recently-enacted federal policies. The Workforce Innovation and Opportunities Act (WIOA) of 2014 (P.L. 113-128) establishes as a national priority competitive integrated employment for people with disabilities (Government Printing Office, July 22, 2014). It also significantly limits placement of people with disabilities – particularly youth transitioning from school – into segregated and sub-minimum wage day programs. WIOA aligns with recent *Olmstead* enforcement activities that target segregated programs like sheltered workshops and day habilitation,

people without disabilities; and more individual control and choice over services.

All of these changes will take work. People with disabilities, their families, and advocates must continue to demand change and fight for resources to make them happen. Providers must be part of the solution. They need technical assistance and resources to help them change from outdated segregated models to individualized best practices. Finally, we need to be vigilant in ensuring that our community system can meet the needs of all people with disabilities, including those with the most significant needs.

Because of my brother’s strong self-advocacy and the support of our family, he is receiving services that help him live the life he wants. Evan lives in an apartment with a roommate he chose, works in a real job in the community, serves as an appointed member of his state’s Council on Developmental Disabilities, and has close relationships with his girlfriend, family, and friends. But Evan’s experience is still the exception, not the rule. It is up to all of us to join in this revolution and ensure that all people with disabilities are full participants and valued members of our society.

*The revolution starts now  
When you rise above your fear  
And tear the walls around you down  
The revolution starts here  
Where you work and where you play  
Where you lay your money down  
What you do and what you say  
The revolution starts now*

(EARLE, 2004)

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NEW FEDERAL POLICIES ARE STRIVING TO ALIGN STATES’ DISABILITY SERVICE SYSTEMS WITH THE GOAL OF GIVING PEOPLE WITH DISABILITIES THE CHANCE TO LIVE IN A HOME OF THEIR CHOICE, HAVE A MEANINGFUL JOB, AND BE AN AUTHENTIC MEMBER OF THE COMMUNITY. BUT DOING SO REQUIRES PERSON-CENTERED PLANNING BASED ON INDIVIDUAL INTERESTS, STRENGTHS AND GOALS...

But this current revolution, like the last one, is not without controversy. A small, but vocal group of providers and families of people with disabilities are pushing back against these changes, arguing that there is a “right” to segregated program models that congregate people with disabilities together and separate them from the community. Nevertheless, the vast majority of those in the disability community agree that the rules are the culmination of decades of progress and are finally bringing long-overdue changes that will help people with disabilities live, work, and participate fully in their communities.

## Federal Policies Regarding Employment of People with Disabilities

Employment is a new frontier in today’s fight for change. Less than 20% of people with disabilities nationally are receiving services to help them work in real jobs (Statedata.info, 2016). Instead they are

and requires the expansion of supported employment services to help people with disabilities get and maintain real jobs, with mainstream community activities available for those not working full-time. The combination of WIOA, *Olmstead* enforcement, and the HCBS settings rules is causing many states to move away from outdated segregated day models and significantly expand opportunities for real jobs.

## Conclusion

New federal policies are striving to align states’ disability service systems with the goal of giving people with disabilities the chance to live in a home of their choice, have a meaningful job, and be an authentic member of the community. But doing so requires person-centered planning based on individual interests, strengths and goals; individualized supports instead of limited choices in congregate settings; opportunities to live among, and to work alongside,





# State Policies and Practices in Behavior Supports for Persons with Intellectual and Developmental Disabilities in the U.S.: Abbreviated Findings From a National Survey

by Kinsey B. Carlson-Britting,  
David A. Rotholz, and  
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In late 2010, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in partnership with the Center for Disability Resources (CDR) at the University of South Carolina, conducted a national survey of state developmental disabilities agency policies and practices regarding behavior supports. The survey, the first of its kind, was initiated in response to the need to document the nature, type, and scope of behavior support services that are provided to adults with intellectual and developmental disabilities (IDD) through publicly funded service systems in the United States. Specifically, the study assessed: (a) the settings in which behavioral supports are offered; (b) qualifications practitioners must meet to be eligible to provide the service; (c) reimbursement strategies and funding mechanisms; (d) behavior support provider training requirements; and (e) state policies and practices governing the oversight and provision of behavioral supports, quality assurance, availability of behavioral support providers, and the challenges experienced by state agencies in this area. The need for this information is pressing as states fund, permit, and regulate a variety of interventions to meet the needs of people with challenging behaviors, all while there is no national standard for behavioral support practices or source of information on the status of behavior support policies, practices, and services for adults with IDD at either the state or national level. In the absence of solid national data on the qualifications of

professionals providing behavior supports and the nature of the services provided, states have historically been left to develop their own service definitions and professional qualifications or draw them from other sources.

While full details of this study and the corresponding results can be found in the original complete manuscript titled “State Policies and Practices in Behavior Supports for Persons With Intellectual and Developmental Disabilities in the United States: A National Survey” in the journal *Intellectual and Developmental Disabilities* published by the American Association on Intellectual and Developmental Disabilities (AAIDD), this abbreviated adaptation will highlight some of the key takeaways that emerged and that are likely to be of interest. These include:

- › the absence of standard and consistent service definitions;
- › the lack of widespread licensure for qualified behavioral support providers;
- › differing policy/procedural and skill requirements across treatment setting; and
- › the overwhelming need for qualified providers.

The results gathered through this seminal survey, which included responses from 44 states plus the District of Columbia (see Table 1), provide a starting point for appropriately informed and coordinated quality improvement efforts.

**Table 1. States, plus the District of Columbia, That Participated in the Survey**

Alabama	Hawaii	Michigan	New York	Tennessee
Arizona	Idaho	Minnesota	North Dakota	Texas
Arkansas	Illinois	Missouri	Ohio	Utah
California	Indiana	Montana	Oklahoma	Vermont
Colorado	Iowa	Nebraska	Oregon	Virginia
Connecticut	Kentucky	Nevada	Pennsylvania	Washington
Delaware	Louisiana	New Hampshire	Rhode Island	West Virginia
D.C.	Maryland	New Jersey	South Carolina	Wisconsin
Georgia	Massachusetts	New Mexico	South Dakota	Wyoming

## Setting the Stage: Positive Behavior Supports as a Personal, State, and National Issue

Publicly financed service systems for people with IDD are significantly challenged in their efforts to support individuals with intensive behavioral needs, their families, and the providers who work with them. Ideally, support strategies and therapeutic approaches are tailored to the specific needs of the individual and function to

IDEALLY, SUPPORT STRATEGIES AND THERAPEUTIC APPROACHES ARE TAILORED TO THE SPECIFIC NEEDS OF THE INDIVIDUAL AND FUNCTION TO STRENGTHEN HIS OR HER ABILITY TO LIVE A PRODUCTIVE AND SATISFYING LIFE IN THE COMMUNITY WITH FRIENDS AND FAMILY.

strengthen his or her ability to live a productive and satisfying life in the community with friends and family. State IDD agencies support a variety of interventions to meet the needs of people with problem behaviors. A review of the service definitions included in states' home and community-based Medicaid waiver programs furnished under Section 1915(c) of the Social Security Act reveals that virtually every state offers some type of behavioral support service to eligible individuals with IDD. The application of behavioral supports, particularly positive behavior supports (PBS), has resulted in significant behavioral and quality of life changes in the lives of many people with IDD (e.g., Carr et al., 1999; Carr et al., 2002; Reichle, Freeman, Davis, & Horner, 1999; Risley, 1996). Unfortunately, research into the widespread use of behavioral approaches has been hampered by two of the survey's key takeaways – service definitions and provider qualifications.

## Service Definitions and Terminology

The term “behavior supports” was used in this study to capture information on services that include behavioral assessment and intervention to increase appropriate behavior, decrease inappropriate behavior, and teach new skills to replace problem

behavior. Such services are referred to in different settings and states as applied behavior analysis, behavior management, behavioral intervention, behavior supports, and/or positive behavior supports. These services can be provided alone or as part of a broader support plan (ideally, person centered). Depending on a state's service definition, the plan may be called a behavior support plan, behavior intervention plan, PBS plan, or document with some other title.

From a professional perspective, applied behavior analysis (ABA refers to “the science in which tactics derived from the principles of behavior are applied systematically to improve socially significant behavior and experimentation is used to identify the variables responsible for the improvement in behavior” (Cooper, Heron, & Heward, 2007, p. 20). From a more practical perspective, ABA uses functional assessment and analysis to determine the relationship between a person's behavior and environmental variables, and then makes changes in those variables to improve the occurrence of socially significant behaviors. These changes are then experimentally assessed to verify the impact of the intervention (see Baer, Wolf, & Risley, 1968 for a more complete description).

Many states and treatment programs have begun using the term “positive behavior support” (PBS) to refer to certain types of services available to ameliorate problem behaviors. The term PBS, originally introduced by Horner et al. (1990), is defined as “a set of research based strategies used to increase quality of life and decrease problem behavior by teaching new skills and making changes in a person's environment” (Association for Positive Behavior Support [APBS], 2007). It was recently described as an approach that “grew from the scientific and procedural foundations of applied

behavior analysis, benefitting, in particular, from the technologies of functional assessment and analysis” (Dunlap, Carr, Horner, Zarcone, & Schwartz, 2008, p. 683).

Key literature on PBS has described the approach as emerging from “three major sources: applied behavior analysis, the normalization/inclusion movement, and person-centered values” (Carr et al., 2002, p. 4). Although the practice of PBS has become more fully developed for use with both children and adults over the past 20 years (see, generally, *Journal of Positive Behavior Interventions*), the PBS literature includes a preponderance of studies focused on children (Marquis et al., 2000), particularly within primary and secondary education systems (see [apbs.org](http://apbs.org) and the *Journal of Positive Behavior Interventions*). Given the gap in the literature, this study focused on the use of behavior support strategies in publicly funded services for adults with IDD.

When states were asked if their agency uses the term “positive behavior supports” in its policy or training efforts, 87% of states reported such use of this term. Those responding “yes” to this question were asked to provide an indication of how PBS is defined in their state. However, only 62% of the states that reported using the term positive behavior supports provided a definition. Of those states that did provide information on their state's definition of PBS, very few included information reflecting even a minimal number of the components that comprise this approach (e.g., addressing the function of the problem behavior, focus on teaching skills to replace problem behavior, increasing quality of life). In fact, many of the responses regarding states' use of the term positive behavior supports indicated that the state (a) did not have a definition of PBS, (b) that the definition is currently under development, (c) that the term is loosely defined, or (d) that the term is defined differently depending on the audience.

The findings concerning how states are defining PBS are problematic given that the term PBS directly implies implementation of supports that use research/

evidence-based strategies to first enhance the person's quality of life and, second, to minimize problem behavior (APBS, 2007; Carr et al., 2002). The appropriate definition of PBS "renders problem behavior irrelevant, inefficient, and ineffective by helping an individual achieve his or her goals in a socially acceptable manner, thus reducing, or eliminating altogether, episodes of problem behavior" (Carr et al., 2002, p. 5). Thus, it is quite possible that "definition creep" is occurring in many states, if not nationally, regarding the use of the term PBS. That is, the term is being used by state IDD agencies in a manner that does not reflect the actual implementation of PBS practices.

### Qualifications of Behavioral Support Providers

Regardless of whether behavioral support services are referred to as behavioral supports, behavior management, PBS, or applied behavior analysis, important questions remain regarding the specific nature of the services that are furnished underneath these titles; the qualifications that are required to provide the service; and the methods used to ensure, measure, and maintain quality. Expertise in delivery of behavior supports requires specialized

based on a foundation of applied behavior analysis. In highlighting the complexity of the issue, Rotholz and Jacobson (1999) noted that most licensed psychologists do not have training in applied behavior analysis or PBS, nor do they practice in these areas. Likewise, certification in applied behavior analysis does not provide sufficient indication about the certificate holder's qualifications in the broader field of psychology or PBS. Although there is overlap in professionals practicing applied behavior analysis and psychology, the authors concluded that it would be a mistake to make assumptions about the qualifications of an individual professional based on certification or licensing alone. Complicating matters further, receiving certification in applied behavior analysis does not provide assurance of the certificate holder's experience in the services required to competently serve individuals with IDD. Applied behavior analysis is a broad field and not all practitioners work in the area of IDD nor do they all have expertise in all of the areas pertinent to the provision of person-centered planning and positive behavioral support.

To explore the provider qualification requirements that are in place across the nation, the survey asked respondents

degree was the minimum requirement, followed by other (33%) (see comments below), Qualified Mental Retardation Professional (QMRP) (29%), psychology license (29%), BA/BS under professional supervision (22%), BA/BS without supervision (16%), BCBA (13%), and doctoral degree (13%; see Table 2).

**Table 2. Percentage of States Reporting Specific Requirements to Provide Behavior Support Services**

Educational requirements	% of states reporting the requirement
Master's degree	47
Other	33
QMRP	29
Psychology license	29
BA/BS with supervision	22
BA/BS with no supervision	16
BCBA	13
Doctoral degree	13

As noted above, one third of the respondents reported having "other" minimum requirements for a person to write a behavior support plan that were not among the alternatives included in the survey form. Approximately 2% of states indicated that a person must be a "PBS specialist certified by the University Center for Excellence," 4% of states indicated the requirement of BCBA, and 4% of states reported having no minimum requirements. The comments also listed additional qualifications such as master's degree in psychology, special education, social work, or counseling, and licensure as a psychologist, mental health counselor, physician, nurse, or social worker. Although one state required that the licensed professional have "competencies in applied behavior analysis, PBS, ethics, co-occurring mental disorders, and neurocognitive disorders," most did not. The comments provided by respondents indicated that a majority of states required qualifications that include training, experience, skills and/or licensure in areas that do not necessarily reflect competence in applied behavior analysis or PBS.

REGARDLESS OF WHETHER BEHAVIORAL SUPPORT SERVICES ARE REFERRED TO AS BEHAVIORAL SUPPORTS, BEHAVIOR MANAGEMENT, PBS, OR APPLIED BEHAVIOR ANALYSIS, IMPORTANT QUESTIONS REMAIN REGARDING THE SPECIFIC NATURE OF THE SERVICES THAT ARE FURNISHED UNDERNEATH THESE TITLES; THE QUALIFICATIONS THAT ARE REQUIRED TO PROVIDE THE SERVICE; AND THE METHODS USED TO ENSURE, MEASURE, AND MAINTAIN QUALITY.

study, training, and skill, but the practice does not constitute a licensed and/or certified profession, as is the case with medicine, physical therapy, social work, speech and language pathology, and other disciplines. Recent licensure of behavior analysts in a small number of states may be changing this picture in some areas, but for the most part, there is not universal agreement on the professional domain that has the right to provide these services, even though behavior support is

to indicate the minimum requirements needed for a person to write a behavior support plan for a person with IDD. Types of requirements from which respondents could select included psychology license, Board Certification in Behavior Analysis (BCBA), doctoral degree, master's degree, Qualified Mental Retardation Professional (QMRP), BA/BS under professional supervision, BA/BS with no supervision, not applicable, and other. Forty-seven percent (47%) of states reported that a master's



**Table 3. Difference in State Behavior Support Provider Qualifications: Required Skills for State and Non-state Employees by Percentage of States**

Skills	State employees (% of states)	Non-state employees (% of states)
Conducting functional assessment or functional analysis of behavior (FBA)	36	51
Defining behavior in objective terms	38	49
Development of behavioral support plan based on FBA Results	33	49
Analysis of data to determine function and assess progress	33	47
Objective(s) and data reporting on target behaviors to BOTH increase and decrease behavior	33	44
Training caregivers	33	44
Design of data collection systems	31	44
Specific procedures to teach/increase replacement behavior	33	42
Assessment of consumer's interests and preferences	31	40
Conducting consumer interviews	36	38
Conducting staff interviews	33	38
Working collaboratively with a team	33	38
Person-centered planning	29	31
Graphing of behavioral data	20	27
Assessment of consumer satisfaction	20	18
Assessment of quality of life	18	18

### Policy, Procedural, and Skill Requirements Across Treatment Settings

In addition to the significance of service definition and the discussion surrounding provider qualifications, the settings in which behavior supports are provided and the corresponding procedural requirements of that setting warrant attention. The survey asked several questions on policies, the first of which ascertained whether or not procedural requirements for behavior support services differed between Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) and home and community based settings (HCBS). Fifty-six percent (56%) of states indicated that such requirements differed across settings, with 36% of states whose requirements differed indicating that the requirements were less stringent in HCBS.

Although a significant proportion of the individuals served in institutional settings are in need of behavior support services, the overwhelming majority of adults receiving services funded by state developmental disability agencies, including those with significant problem behaviors,

are being supported in local communities and settings (although the quality of this support has not been well scrutinized [Larson, Scott, Salmi, & Lakin, 2009]). Twelve states have closed all of their public institutions for people with IDD and have

with key PBS skills more often required for non-state employees. While it is unclear whether this discrepancy results from the progression from public to private settings as the primary choice for services, closer examination of the reasons

THE LACK OF A RIGOROUS, PROFESSIONALLY ENDORSED NATIONAL STANDARD SUCH AS MEDICAL LICENSURE THAT APPLIES TO BEHAVIOR SUPPORTS FOR PEOPLE WITH IDD RAISES SIGNIFICANT QUESTIONS REGARDING THE ABILITY OF STATES AND PROVIDER AGENCIES TO SET PRACTICE CRITERIA AND ASSURE THE QUALITY AND APPROPRIATENESS OF THE SERVICES BEING PROVIDED ACROSS SETTINGS...

shifted the base of service delivery to the community. The movement of significant numbers of individuals with intensive needs to the community raises questions regarding the appropriateness of the less stringent requirements in community programs regarding the provision of behavior supports, provider qualifications, and state oversight responsibilities.

A discrepancy in qualification requirements between state and non-state employees was also evident (see Table 3),

why the requirements differ is crucial. This discrepancy is particularly important since most people with IDD are supported in community settings (i.e., HCBS) and these individuals experience behavioral and other challenges just as serious and complex as those served in ICF/IID programs. Thus a key question is why many states have different requirements for ICF/IID programs and HCBS and how best to ensure appropriate requirements in the HCBS.

It is evident that state agencies serving individuals with IDD are challenged in their efforts to develop and maintain high standards in provider qualifications, training, and quality assurance. While in most areas of professional practice (e.g., medicine) clear professional requirements set the minimum qualifications for practitioners with respect to education, training, supervised experience, and licensure necessary to insure “industry standards of quality,” this is not the case in the area of behavior supports. The lack of a rigorous, professionally endorsed national standard such as medical licensure that applies to

While this finding has relevance in many ways, we can only speculate on the reasons that led to such responses. For example, while the 82% of states that reported insufficient numbers of highly qualified providers demonstrated an important national need, we cannot report on how some states meet that need. It’s possible that some states have training programs that either enhance professionals’ skills in this area or train new providers in PBS sufficient to meet service needs. It is also possible that some states excel at providing truly person-centered community training

WHEN ASKED IF THERE ARE ENOUGH HIGH-QUALITY PROVIDERS OF BEHAVIOR SUPPORTS IN THEIR STATE, 82% OF STATES RESPONDED “NO” AND 18% RESPONDED “YES.”

behavior supports for people with IDD raises significant questions regarding the ability of states and provider agencies to set practice criteria and assure the quality and appropriateness of the services being provided across settings (i.e., ICF/IDD and HCBS). Although it is worth noting that there is a national certification in applied behavior analysis from the Behavior Analyst Certification Board, that certification does not address the skills required for PBS that go beyond applied behavior analysis. At present, it appears that states interested in ensuring provision of PBS may need to take direct action to meet this obligation.

### Lack of Qualified Providers

The last set of questions asked in the survey had to do with state policies and practices that govern the oversight and provision of behavioral supports, quality assurance methods, the availability of behavioral support providers, and the challenges experienced by state agencies in these areas. When asked if there are enough high-quality providers of behavior supports in their state, 82% of states responded “no” and 18% responded “yes.”

and supports that reduce the need for behavioral supports from their state ID/DD agency. In either case, this is an important topic to explore in future research.

### Conclusion

The finding that behavior supports are furnished by all states responding to the survey underscores the importance of this key service. But the data also reveal many of the challenges that state agencies serving persons with IDD experience in the delivery and oversight of behavior supports and behavior support providers. The vast majority of states indicated that they did not have enough high quality providers of behavior supports. This shortage, plus the lack of a national consensus or standard regarding staff qualifications, service definitions, professional oversight, and quality assurance, underscores the need to address these issues at both the state and national levels. This study undertaken by NASDDDS and CDR was intended to be the first step to that end. Hopefully, the next step is for collaborative efforts to improve policy and, most importantly, practice in the area of behavior supports in all states.

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## It's About Relationships: Individualized Supports at Upper Valley Services

by William Ashe

**William Ashe** is Executive Director of Upper Valley Services, Moretown, Vermont. He may be reached at [billa@uvs-vt.org](mailto:billa@uvs-vt.org) or 802/496-7830.

**At Upper Valley Services** we base our supports for individuals with intellectual and developmental disabilities on the concept of relationship. This is as true for people who have histories of challenging the system as it is for people who do not. We do not believe that we have the ability to control or change behavior of another through external means (e.g., compliance based programs). We do believe we can assist an individual in changing their own behaviors as a result of providing supports that are valuing, respectful, and educational. We feel that we need to empower people, which requires that we become their allies. Rather than controlling and directing, our energy is spent providing support and fostering a climate where individuals feel safe and empowered. When this is achieved, people become open to guidance, and positive change in the behavior patterns that have historically been problematic change in time to more adaptive, functional, and satisfying responses.

Upper Valley Services (UVS) is a non-profit organization located in the central part of Vermont that uses person-centered plans to support nearly 200 individuals with intellectual and developmental disabilities in any area of need that prevents them from being full participants in community living. It is one of Vermont's Designated Agencies, which means UVS has a defined catchment area for which it is responsible. This responsibility includes providing or arranging for services and supports for anyone residing within the catchment area who is both eligible for services (as defined by State of Vermont regulation) and who meets a priority for funding as defined by the Vermont State System of Care Plan.

The primary service model in Vermont is a foster home model called *shared living*. For the most part, these are typical home settings where a person is supported as part of a family-based approach. In most instances, only a single individual is supported in a shared living setting. There are other support models also available, which include supporting individuals in their own apartments, supporting individuals to

remain in natural family settings, supporting people to live with a roommate or supporting people to live in a small group home (UVS has a single group home that supports three people with significant medical needs). Through UVS a person is able to access supports that are appropriate for their specific needs and interests ranging from a shared living setting, to a supported apartment, to semi-independent



**RATHER THAN CONTROLLING AND DIRECTING, OUR ENERGY IS SPENT PROVIDING SUPPORT AND FOSTERING A CLIMATE WHERE INDIVIDUALS FEEL SAFE AND EMPOWERED.**



living. As Vermont fully supports service models that are individualized, the type of setting is based on need and interest. Day support options are similarly individualized with the priority being given to supported employment. Non-work community support strategies are directed towards assisting individuals to learn and use the communities within which they live and work. UVS recognizes that community inclusion goes beyond community presence and must include reciprocal participation with other community members.

Most of the people we support with histories of challenging behavior are people who have significant trauma histories. They are also people who, in many instances, have an absence of healthy attachment relationships. These realities must play a primary role when thinking through how to create a supportive environment. We need to meet individuals where they are at, where strong positive relationships can be developed, where environments are safe, where support people see themselves in an ally role, and where the individual has the ability to feel increasingly empowered and in control of as much of their life as is possible. Teaching people how to recognize stressors that influence challenging



behaviors, helping them to develop alternative responses that are more adaptive (i.e., through self-regulation strategies), and supporting individuals to arrive at satisfactory solutions to problems are all strategic elements.

In our experience, in most instances the behaviors that are the most challenging are ones that have origins that (when recognized) make the behaviors understandable. Medical causes are always the first to be explored and to

be re-explored. Many individuals are unable to effectively communicate their distress and the resulting expression of this discomfort is excessive behavior. This is true when the origin is medical as well as when the origin is non-medical. In many instances the “treatment approaches” that have been followed historically have been ones that have actually sustained the challenging behavior rather than assisting the individual to develop more adaptive alternatives. For many of the people we

support, previous approaches have often been compliance-based programs with contingency management components that simply have not worked. In most instances, the intensity of these compliance requirements (often in conjunction with various forms of penalty provisions) have resulted in an almost endless war between the individual and those trying to modify the person’s behavior. We try to approach these individuals from more of a partnership perspective. We accept

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## PERSONAL STORY



# My Journey to TRUST AND GRATITUDE

by Lee Potter

**My story is** very different and separate from the average story you would find in a typical mental health establishment. It is that of many great steps forward and a few giant mistakes that taught me my values in life.

My family, like many others, has faced several challenges in the few decades of our co-existence. But in the great scheme of things, we came out much better for them in the end.

The support system I receive at Upper Valley Moretown is unlike any support I’ve had in my life. The people there have become my family and friends, and have

always been there to work around me and my needs. You may ask what makes Upper Valley Moretown unique and unlike other agencies? Well, it is the simple notion that they treat each person as an equal individual. Not as someone whose needs differ greatly from any other person’s needs, but as someone who can be treated the same as anyone else you might meet. In the course of this they address jobs, personal and community care, relationship etiquette, ethics, forming healthy relationships, and being able to recognize changes in one’s self.

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that behavior is communication, and that the most excessive forms of behavior are based in poor relationships between the individual and those trying to provide support. Assisting a person in better self-regulation must begin from the understanding that trusting and respectful relationships must be at the core.

Upper Valley Services has assisted a large number of people to live and work successfully in communities of their choosing. We believe that people must be

able to exercise control over their lives. We also believe that we, as providers and supporters, must be extremely careful not to assume a parent-like role in our relationships with those we support. We must be their allies and not their supervisors. Only when these relationships are more evenly balanced are the trust bonds that are so essential able to evolve. We believe that a program based in “support and guidance thinking” will be more effective than one based in

“supervision and control thinking.” We also believe that everyone is an individual, and this necessitates support plans that are unique to the person, rather than being a function of program-wide rules requiring uniform compliance.

In the years before I was introduced to this program, I struggled with mood swings; learning how to cope with behavior issues in the community, workplace, relationships; and with learning how to cope with honesty issues. I was mainly living in Montpelier for several years before placement through Upper Valley. I had a multitude of roommates and mentors, chosen by my parents, some of which pairings were successful while others weren't.

Recently we held a life planning meeting, and as I have been a poet for the last 16 years I wrote a poem of thanks to show how much I appreciate my team's efforts. However, before this meeting we had several similar planning meetings where I was finally able to grasp the concept of the need to work with these types of willing life coaches. For years I thought it was pointless to take advice or help from people, until I saw how useful this thought process was, not only to my own growth throughout time but for other people with the same struggle. Here is a piece of my poem to them:

*You all are my family  
You all are my friends  
That is why we are gathered here  
Together today  
Beginning to make amends  
I see you as equals  
I see you as peers  
I've made my soul confessions  
And prayed to all the heavens  
Now I choose my own defense  
It's the ink within this pen  
Now may I recess  
To the corners of my mind.*

The idea of this piece came after years of successfully navigating hard situations with my family and support team. By all of us meeting together at this planning meeting, I was able to lay out an idea that everyone could get their head around while still validating their concerns and questions. In a way, this was the beginning of me teaching myself and everyone else it's ok to trust and try to let go, even if fearful of the next step.

In the search to find the perfect organization to serve my needs, we of course came across some undesirables. I know that without having gone through that trial period, though, I never would have become the man I am today. It allowed me to find a calm and a peace within my center that never need be compromised. This process also instilled in me a belief system of simple spirituality and life acceptance, knowing I can't always control what happens to the people I care about.

I was also able to successfully build an outside trusting relationship with my parents, where before there had been a sense of resentment. That feeling now has washed away with pride, love, and respect. If not for the efforts of my team at Upper Valley Moretown, my surrounding family and community, and the inner efforts of myself, I doubt whether many of these amazing changes would have happened. Upper Valley is responsible also for my part-time employment in the workplace and in developing my working relationships in a healthy, mature way. I am forever grateful to these people who I am proud to call friends and family.

**Lee Potter lives in Berlin, Vermont.**



# Implementing Evidence-Based Positive Support Practices in Applied Settings

by Rachel Freeman

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In the past decade, there has been an increasing value placed on using evidence-based practices to improve quality of life for children and adults with intellectual and developmental disabilities (IDD). While great strides have been made during this time in the development and identification of evidence-based practices, difficulties translating these research-based strategies into everyday settings continue to be problematic. In fact, some experts suggest that translation of research into practices that are meant to support people in real-world settings can be delayed up to 20 years or more (Metz & Bartley, 2012). A growing interest in improving the impact of evidence-based practices in home, school, work, and community settings has led to a *science of implementation*.

The purpose of this article is to describe how the principles of implementation science can help ensure the effective and sustainable use of evidence-based positive support practices by organizations working with persons with IDD.

## The Meaning of Positive Support

The term *positive support* is used in this article to refer to practices that have these characteristics:

- › evidence-based and evidence-informed
- › person-centered
- › culturally competent
- › implemented in a manner that allows for ongoing evaluation and monitoring

Each of these characteristics is further described below.

## Evidence-based Practices

*Evidence-based practice* is a term used across education, medical, and human service systems. The American Psychological Association definition states that evidence-based practice is "...the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences" (APA, 2002). According to the Association for Positive Behavior Support,

"Evidence-based practice...is defined as the integration of rigorous science-based knowledge with applied expertise driven by stakeholder preferences, values, and goals within natural communities of support." (APBS, 2016). Although there are slight differences, many evidence-based practice definitions have the same major themes. *Evidence-informed practices* are strategies that have not established the amount of research necessary to be considered evidence-based, but have data collection systems in place to evaluate their effectiveness in applied settings.

## Person-centered Values

In the past, there was an assumption that people received services and, as consumers, should be placed into existing services and supports that were considered by others to be the best fit. The opinions and preferences of people with disabilities were often ignored in this older paradigm of service provision. *Person-centered values* place the person at the center of important decisions that impact his or her life. In this new paradigm, people with IDD have the right to live life in the same manner as any other person within their communities. Supports are tailored to meet the needs of each person.

## Culturally Competent

The development of cultural competence refers to the ability of a person or system to respect, understand, appreciate, and interact with the people who live or work within a setting. Examples of cultural differences include age, abilities, religion, beliefs, ethnicity, geographic or social groups, race, gender identity, sexual orientation, and socioeconomic status.

## Ongoing Evaluation and Monitoring

Positive support practices include systems to assess whether practices are increasing quality of life over time. Fidelity of implementation, the extent to which a practice is being implemented in the manner intended, is an important tool in the evaluation process. Quality of life data, the frequency and intensity of incidents



related to problematic events, staff climate, satisfaction levels of people being supported, and staff and retention/tenure data are all examples of types of information used to evaluate a positive support.

## The Multi-tiered Systems of Support Model

The term *three-tiered systems of support* refers to a conceptual model from the field of public health, where it describes a strategy designed to prevent the spread of disease by outlining three levels of prevention (Gorden, 1983). The model has been adapted for education and human service settings as a way to

encourage success and prevent failure in achieving positive academic, social, and/or quality of life outcomes for children and

A GROWING INTEREST IN IMPROVING THE IMPACT OF EVIDENCE-BASED PRACTICES IN HOME, SCHOOL, WORK, AND COMMUNITY SETTINGS HAS LED TO A SCIENCE OF IMPLEMENTATION, WHICH CAN HELP ENSURE THE EFFECTIVE AND SUSTAINABLE USE OF EVIDENCE-BASED POSITIVE SUPPORT PRACTICES BY ORGANIZATIONS WORKING WITH PERSONS WITH IDD.

adults across a number of different settings including schools, mental health services, juvenile justice, and residential supports.

The terms *primary, secondary, and tertiary prevention* are used to describe each of

the three levels. **Primary Prevention** refers to the use of universal strategies for all people within a setting. These universal strategies increase the use of positive supports and decrease the need for more intensive strategies. **Secondary Prevention** involves using data for early identification so that people can benefit from positive supports before academic, social or quality of life problems are encountered. At the **Tertiary Prevention**

level, people receive more intensive supports based on their unique needs. When more than one type of practice is being implemented using a three-tiered model, it is referred to as *multi-tiered systems of*

Figure 1: Implementing Multi-Tiered Systems of Support

### Person-Centered Practices & Planning

#### Tertiary Prevention

- Individualized Integrated Plans (PBS, Trauma-informed Therapy)
- Person-Centered Plans
- Teams Monitor Progress

#### Secondary Prevention

- Add Supports to Improve QOL
- Independence and Community Involvement Encouraged
- Mental Health and Wellness Strategies

#### Primary Prevention

- Person-Centered Thinking
- Encourage Self Expression
- Self-Determination and Choice Making
- Predictable and Proactive Settings
- Meaningful Participation in the Community

### Positive Behavior Support

#### Tertiary Prevention

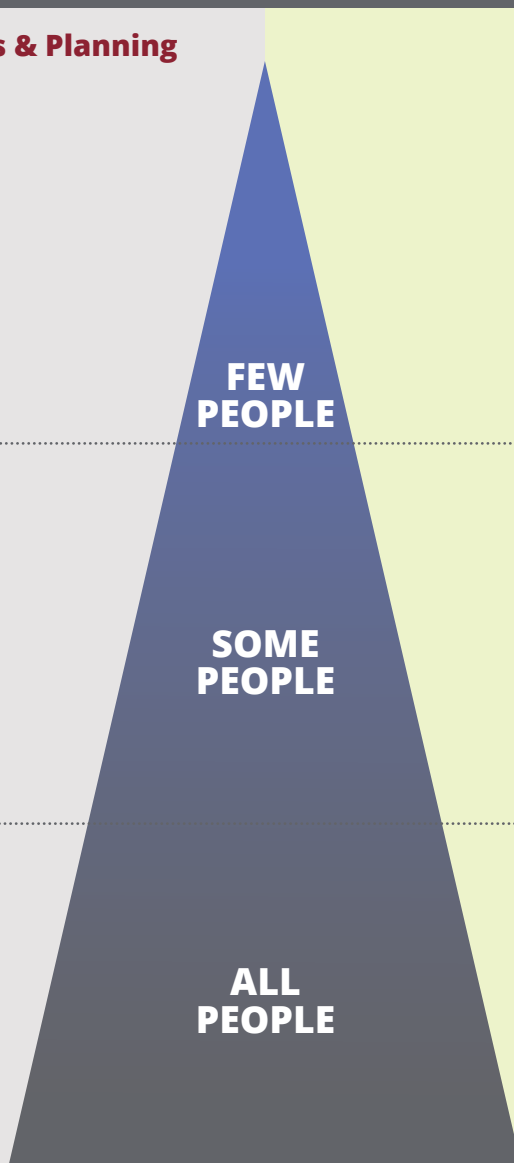
- Individualized PBS Plans
- Integrated with Other Positive Supports (PCP, Trauma-Informed Care, DBT, Etc.)
- Plans Are Evaluated to Ensure Fidelity
- Outcome Measures
- Teams Monitor Progress

#### Secondary Prevention

- Use Data to Identify People At Risk
- Additional Supports for Key Social Communication Skills
- Group and Individual Interventions
- Simple Function-Based Interventions
- Mental Health and Wellness Interventions

#### Primary Prevention

- Teach and Encourage Communication
- Encourage and Reinforce Social Skills
- Consensus-Based And Team-Based Planning
- Emphasis on Using Data For Decisions
- Integrated with Other Positive Support Practices (PBS, Trauma-Informed Care, Etc.)



support. Figure 1 provides an example of person-centered practices and positive behavior support strategies implemented using multi-tiered systems of support.

## Effective and Sustainable Implementation of Positive Supports

A review of research on evidence-based practices (Fixsen, Naoom, Blasé, Friedman, & Wallace, 2005) was conducted in order to identify the most important features of effective and sustainable implementation. These implementation features are becoming better understood. Indeed, many of the important principles of implementation are like “gravity”: They apply across human service sectors (U.S. Department of Education, 2012). The findings from the 2005 review by Fixsen and his colleagues (2005) resulted in the development of four implementation frameworks:

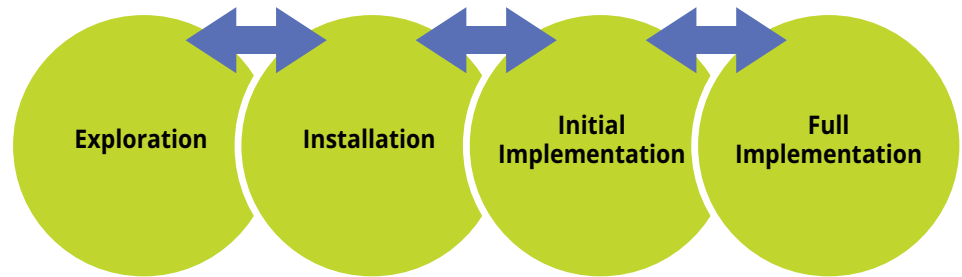
- › Implementation stages
- › Implementation drivers
- › Policy-practice feedback loops
- › Infrastructure for implementation support

The information below provides a summary of these implementation frameworks (see the National Implementation Research Network’s Active Implementation Hub for more detailed information at <http://implementation.fpg.unc.edu>).

### Implementation Stages

Strategies used to launch a positive support do not remain fixed and unchanging. The initial efforts to implement a new practice will start with an *exploration stage* (see Figure 2). Teams assess how well practices will fit the culture of an agency or organization. Once exploration has been completed, a great deal of energy is dedicated to *installing* a new practice by allocating financial resources and developing capacity of staff members via training and coaching systems. The *initial implementation stage* is established once a positive support has been installed. This is an important time for agency and organizational teams as a new positive support is being implemented and is expanding across an organization.

Figure 2: Implementation Stages



Source: Adapted from National Implementation Research Network, 2016. Used with permission.

Teams successfully completing the first three stages move into *full implementation* using data to make modifications to training and communication systems. Full implementation is in place when practices are embedded across all levels of an orga-

*implementation drivers* (Metz & Bartley, 2012). Three types of drivers are used concurrently to implement positive supports with a high level of fidelity and in a sustainable manner: competency, organizational, and leadership drivers.

SUSTAINABILITY REFERS TO THE LONG-TERM IMPLEMENTATION OF A POSITIVE SUPPORT PRACTICE THAT INCLUDES EVIDENCE THAT HIGH LEVELS OF FIDELITY OF IMPLEMENTATION HAVE BEEN DOCUMENTED AND WHERE VALUED OUTCOMES ARE ACHIEVED.

nization. Issues related to sustainability become the focus of attention as an organization moves into the full implementation of a positive support practice.

*Sustainability* refers to the long-term implementation of a positive support practice that includes evidence that high levels of fidelity of implementation have been documented and where valued outcomes are achieved (Macintosh, Horner, et al., 2009). A key mechanism for sustaining a positive support practice is the extent to which performance assessments are conducted to evaluate implementation (McIntosh, Filter, Bennett, Ryan, & Sugai, 2010). Ongoing performance assessment allows trainers to identify problems and intervene before implementation falters. Ongoing progress monitoring, data-based decision making, and capacity-building activities are used to encourage sustainable implementation efforts.

### Implementation Drivers

A core element of any training and technical assistance effort is referred to as

**Competency Drivers.** These drivers focus on strategies that will develop and improve staff and supervisor skills in implementing a positive support. Effective training starts with the selection of staff members who are the best fit for different roles related to implementation. Readiness of staff members to participate in implementing a new positive support is assessed before implementation begins. Training and strategies for providing staff members with coaching on an ongoing basis is an important part of any implementation effort. Performance assessments are used regularly to ensure sustainable and effective practice.

**Organizational Drivers.** The organizational support systems that are identified by a team implementing a positive support create an environment where change can occur. Data-based decision-making systems are established to assess overall performance. Quality assurance, fidelity of implementation, outcome, and organizational data are reviewed regularly.

Successful teams build data-based decision making into meetings in a manner that encourages sustainable routines. These data are used by teams to create actions for improving positive support practices. Facilitative administration within an organization is used to make sure that problems are solved, staff members are organized, policies and procedures align with positive supports, and resources are allocated in a manner that supports implementation efforts. Teams focus on aligning external systems (partner organizations, sources of funding) that impact an organization.

implementing positive supports. Creating internal cycles of communication that intersect with organizational, regional, and/or state processes will assist organizations in aligning person-centered values and positive support practices.

### Infrastructure for Implementation Support

Traditional strategies for implementing evidence-based and evidence-informed practices have often left organizational leaders on their own to figure out how to implement a practice. Establishing an

implementation team within the organization is one way to avoid relying on one-shot workshops to introduce new practices. This organization-wide team includes representatives across key stakeholders who, together, provide oversight and leadership to implement a new practice over time.

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ADAPTIVE LEADERSHIP INVOLVES REACHING OUT TO STAFF, LISTENING TO PEOPLE EXPRESS THEIR FEELINGS AND BELIEFS, AND WORKING TOGETHER WITH A GROUP TO IDENTIFY SOLUTIONS THAT WILL ELIMINATE RESISTANCE TO IMPLEMENTING A POSITIVE SUPPORT.

**Leadership Drivers.** Two types of leadership are involved in systems change: *technical* and *adaptive*. Technical leadership is used to manage positive support training systems by overseeing competency and organizational drivers described above. Adaptive leadership is needed when traditional problem-solving strategies are not effective. An adaptive leadership approach is needed when resistance is encountered by staff members implementing a positive support. Adaptive leadership involves reaching out to staff, listening to people express their feelings and beliefs, and working together with a group to identify solutions that will eliminate resistance to implementing a positive support. A common mistake that is made by leaders who are implementing a new positive support practice is to attempt to apply technical leadership strategies in situations requiring adaptive leadership skills (Heifetz & Laurie, 1997).

### Policy-Practice Feedback Loops

Strategies for assessing and connecting policies that are related to positive support practices can be key factors for effective implementation. Without a process for aligning practices with the policy level, trainers, organizational leaders, and staff members may experience barriers while

implementation team within the organization is one way to avoid relying on one-shot workshops to introduce new practices. This organization-wide team includes representatives across key stakeholders who, together, provide oversight and leadership to implement a new practice over time.

Effective implementation teams share progress regularly with all stakeholders and engage in celebration of successes. Establishing feedback loop systems for communication within organizations improves technical assistance when it is provided by external trainers and provides a way in which information can be systematically shared across the organization.

### Conclusion

Evidence-based and evidence-informed practices must be identified and implemented by organization-wide teams who have clearly articulated the values important to the people who will be implementing new changes. The term positive support has been used in this article to refer to evidence-based and evidence-informed decision making practices that include core values of person-centeredness and cultural competence. Organization-wide teams may add additional values that are

### Additional Resources

Implementation Science Resources

- › Implementation Research: A Synthesis of the Literature <http://ctndisseminationlibrary.org/PDF/nirnmonograph.pdf>.
- › The National Implementation Research Networks' Active Implementation Hub Modules and Lessons: <http://implementation.fpg.unc.edu/modules-and-lessons>.





## How Staff Treats Me has an Impact on How Well I Do:

### An Interview with John Daly

by Susan O'Neill

*John lives with a brain injury, physical disabilities, a developmental disability, and a treatment-resistant mood disorder. The mood disorder has worsened with age and includes rapid cycling swings from major depression to mania. In this interview he talks about his life, his conditions, and the support he needs to do well. Joining in the interview are some current staff (Ann and Bill) and one of his guardians (Susan).*

*John has lived many places. He lived with Susan and her family as part of an in-home foster care program as an adult. He lived with JoAnn's family as a youth growing up also through foster care. John relies on JoAnn and Susan for advice and support to make life decisions. As John aged, his disorder started to include higher highs. He went to the hospital frequently. His community provider did not know how to support him to stay safe. Twice he ended up in short-term locked residential placements. It was difficult for JoAnn and Susan to help John when he was in crisis due to the way many providers interpreted HIPAA laws. With John's permission, Susan and JoAnn became limited co-guardians for John's medical and services to support him better.*

*When John moved to his current provider his symptoms were not better. However, staff approaches and the environment were different. John has done well in his new home. This interview provides some of the key events in his life and how staff responses to his mental health condition make a difference.*

**Susan:** Before we talk about strategies that have or haven't worked for you when it comes to your mental health, let's talk a little bit about you. Tell me about your life. Where were you born?

**John:** I live in Minnesota, the Twin Cities. I was in the hospital after an accident when my Grandma and Grandpa came and took me home. I stayed with Grandma and Grandpa for a long time.

**Susan:** So that happened when you were pretty young. You were in a bad car accident. You lost your family and had serious injuries. In fact, when you went to the



*John Daly enjoyed Thanksgiving dinner with friends and support staff.*

hospital, they did not think you would walk or talk ever again. Do you remember being told that?

**John:** Yes.

**Susan:** So "Grandma" and "Grandpa" were your new foster parents. They were the people you went to live with after the accident.

**John:** Yes. I lived near Lake Nokomis and they had nine other kids plus me.

**Susan:** What I remember you telling me about Grandma is that she really expected you to do everything you could for yourself. I think that's been really helpful for you. And even though Grandma and Grandpa passed away, you have stayed close to the family. They are your family for holidays and when important things come up. Especially JoAnn and Dale.

**John:** Yes.

**Susan:** Where else have you lived?

**John:** I lived in Clara Doerr-Lindley Hall.

**Susan:** What was it like there?

**John:** There were lots of people. They gave me food to eat and had a bed for me in my own room. Sometimes I would do things I shouldn't do. I went to church there, St. Stevens. I took religion class. I had friends there.

**Susan:** Your religion is really important to you, isn't it?

**John:** Yes. I am a greeter. I can meet new friends at church. They have coffee and donuts there.

**Ann:** John dresses up nice. He sits through the mass and can really belt out the hymns. Two of the priests visited him when he was in the nursing home this year.

**Susan:** John, when you are feeling down that means your depression is back. What does that look like?

**John:** Not talking much.

**Ann:** Not really talking at all for the first day and then by the third day of the cycle maybe three words.

**John:** Staying in bed. Not wanting to do things.

**Susan:** What do you do during this time? What works?

**Ann:** We offer him something to drink regularly through the day. And try to have him to get up by the time everyone gets home in the afternoon. When I go in I remind him of what happens if he doesn't drink or go to the bathroom, how his body will feel.

**Bill:** I am more like his buddy. I go in and sing a song or tell a joke. We are all different with John. Sometimes the way I do things works, but not always. Sometimes he needs someone else. I might go ask Ann to check on him if she's here.

**Ann:** By afternoon he will get out of bed, but he doesn't talk. He moves so slowly.

**Susan:** John, sometimes you get a little too "up." What does that feel like when you are too up?

**John:** I talk kind of loud. I like to go out.

**Ann:** He really runs, runs, runs. We get him out as much as possible. He likes to cook and help around the house. There is not very much full mania right now. If it happens it lasts only a few hours. You can tell because he might be cursing or sweating. We try not to have staff talk very much. Or we swap out the staff to work better with him.

**Susan:** Sounds like one strategy you are using is to see which staff has the right energy and approach for John at the time. John, we've tried and keep trying a lot of medications to help you with this, but not a lot has changed for you. You still have lots of ups and downs that affect your days. You are really about the same as when you lived in the other place. But you didn't do as well there. You were arguing with staff and leaving the house a lot. Sometimes it was even dangerous. What's different now?

**John:** I don't have a bus outside. Staff go with me places when I want to go somewhere. Or sometimes I have to wait.

**Susan:** What helps you when you have to wait?

**John:** Talking to me or offering quiet time. But sometimes staff talks too much. One is a jabber-jaws. *[He puts his hand up to imitate a mouth opening and closing]*

**Susan:** What do you do?

**John:** I go to my room or say, "Pipe down jabber jaws!"

**Susan:** Well, hopefully working on trying to talk to staff respectfully and asking them to respect you.

**John:** Yeah. But sometimes that doesn't work and I just go to my room.

**Bill:** I read the paper to him and he likes that. Or we go to church. John will go to church or Fleet Farm almost any day.

**Ann:** It really helps to have a plan for the day. On up days we have John do "quiet time" until about 11 a.m. He can color or journal or listen to the radio.

**Susan:** So, John, what I see is that the staff here really pay attention to you and try to help you figure out what is going to help you do your best and feel your best. They really see these shifts as symptoms and not "problem behavior." So they respond by helping you in ways that work for you. That's really different than in the past where people expected you to figure that out for yourself. I've been really impressed with this staff and how much they have been able to help you. I think this has been a good move. What do you think?

**John:** Yeah, I think so too.

**John Daly** lives in New Brighton, Minnesota.

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# Community Living and Participation for People with Intellectual and Developmental Disabilities

*Joint Position Statement of AAIDD and AUCD*

Adopted:



American Association on Intellectual and Developmental Disabilities

Board of Directors, June 5, 2016



Association of University Centers on Disabilities

Board of Directors, June 23, 2016

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## Statement

**Community living** is a major focus of national policy and related litigation (e.g., the Americans with Disabilities Act in 1990, the Supreme Court *Olmstead v. L.C.* decision in 1999, Workforce Innovation and Opportunity Act in 2014, and the Home and Community Based Services Final Rule in 2014). Increasingly, public policy is promoting and requiring that federal funding be used to support people to live, work, and participate fully in their communities.

Community living and participation means being able to live where and with whom you choose; work and earn a living wage; participate in meaningful community activities based on personal interests; have relationships with friends, family and significant others; be physically and emotionally healthy; be able to worship where and with whom you choose (if desired); have opportunities to learn, grow and make informed choices; and carry out responsibilities of citizenship such as paying taxes and voting.

Of the estimated 6.2 million people in the United States with intellectual or developmental disabilities (IDD), most live with their families and many need and receive long-term services and supports. When people live outside of their family home they have several options for community living, including opportunities to live in apartments with individualized support, with one or two other people with support, with host families, and in small group homes with other people with disabilities and 24-hour support. Unfortunately, many people with IDD also may still live in large, segregated congregate places including large group homes (with 7 or more people living there), residential programs located on campuses, and state and private institutions, which could limit community inclusion.

The benefits of living in smaller community settings are well-documented. People who live in these environments have more choices and control over their lives, have

more friendships, are engaged in their communities, are safer, and experience greater life satisfaction. The ability to live and thrive in individualized living situations and be in charge of their own home (e.g., staff schedule, what/when they eat, who visits and when) is possible for all persons regardless of need when the funding and supports are made available to them. That is, all people, regardless of the significance of their disability, can lead lives they control by being supported to experience the opportunities that community life offers and to choose how they will participate in their communities. All too often, many individuals with IDD are never afforded these opportunities and, in many instances, there is systemic denial of choices due to constraints of service delivery systems to provide such opportunities. Instead, low expectations sometimes held by professionals, families, community members, and others who touch the lives of people with IDD result in perpetuated assumptions that people with IDD need and require 24-hour support, group employment, and group living. Approaches such as *Community First* and *Employment First* statewide initiatives emphasize an alignment of policies, funding, and practices to promote people with disabilities living, working, and contributing in their communities as the first option in the provision of services and supports.

Despite the evidence, there is a growing interest in many states by some advocates to move away from community living in favor of building new congregate programs that segregate people with IDD from their communities (e.g., working farms, campus models and gated neighborhoods). Often the interest and desire to create new congregate settings is in response to advocates' frustrations with: a) long waiting lists for community living, b) issues related to quality of community services, c) lack of options that are person-centered and able to meet the specific needs of each individual person, and d) staff who are not adequately prepared and not specifically trained to support people with certain types of significant needs. These concerns



## EMBRACING POSITIVE PRACTICES

*In 2016, the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Association of University Centers on Disabilities (AUCD) came together to develop a position statement on community living for people with intellectual and developmental disabilities (IDD). This statement provides a bold message that all people with IDD can and should have the opportunity and be supported to live full lives of their choosing in their communities. Person-centered planning, positive behavior support, trauma-informed practices, and other positive supports are essential to supporting people with IDD to live in their communities. Fully integrating and using these practices will require changes to state infrastructure such as 1) building better systems for training and education for people with IDD, their families, advocates, allies, policymakers and practitioners (including all direct support professionals) on positive practices; 2) changes in policies that require use of positive practices; 3) building data and accountability systems that monitor outcomes*

*of using positive practices; and 4) ensuring opportunities to emerge, try, and implement new positive practices.*

*It is often challenging for organizations and systems to implement, evaluate, modify, and scale-up the use of existing and emerging positive practices. Scaling up is challenging for many reasons including, but not limited to, implementing without reflection and evaluation; not taking into full consideration cultural difference at individual, organizational, and community levels; and the need for ongoing refinement, training, and retraining due to staff turnover at all levels. In order to assure community living opportunities for ALL individuals with IDD, it is important for practitioners/providers, policymakers, and researchers at all levels and in all systems to embrace the opportunity and need to scale-up the use of positive practices that will support community living.*

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about community living are both real and significant, but the solution to return to building large, segregated, isolated living programs is not the answer to improving quality of life for people with IDD and could result in less positive outcomes. It is tempting to revert to institutional-type congregate settings when the resources or capacity to improve community living options are lacking. The alternative is to create and advocate for high quality community living options that are supported by federal and state governments. It is also important to make people aware of what is possible and what practices exist that result in quality community living. People with significant disabilities do, can, and should live in the community with the support they need and deserve. They have a fundamental right to do so.

### Issues

#### Access to community services.

Many people with disabilities experience access challenges to individualized community supports. There are many issues that create barriers for people with significant disabilities to live and work in the community. Some of these are:

- › Nearly every state has significant waiting lists for Home and Community Based Services, the foremost funding source for community living. Recent data (2013) indicates an estimated 232,204 people in the U.S. are on waiting lists for community services.
- › Many states have built systems that utilize group homes as a key way to support people in the community. When people find themselves in a situation where they need to live outside of their family home, they are often placed in an “open bed” versus being offered person-centered supports designed specifically to meet their needs. In many of these situations, people remain as isolated in these settings as they do in a large-scale institution. A process for creating and sustaining supports that make their living situation a home in a neighborhood is needed.
- › In most states and communities, it is not unusual for people with IDD to transition from school to sheltered workshops or non-work day services with little opportunity to move out of those environments into supported or competitive employment. These assumptions place

low expectations on people with IDD and both underestimate and undermine their potential achievement of supported or paid community employment.

- › People with IDD do not have equal access to various forms of technology (e.g., communication devices, mobility devices, smart home, digital information) that could greatly increase their ability to live and work in the community.

#### Quality in community services.

There is wide variability of quality within community residential, employment, and other support models across the U.S.:

- › Ensuring the quality of community living is an ongoing challenge in the United States. Federal requirements related to quality do not exist and each state develops, implements, and monitors the quality of programs in different ways. This leads to wide variability in quality of services that often lack characteristics that are necessary to promote a self-determined, interdependent life for people with IDD.
- › Many of the best practices that have evolved to promote community living and participation have not been brought

to scale (e.g., individualized supported living, supported employment, technology, supported decision making). The best models are not disseminated broadly nor funded in ways that providers can fully implement. Sufficient, affordable models don't exist for agencies that provide the best services to share their practices with others.

### **Funding for community services.**

The various funding mechanisms used to support community living and employment are using antiquated models; the funding policies are not flexible, do not meet the needs of individuals, and over-rely on 24-hour staffing models:

- › In the United States more money is spent *per person* on institutional and segregated services than is spent on community living and supported employment. \$260,970 was spent on institutional services per person (2013 state operated ICF/IID expenditure) compared with \$42,713 on community (2013 HCBS expenditure).
- › About \$7,000 annually is spent per person on supported and integrated employment including both individual jobs and group supported jobs by state IDD agencies. For all day and employment services the annual expenditure is about \$13,000 per person. While an estimated \$947 million is spent in total by state IDD agencies on supported and integrated employment, over \$7.2 billion is spent on sheltered or segregated employment and non-work day services. Integrated employment represents 13.5% of all spending for day and employment services (2014 expenditure data).
- › The costs of archaic service models result in many people with IDD unnecessarily receiving 24-hour daily supports and they are therefore being over-served.
- › Medicaid is a health care program based on a medical model of services and supports and often creates a lack of flexibility in funding systems. This can lead to the inability to readily respond and adapt in a timely manner to the changing needs of each individual at any given point in time based on their unique context and individual characteristics.

**Workforce challenges.** The ability to meet the needs of people with IDD in the community, ensure quality of community services, and offer more flexible and individualized options requires a better compensated, stable, highly ethical, and competent workforce:

- › It is difficult for individuals, families, and providers to find and keep direct support staff. The demand for workers far surpasses the number of qualified job seekers, resulting in a significant personnel shortage.
- › The direct support workforce is paid low wages (national estimated average is \$10.50 per hour) and consequently most direct support professionals work more than one job in order to pay their bills. This results in high levels of burnout and resignations, and workers who are often chronically tired.
- › Direct support professionals have demanding roles, both physically and psychologically, and as a consequence have one of the highest rates of workforce injury.
- › The direct support workforce has few opportunities for training and professional development. Training requirements that do exist in states are not comprehensive nor do they ensure that direct support staff are trained to meet the needs of the people they support. This has resulted in diminished quality and a caretaking model of service instead of one that creates high expectations of people with IDD and supports them in learning, growing, and developing new skills for community living and work.

### **Position**

Everyone with an intellectual or developmental disability deserves to live in the community where they have the opportunity to experience vibrant lives that include work, friends, family, and high expectations for community contributions. Our systems to support people with IDD should promote individual growth and development through the provision of best practices in fully integrated community settings. It is essential to close institutions and at the same time create and support our existing communities to develop the

capacity to support all people with IDD in their communities through individualized supports that:

- › Ensure federal, state, and local governments have an infrastructure in every existing community that results in people with IDD getting the support they need to live and work in their communities. This infrastructure should also focus on the need for community intervention and strongly encourage communities to take responsibility for full inclusion of people with IDD in all aspects of community life.
- › Ensure a skilled, stable, and fairly compensated workforce that adheres to high ethical standards to support people to live self-determined lives in the community.
- › Promote public policy that provides incentives for states and local communities to expand access to individualized community living and employment. This funding should be spent on integrated inclusive community services and incentives provided to states and local governments to move away from segregated programs such as day programs, sheltered workshops, and congregate living.
- › Expand the availability and use of technology by people with IDD to further promote community living and employment.
- › Expand opportunities for self-directed funding and services that put the individual with IDD in control of designing, implementing, and monitoring their services and supports.
- › Ensure there is an infrastructure and capacity in existing communities designed specifically to meet the support needs of people with complex health and behavioral challenges.
- › Ensure community living supports are adequately funded and are of high quality.



**Lessons Learned in Person-Centered Support: Holding True to Our Mission at Community Vision**

*by Joe Wykowski*

In 1989, I had the fortunate opportunity to meet the Bos Family. Their son, Donald, requested to move home from Fairview Training Center, the state institution in Salem, Oregon. Donald, who experienced a rare neurological disease and would only live into his early twenties, wanted to live the last few years of his life with his family in the community and neighborhood where he grew up.

From this challenging but successful individual support adventure our agency, Community Vision, was born. It has now been almost 27 years and the lessons we have learned from the Bos family still ring true today in terms of the vision and mission of our organization we adopt on behalf of each person we support. Over the years, we have learned that person-centered practices are the only way to support one person at a time and to truly assist people to find connection to one’s community. We have learned that perseverance and the ability to back up and reconfigure supports are key to assisting people to create lives they desire on their terms. We have also found that the term “independence,” which is so loosely thrown about in the culture of disability, is a myth. Sure, we all yearn to make choices and assert control in our daily lives, yet we need to be engaged with others in community as we depend upon each other to thrive and survive. This has become increasingly true during a time when as a society we have tended to move away from each other and our neighborhoods.

Today, Community Vision supports over 70 individuals to live in the communities of their choice. Many of the people we support came to us with challenging backgrounds due more to where they lived than the disability they experienced. The segregated programs, institutions, nursing homes and group homes they previously experienced did not promote personal growth, and in many ways contributed to each person’s personal struggles.

Community Vision also assists with individualized employment and for the last 15 years has facilitated the creation of an asset arm of the organization called Portland

Community Asset Builders, which promotes home ownership, individual savings accounts or IDAs and accessibility and technology loans. All of the asset programs are cross-disability, which has given us the opportunity to meet a variety of new people experiencing disabilities and to grow and learn from them as they work on asset creation.

Everything we do in terms of supporting people to live full lives is attentive and respectful while being individually focused and person-centered. This simply means individuals and families tell us how they want to move forward with their personal journey of supports, and we listen, and we plan and revise as needed. We have learned over time that everything in life changes and this is true for the people we support. We have accepted that change is part of life. So, we have never said here is your house or apartment, your job, and expected that individuals would stay in the same place or with the same employment forever. We don’t think of ourselves as providing a program – it’s about supporting an individual to live their life. For those that choose to stay in one place and anchor to one’s community, fantastic; that is what life can develop into with the right connection and support. Too often in traditional programs we have found that individuals are offered limited choices and control; it takes time to find your place and your community. Given true choices, people have chosen to move to different parts of the city, to become home owners, and to request new employment opportunities and different types of supports as they grow and change over time.

The backbone of our person-centered support approach is that we assure individuals hold the cards to the big ticket items or choices. They decide who is the boss in hiring and firing their personal assistants. They decide who controls the budget. They determine where they’ll live and work. And we continue to focus on how people can connect with others in the community to enrich their lives through non-paid relationships. No one creates a community by simply renting an apartment or buying a home. It takes concentrated effort

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around connecting and building community over time. How we assist people to connect to the greater community is paramount in terms of each person's happiness. Recently, this work is taking on new focus for us as we have matured into a larger agency. Growing in terms of the number of people we assist has been the biggest challenge in terms of assuring we stay true to our original mission and vision.

As in all of our work we have found it is important to back up periodically and take a look at how things are working. Reflecting backward has led us to hire a person who is leading the process to help individuals connect with their various communities and neighborhoods. Although we have had general success with this over the years, we can lose our focus in relation to assisting people to create a more

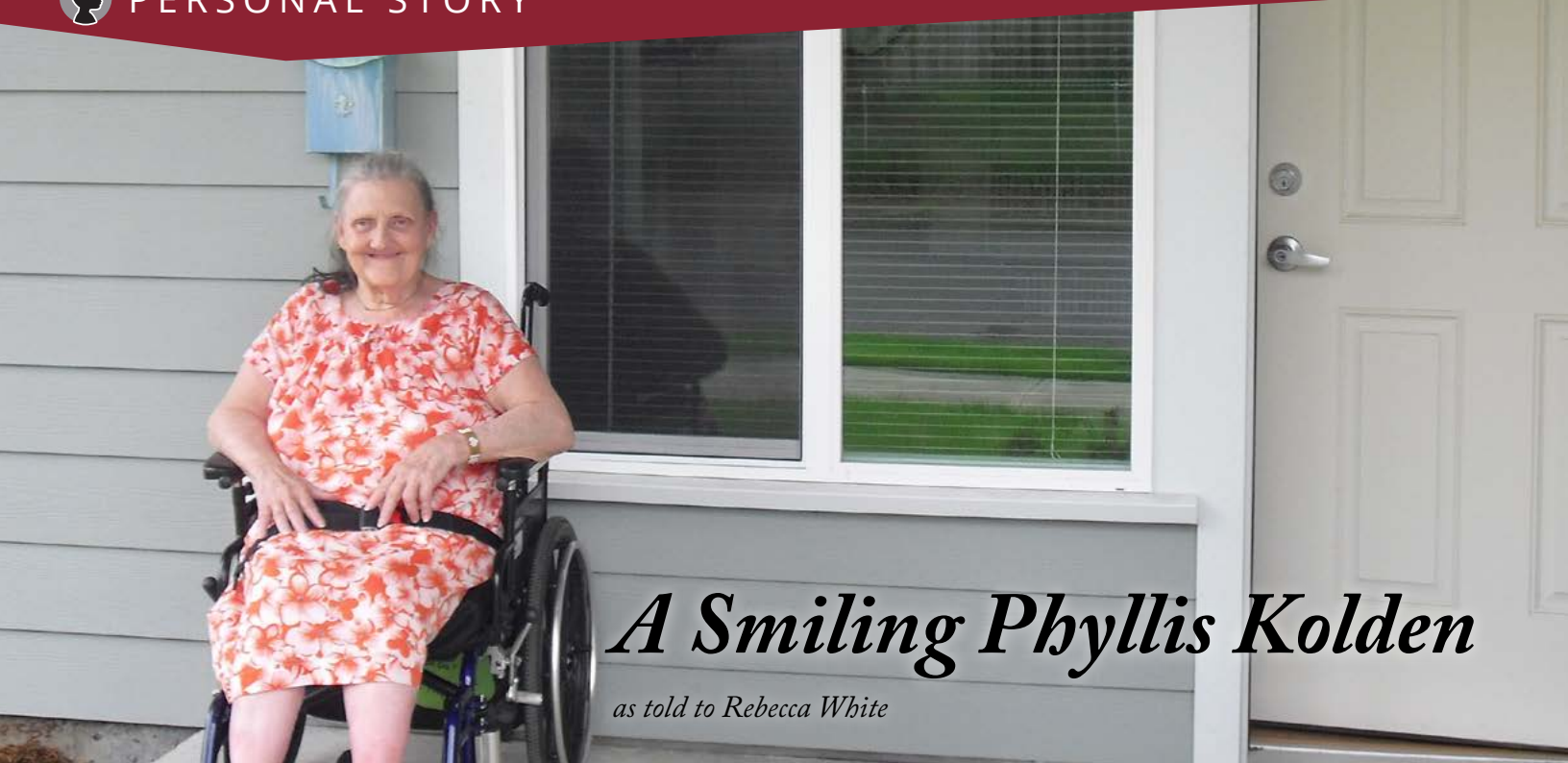
connected life. Rather than being satisfied knowing many people have full lives, we have backed up to focus on the additional people who may want to create better connections within their neighborhood, and to find the places that can happen for each person in and around Portland.

To make this process flourish, we have reviewed our work in supporting people

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## PERSONAL STORY



# *A Smiling Phyllis Kolden*

*as told to Rebecca White*

*Phyllis Kolden smiles as she sits on the porch of her home enjoying the cool breeze on a bright sunny June day while two men from the Community Energy Projects Program of Multnomah County are helping with weatherization needs at her Portland, Oregon home. I ask Phyllis if she could share with me about her journey in life because she is a very wise woman, age 82, who has a wonderful smile. I think we can all learn a little more about life simply by listening to Phyllis.*

**Rebecca:** Tell me about your life when you were younger.

**Phyllis:** My life as a child was very difficult. I had nine brothers and sisters while living in Minnesota with my mother and father. It would snow quite a bit in

Minnesota and it was very cold there, and the summers were very hot. *[She looks down].* My father left when I was very young and my mother struggled to raise me and my brothers and sisters. I don't remember how or when I arrived in Oregon, but I remember that I came here as a young girl. I was a very brave young girl. I used crutches and was diagnosed with cerebral palsy, and when I arrived in Oregon I was placed by my mother into a large institution for disabled individuals not far from Portland.

**Rebecca:** What was the name of that place?

**Phyllis:** *[She shrugs her shoulders and looks down].* I'm glad that I don't live there anymore.

*[Phyllis looks very sad talking about the years that she spent locked up in that large institutionalized facility, which she left as a young woman].*

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to find employment. Our person-centered planning process, listening to where people really want to work, has led to many wonderful community jobs. We tend to look for businesses that create an environment that is social and supports people connecting beyond employment. We are reviewing the success of that process to help us think about building community in neighborhoods. Therefore, this is where we are

starting as we look to assist individuals living in their own homes to move forward. With each person's permission, the process has started with mapping the communities where people currently spend their time and looking at the places they would want to increase their community connections.

All of the above-mentioned support strategies and value-based tenants of

our work are inherent to providing good person-centered supports. As we continue to grow and mature as a support agency working on behalf of people experiencing disabilities, we understand we must hold true to the original mission and the lessons we first learned in the early years supporting one family, one person at a time, as our vision continues and evolves today.

**Rebecca:** Tell me more about your life in Portland.

**Phyllis:** I married a wonderful man by the name of Carl, then adopted my daughter Pammie, who also has a disability. After I met Carl I began attending Saint Ignatius Church and have attended for over 30 years. I love going to church. My life changed when Carl passed away. I was alone. After Carl died, I was really alone and I was taking care of my daughter Pammie. I felt scared and alone.

**Rebecca:** How did you come to own your own home?

**Phyllis:** I don't know, but I sure like living here, honey. I hope I don't ever have to move. *[She laughs, and watches the men on ladders cleaning her gutters. Then she points to a tree in her yard].* That tree is new. Will it have any flowers?"

**Rebecca:** Yes, I think it will have flowers, lots of pretty flowers.

**Phyllis:** I think so too, honey. *[She smiles]*

*[Community Vision began assisting Phyllis several years ago and helped her to buy her home. She and her daughter moved into her house together, but now Pammie is living in another house nearby].*

**Rebecca:** Do you miss living with Pammie?

**Phyllis:** I miss seeing Pammie, but I'm glad she has her own life.

**Rebecca:** What are some of the favorite things you like to do?

**Phyllis:** I enjoy helping the children at My Father's House, where I volunteer on Fridays. Just one good day after another good day volunteering at My Father's House.

*[My Father's House is a homeless shelter in Gresham, and she assists parents with children. One morning while Phyllis*

*was volunteering at MFH, a timid little boy crawled up into her lap while she was sitting in her wheelchair. Phyllis hummed and sang to the small 4-year-old while hugging him, until he fell soundly asleep in her arms, and stayed asleep in her arms until his mother arrived to pick him up].*

I enjoy visiting the East Portland Community Center in Portland with Meals on Wheels. I like playing Bingo with my friends on Wednesday mornings, and having lunch at Applebee's and IHOP, and shopping.

*[Recently, Phyllis signed up to be an Ambassador with the Oregon Food Bank, which involves traveling to some nearby schools educating students about the programs offered through the Oregon Food Bank and also fundraising events. Phyllis is very active...it is very common for her to ask, "Honey, where are we going today?"]*

**Rebecca:** What is your favorite activity?

**Phyllis:** Going to church, dear.

*[Phyllis attends church three or four times a week. On Wednesday nights, she attends a church in Gresham, having dinner and singing worship songs with other members. She has been attending the Wednesday night service for about three years and has made many new friends.]*

**Rebecca:** Is there anything you can share about your life as "wisdom" to anyone else?

**Phyllis:** I have a lot of faith in God. *[She smiles].*

*As a support facilitator for Phyllis it's nice having the chance to see her friends approach her in the community to hug her and say nice words. She simply lights up with a smile and warm hug for them. She calls anyone and everyone "honey." Yes, anyone who has had the opportunity to have any contact with Phyllis is encouraged by her good nature, faith, and wonderful smile. Funny how we soon forget about the fact that she is 82 because she is a delightful-spirited woman on the go with good things to do with her life.*



# Applied Behavior Analysis: A Tool to Support Individuals with Intellectual and Developmental Disabilities

by Quannah Parker-McGowan  
and Joe Reichle

**Person-centered positive supports** relies on evidence-based practices that are person-centered, promote quality of life, and prevent the use of aversive procedures for children, youth, and adults. This description is consistent with the objectives associated with both applied behavior analysis (ABA) and positive behavior support (PBS). In this article we will provide a brief overview of applied behavior analysis and its relationship to the origin of positive behavior support and person-centered planning (PCP) (see Figure 1).

## What is Applied Behavior Analysis (ABA)?

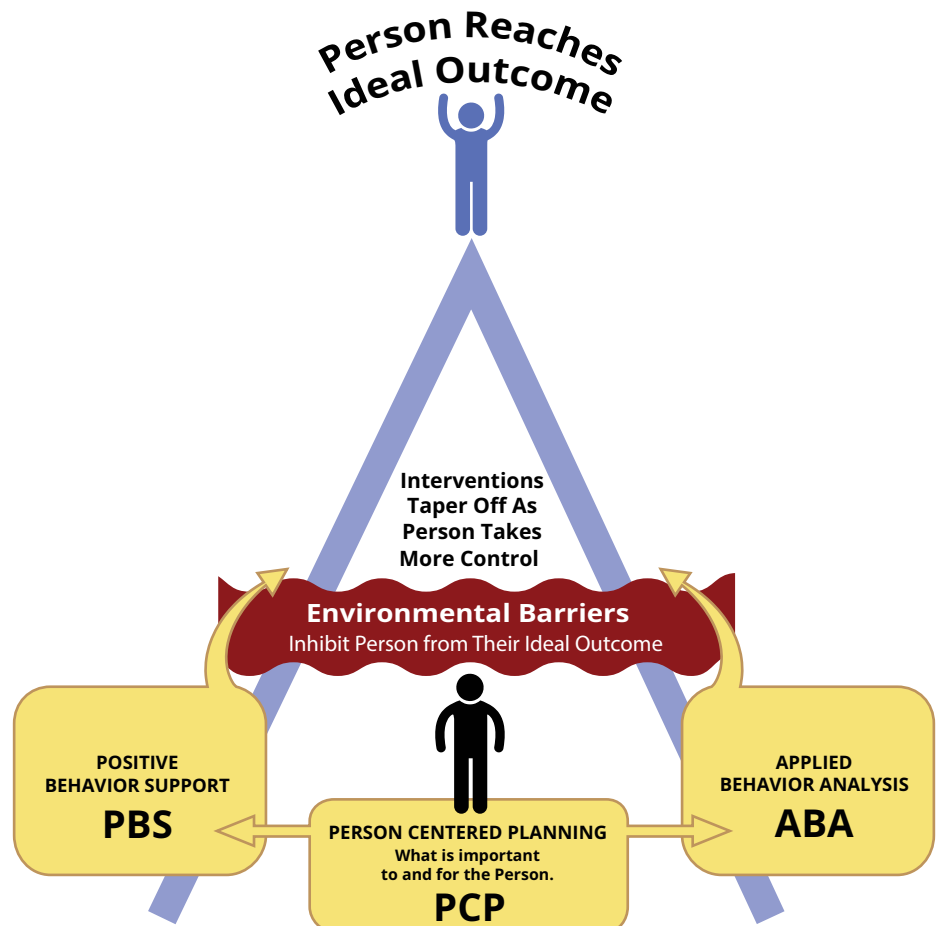
The best definition of ABA was written by the founders of the journal bearing the name of this area of study in an article written by Baer, Wolf and Risley (1968).

In it they state that applied behavior analysis:

...is the process of applying sometimes tentative principles of behavior to the improvement of specific behaviors, and simultaneously evaluating whether or not any changes noted are indeed attributable to the process of application – and if so, to what parts of that process. In short, analytic behavioral application is a self-examining, self-evaluating, discovery-oriented research procedure for studying behavior. (p.91).

The foundations of applied behavior analysis were described by Baer, Wolf, and Risley (1968). They proposed seven criteria that should be included in ABA research when considering procedures for addressing behavior(s) that may be challenging in

**Figure 1: The Relationships Between ABA, PBS, and PCP**



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nature. These criteria indicate that behavioral interventions should:

- › Be socially significant (i.e. applied).
- › Indicate a behavior is in need of improvement.
- › Be clearly defined.
- › Reflect a relationship between the behavior and the environment.
- › Permit a demonstration of relationships that are reflective of basic principles of behavior.
- › Be implemented with behavior that can be effectively changed.
- › Result in lasting change that occurs across a range of environments.

Person-centered planning complements PBS because it helps create a person-centered environment in which socially significant behavioral interventions will be successful. Applied behavior analysis principles can be used within PCP to support goals related to independence, communication, and building relationships. It is important to acknowledge from the outset that there are a number of variables involved in positive supports. Some of those involve internal variables within the individual and it is important to note that not all of the components of support are easily defined. We embrace eclectic approaches to positive support that are evidence-based and further propose that it does often require a “village” of support components for many individuals with challenges that require a plan of positive supports.

## The Role of Applied Behavior Analysis in Positive Support

Applied behavior analysis has had a significant impact on society and many individuals are familiar with at least some of the common terms and concepts. With this familiarity, however, there have also been misunderstandings and reactions both in support of and against ABA.

The idea that behavior can be shaped and changed, for some, is equated with control. Embracing ABA does not automatically mean that control is the only way of understanding behavior. Instead, ABA is one tool set that can assist in explaining why we behave the way that we do in certain situations. Some feel that ABA is just a cookbook used to govern behavior. On the contrary, ABA emphasizes the importance of understanding environmental variables unique to an individual and understanding the function of the behavior that is unique to the individual. Unfortunately, some interventions from ABA's early history have resulted in a view of ABA as an intrusive approach. While this is true to some degree, the trend by practitioners and researchers in ABA has been to minimize intrusive prompts; when they are used they are faded as quickly as possible.

PERSON-CENTERED PLANNING SHOULD BE IMPLEMENTED PRIOR TO PBS BECAUSE IT HELPS CREATE A PERSON-CENTERED ENVIRONMENT IN WHICH SOCIALLY SIGNIFICANT BEHAVIORAL INTERVENTIONS WILL BE SUCCESSFUL. APPLIED BEHAVIOR ANALYSIS PRINCIPLES CAN BE USED WITHIN PCP TO SUPPORT GOALS RELATED TO INDEPENDENCE, COMMUNICATION, AND BUILDING RELATIONSHIPS.

Positively speaking, ABA has been associated with fundamental changes in how we view behaviors in a variety of settings and across a variety of behaviors with respect to persons who engage in problem behavior. For example, the principles of ABA form the basis for a number of preventative and proactive strategies aimed at facilitating a balance between empowering individuals to more clearly communicate their wants and needs (Wacker & Reichle, 2016) as well as facilitating improved self-regulatory skills (Reichle & Wacker, 2016). When implemented in combination, these supports have enhanced the contributions to society made by individuals with a propensity to engage in problem behavior.

Professionals implementing ABA now consider the increase in quality of life and

socially important outcomes (social validity) a necessary part of behavioral support. Additionally, they are respectful of the values and experience of people who provide support for persons with disabilities. This focus on individual preferences and goals is often referred to as *contextual fit*, a component of social validity. Lucyshyn (2005) defined contextual fit as, “The extent to which the elements of a behavior support plan are consistent with the values, skills, resources, and administrative support of those individuals who must implement the plan” (p.1). Wolf (1978) first described the importance of evaluating the significance of the goals of an intervention program, the appropriateness of the program's procedures. Schwartz and Baer (1991) refined the concept of social validity to include a summative intervention satisfaction measure and the *feasibility of carrying out the treatment*. The authors also concluded that contextual fit is an important aspect of social validity.

Principles and practices associated with ABA were the driving force in the development of PBS. For example, conducting a functional behavioral assessment (FBA), a common tool

used in schools and in clinical settings, has been driven largely by ABA research (Reichle & Wacker, 1993; Scott et al., 2005; Shriver, Anderson, & Proctor, 2001). An FBA provides specific strategies used to gather and analyze information about how certain environmental variables influence behavior. It also focuses on observational strategies, which generate information about the way the individual reacts to environmental variables and the way that we, in turn, react to the individual. The results of an FBA shed light on a number of reasons why a person may engage in problem behavior (e.g., the function of the problem behavior) and allow a precise matching of support strategies to an individual's interests and needs. Together, they better inform how to assist in improving a person's quality of life.

The basic principles of ABA are easily linked to principles associated with PBS and PCP. All of these areas focus on identifying socially important supports (which can involve individual and/or social partner behavior) that will result in fostering a range of behaviors that can be well maintained and generalized. This is also an important outcome associated with PCP and PBS activities. Identifying the function of a problem behavior, linking results of that assessment to positive support strategies, and evaluating the effects of those support strategies for persons are all important components of PCP and PBS. Many tools useful in the evaluation of PCP and PBS outcomes were developed via ABA research.

There are several underlying values that are critical to ABA, PBS and PCP. These include that:

- › The focus person and family members' views are critical for successful planning.
- › The processes used to derive support plans are collaborative and dynamic.
- › There is a commitment of all team members to the process.
- › The major focus of the planning process is to increase quality of life for the focus person by developing his or her relationships and strengths.
- › A balance of supporting what is important *to* people and what is important *for* people is critical.

## The Role of ABA in Person-Centered Planning and Mental Health

Similar to ABA and PBS, the ultimate goal of person-centered planning is to help the person live a meaningful life in which the person serves as a valued member of both community and society, facilitated by enhanced support and community participation. The PCP process focuses on an individual person's desires and aspirations. It engages the person and other stakeholders, such as the person's family and treatment professionals, in the ongoing task of designing strategies that support what the person needs in order to live a preferred life with

hope for a desirable future. Just as with ABA and PBS, PCP is fluid, responsive, and ongoing.

PCP processes are designed to discover and organize information that offers support to the development of a positive behavior support plan. As mentioned previously, ABA, PCP and PBS put the individual at the center of the process and all supports are designed with this in mind. There is a focus on the individual and creating supports to meet their unique needs rather than fitting an individual into existing programs and services.

## Future of ABA

Among a large array of areas of growth for ABA is the area of *setting events* as they relate to many populations that include aged people as well as people with mental health issues. Bambara and Kern (2005) defined setting events as a physiological, cognitive/emotional, social, or environmental condition, past or present, that heightens the relevancy of an antecedent event that is associated with problem behavior. Better understanding and identifying of setting events, especially physiological and cognitive/emotional, may help to better inform mental health treatment. For example, the tone of voice that one uses in speaking may act as a trigger for problem behavior for a particular person. Altering one's tone may have a significant impact on the propensity for problem behavior to be emitted. Similarly, not having a first cup of coffee in the morning may make an individual much more likely to become annoyed with a peer. Both of these can be remedied by altering events external to the person who is the focus of a support plan.

It is important to remember that the principles of ABA focus on increasing an individual's ability to participate meaningfully in their community by:

- › Reducing barriers.
- › Teaching self-regulatory skills.
- › Enhancing communicative as well as other self-advocacy skills.
- › Increasing their overall quality of life.

## Summary

Applied behavior analysis, positive behavioral support, and person-centered planning share common goals of:

- › Increasing the focus person's involvement and participation in the community.
- › Creating, developing and enhancing meaningful relationships between the focus person and others.
- › Expanding the opportunity for the person to express and make choices.
- › Creating a dignified life and relationships based on mutual respect and need.
- › Developing skills and areas of expertise for team members and the focus person that lead to improved quality of life.

Looking forward, PBS and PCP may become better blended. When this occurs it will greatly enhance our support capability with a wide range of persons who currently require a significant improvement in the quality of their lives.

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# 10

## Ways to Respond to Meaning-full Behavior

by David Pitonyak

**What follows are** 10 things you can do to support a person with intellectual or developmental disabilities whose behavior is troubling you. It is not a list of “quick fix” strategies for stopping unwanted behavior. It is a list of ideas for uncovering the real things that a person might need so that you can be more supportive.

### 1 Get to know the person.

The first step almost seems too obvious to state: *Get to know the person!* It is too often the case that people who develop interventions do not know the person in any meaningful sense. They know the person as the sum total of his or her labels, but know little about the person as a “whole” human being.

Make a point of spending time with the person in places that he or she enjoys, during times of the day that he or she chooses. At a time that feels right (you will have to trust your intuition on this one), tell the person about your concerns and

ask for permission to help (it’s rude not to). If the person has no formal means of communication, *ask anyway*. Sometimes people understand what is being said, but they have a difficult time letting others know that they understand.

### 2 Remember that all behavior is meaning-full.

Difficult behaviors are “messages” which can tell us important things about a person and the quality of his or her life. In the most basic terms: *Difficult behaviors result from unmet needs*. The very presence of a difficult behavior can be a signal that something important that the person needs is missing (*see chart below*).

Obviously there are many needs that a person may be conveying with behaviors. A single behavior can “mean” many things. The important point is that difficult behaviors do not occur without reason. All behavior, even if it is self-destructive, is “meaning-*full*.”

### Here are some examples of the kinds of messages a person may be conveying with his or her behavior:

<b>I’m lonely.</b>	Michael’s brother was invited to a friend’s house for a sleep over. Michael is never invited to the homes of children because he goes to a “special” school 35 miles from his neighborhood. Michael has no friends to play with.
<b>I’m bored.</b>	Roberta works at a sheltered workshop where she packages plastic forks and knives all day. Roberta is bored and she wants a real job. Her case manager says she “daydreams too much.”
<b>I have no power.</b>	John’s mother is bossy and he sometimes sits down on the grocery store floor to let her know he is angry and fed up.
<b>I don’t feel safe.</b>	Conrad often refuses to use the restroom. He was attacked in a restroom when he was younger and he is afraid.
<b>You don’t value me.</b>	Gloria has a reputation for engaging in troubling behaviors, but few know that she is an avid supporter of environmental issues and a loving aunt. Gloria resents the way others see her.
<b>I don’t know how to tell you what I need.</b>	June is not able to use words or signs to communicate. What “works” in the institution that she lives in is to bite her arms when she needs something different to happen.
<b>I don’t feel well.</b>	Walter hits his ears with his fists. He has chronic ear infections but it is assumed he hits his ears to “get attention.” What he needs is a doctor’s attention.

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A longer version of this article is available on his Web site, in English and Spanish, at [www.dimage.com/10things.pdf](http://www.dimage.com/10things.pdf) and [www.dimage.com/10ThingsSpanish.pdf](http://www.dimage.com/10ThingsSpanish.pdf).



### 3 Help the person to develop a support plan.

Instead of a behavior plan to “fix” the person, help the person to develop a support plan that reflects a real and authentic life. John and Connie Lyle O’Brien (1987) suggest the following questions for building a support plan:

- How can we help the person to achieve health and wellbeing?
- How can we help the person to broaden and deepen his or her relationships?
- How can we help the person to increase his or her presence and participation in everyday community life?
- How can we help the person to have more choices in life?
- How can we help the person to learn skills that enhance his or her participation in community life?
- How can we help the person to make a contribution to others?

### 4 Develop a support plan with and for the person’s supporters.

Take time with your colleagues to develop support plans for each other. For example, what can you do to increase each other’s level of safety and comfort when someone is behaving dangerously? What can you do to have more fun at work? How can you have more control over your schedule and input into decisions? How can managers better support you?

### 5 Don’t assume anything.

It is easy to make the mistake of underestimating a person’s potential because of her labels or because he has failed to acquire certain skills. This is a tragic mistake. Start with the assumption that the person can understand you. You will be right more often than you think.

### 6 Help the person to develop positive and enduring relationships.

Ours is a social brain. We are hardwired to belong. Sadly, many people with intellectual and developmental disabilities live lives of extraordinary isolation. In my experience, it is not a person’s experience with disability that is at the root of his or her suffering, but rather the isolation that often results from that experience. If you want to help people, help them to form positive and enduring relationships.

### 7 Help the person to make a contribution to their community.

A powerful strategy for helping people to form positive and enduring relationships is to help them find a way to make contributions to others. Remember, it is important to overcome the belief that the person has nothing to share. It takes time and determination to help the person and others to see strength and the capacity to give when deficits were all that anyone ever saw before.

### 8 Instead of ultimatums, give choices.

Choice is a powerful alternative to punishment. If the person’s behavior challenges you, help find more desirable ways to express the needs underlying the behaviors. Instead of ultimatums, give choices (e.g., “Bill, I know you’re upset. What would help? Would you like to go for a walk? or take a ride? You need a chance to calm down.”)

Help the person to make choices all day and make sure there are always desirable outcomes to choose from. Norman Kunc has said that:

**1 option = tyranny,  
2 options = a dilemma, and  
3 or more options = a real choice.**

### 9 Help the person to have more fun.

Fun is a powerful antidote to problem behaviors. People with intellectual and developmental disabilities often live lives devoid of joy. Many must endure reward schedules for “good behavior.” Help the person to add to his or her list of interesting (and really fun) things to do. Spend time in regular community places where people hang out. Make joy the goal.

### 10 Establish a good working relationship with the person’s primary health care physician.

Many people who exhibit difficult behaviors do so because they don’t feel well. The sudden appearance of behavior problems may be a signal that the person does not feel well. Illnesses as common as a cold or ear ache can result in behaviors as inconsequential as grumpiness or as serious as head banging. Help the person to achieve a sense of wellness through healthy habits and regular visits to medical professionals who understand the issues of disability.

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*“When surrounded by walls, people make wall climbing a sport.”*

—BRENTRO, BROKENLEG, AND VAN BOCKERN, 2002, P. 18



## Building Support That Creates Community: *Person-centered Supports in New Mexico*

*by Jason Buckles and Chris Heimerl*

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**The New Mexico** Developmental Disabilities Supports Division (DDSD) authorizes a community-based system for people with intellectual and/or developmental disability (IDD). Central to these endeavors are individualized, person-centered supports adhering to the principles of positive approaches and positive behavior support. In this article, we describe some of the foundational principles, scope of training, and lessons learned through challenges.

### Guiding Principles and Values

We strive to build support that creates community rather than chaos or control. Six factors essential in our process are presented below.

#### **Factor One: Our guiding task must be to help individuals build a life rather than be their life.**

At its root, the practice of person-centered supports stems from the individual’s desired lifestyle – not our own. We focus on their preferences and teach skills necessary to pursue their desired ends. The guiding beacon must come from the person’s perspective. Lovett (1996) reminded, “As long as a group feels it is responsible for another group rather than responsible to them, its peace of mind necessarily depends on the passivity of the controlled people.” A primary goal of our system is to encourage individuals to become active agents of change in their own lives rather than passive recipients of prescribed care.

#### **Factor Two: If you want to change someone else’s behavior, change your own first.**

Too often we keep trying the same or similar interventions, with an exclusive behavioral focus absent enduring impact, and expect a different result. Instead of getting creative, we get louder. A well-crafted support plan highlights

strategies aimed at guiding team engagement with, and reactions to, the individual. At times the “disability” does not reside in the individual so labeled, but in the deficits of the environment and skills of the people around them. Our practice of person-centered supports is grounded in a notion of life-long education for *all* members of the system. To these ends, we remain focused on guiding the team toward understanding possible contributing factors (e.g., genetic predisposition, developmental and physiological compromises, residual impact of abuse and trauma, co-occurring psychiatric conditions, communicative intent, and environmental stress) with a primary goal of adjusting our own understanding and reactions to meet the person’s needs rather than our own goals.

#### **Factor Three: Everyone (including you) is doing the best they can with the tools they have. If they could do better, they would.**

From a person-centered perspective, we believe the work is about helping individuals gain and learn to use new tools. Almost all individual events that challenge our system are efforts toward communication and self-agency. We must determine what a person is trying to communicate, express our interest in “hearing” the message, honor the need behind it (when possible), and then move on to teach new ways of asking/communicating. As challenges are encountered, risk and mistakes are cornerstones of learning. When a person stumbles, the task is to help them up, look back at where the error was made, and look forward to the next opportunity to improve. Interventions based in education, rather than control, are what we all prefer in our own lives.

#### **Factor Four: Proposed interventions should be something you would accept in your own life.**

The connection between stress and behavioral challenges is clear – the more stress an individual encounters, the more times he or she will end up apologizing for missteps in trying to lessen the burdens of daily life. Think about the last time you

acted in a way for which you later had to apologize, felt badly about, or would be embarrassed to share. From the perspective of person-centered supports we would assume that you were doing the best you could with the tools you have and the stress you were under. Now consider how you might respond if the mandated intervention from those around you included removal of important items or activities. What do you need and want when you are distressed? What would this type of intervention do to your stress level? Might you “have another behavior”? Person-centered support is not just for people with IDD – it applies to all of us. Take a step back; ask yourself how *you* might respond if under the gaze of an ever-increasing hierarchy of staff, managers, coordinators, teams, guardians, and courts. It is amazing we do not encounter more behavioral challenges.

### **Factor Five: Punishment comes with a series of side effects. It can almost always be avoided.**

Consider this: When we “take control” of a situation, the person at the center of this interaction is automatically “not in control.” Therefore, we should not be surprised when these types of interventions end up with people acting “out of control.” Further, what skills does a person learn from punishment? Anxiety-based compliance is no way to help a person build a life. The problem here is that people with IDD are, by virtue of the diagnostic label and position in the system, at risk of being overtly controlled and covertly “managed” with little access to recourse. Individuals’ attempts to “get around” aversive programs are often framed as “manipulative” and “non-compliant” rather than sometimes reasonable, adaptive expressions of distaste for a situation that any of us might find paternalistic and offensive. Instead of thinking about what we want *less* of, think about what skills we can *increase* to take the place of the “problem.”

### **Factor Six: Over time, successful programs seek balance between, and benefit for, everyone involved, especially Direct Support Professionals (DSP).**

As described above, our approach to person-centered support insists that we

are vigilant in maintaining a respectful focus on individual interests, preferences, and desires. Beyond this foundational core we hold that an essential aspect of our approach to person-centered support is that *all* parties experience their working relationship as safe, fun, and nurturing. Indeed, the most powerful and inspiring outcomes we witness arise when DSPs have a place and a voice at the planning table and when the same regard is extended toward them as they are expected to extend to those they support.

## **Approaches to Training**

As part of our proactive efforts towards creation of a sustainable and consistent system of person-centered supports DDSD and the Bureau of Behavioral Support (BBS) offer a litany of required and optional trainings that cover a wide range of applied practice and larger philosophical frameworks. Initial mandated trainings include, but are not limited to, *Person-Centered Planning; Teaching and Support Strategies; Advocacy Strategies; Participatory Communication and Choice Making; and Promoting Effective Teamwork*. Further, BBS offers a range of trainings focused on behavioral practice and mental health aspects. These include, but are not limited to, *Foundations of Positive Behavior Support and Positive Approaches; Dignity of Risk and Duty of Care; Co-Occurring Mental Health Conditions in People with ID; Healthy Sexuality; Human Rights Committee Guidelines; and Trauma Informed Care*. In addition, we engage in tailored technical support and training at the levels of individual planning, specific site concerns, and/or provider agency.

Overall, we have found that these curricula help to prepare individuals at all levels of the system to focus their efforts toward support and guidance rather than management and control.

## **Lessons Learned**

For the last 10+ years BBS has systematically examined indicators that are the most potent contributors to a person’s perceived quality of life. We also find a compelling correlation between these indicators and authentic behavioral change. There are five indicators.

First, the most powerful agent for positive outcomes firmly resides in the duration and nature of the person’s relationships with family, support staff, peers, housemates and members of the community. When work life becomes life’s work, and “we and them” becomes life sharing, extraordinary possibilities emerge.

Second, the entire support team has an organized and focused plan for maintaining, enhancing, or building essential skills. We observe enhanced social capacity and functional communication skills as essential for most individuals.

Third, assisting with opportunities for community and social integration must be approached at a pace and scope determined by the individual. We observe a broad spectrum of preferred lifestyles from quiet, contained, predictable routines to wildly, apparently chaotic, variety. We endeavor to understand, appreciate, and honor each person’s preference.

Fourth, we hold an ecological perspective on why people feel and act the ways they do as opposed to directly “treating” behavior. What unmet need or desire drives behavior is a constant inquiry. However, we recognize that DSPs will confront distressing, at times violent, events while providing support. We also provide specific guidance addressing proactive/prevention considerations; direct intervention that emphasizes attending to the person’s distress and safety for all; strategies for restoring stability and returning to desired activities; and in fractional circumstances, assuming a “management” posture for brief periods of time.

Finally, we continually assert the critical contribution that each team member is capable of making. We actively teach DSPs how to organize and communicate what they know, often intuitively, about the individuals they support. Each of us is “expert” in our version of the person’s story. We encourage many authors to draft the next chapter.

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## Seven Years, Seven Words: Finding My Life's Work

by Caroline Chavez as told to Chris Heimerl

*Caroline Chavez has over seven years of experience in a supported living agency, starting as a direct care provider, then becoming house manager, and lastly program manager. Now working for the New Mexico Developmental Disabilities Supports Division, she reflects back on her direct care experience and shares her thoughts about how her view of support, and of her job, changed over time.*

I came into the field with no prior experience and didn't really know what I was getting into. I began working overnight and had little contact with the guys living in the home. It was "just a job." Then I switched to days and everything changed. I began to see the difference I could make in their lives and also began to recognize that I was changing, too. I wasn't satisfied with the behavior programs that sought to shape the guys into compliance. What I saw was unnecessary punishment that made things worse, made their lives miserable and compelled me to do things I wouldn't allow in my life. "Punishment," "consequences," and "solitude" are the terms I was taught. I remember many instances when our intervention actually escalated minor events into full blown crises, all to "teach the person a lesson."

I gradually began changing the way I thought about the guys and how I believed we should design support. I asked for help from more experienced people in the field who were talking about this person-

centered, positive approaches stuff that fit with how I was evolving. We attended to the contributing stressors in the person's life and their underlying emotional upheaval rather than their behavior. As we adjusted our expectations and behavior toward giving the guys a life and control over their lives, remarkable change began to take place. Eventually, I was offered the opportunity to train and mentor staff toward these practices. Staff began to shift away from discipline, control, and management toward nurturing support.

I have found that most DSPs are able to make this necessary shift. We have been successful in helping some transition from working in prison and institutional settings to being compassionate DSPs in the community. I find that genuinely promoting the voice of DSPs in planning processes, formal and informal recognition of their efforts and outcomes, demonstrations of appreciation, and encouraging them to draw from their personal experiences all contribute to their fully adopting the practices I believe in.

To me direct care is now an investment, not a job. One of the



*Caroline Chavez began direct support work in settings emphasizing control and compliance. Today, she helps support services take a nurturing approach instead.*

guys never addressed staff by name, ever. He simply saw no value in forming an attachment. I had worked for a long time to remove the intrusive, shaming aspects of his plan, often by simply asking him how he would like to be treated. I let him define what support and assistance looks like for him. One day, out of the blue, he addressed me by name. My stunned co-workers asked why? "She treats me like a human being." Seven words and my seven years are worth it. Seven words and I no longer have a job. I have my life's work calling.

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# Improving Quality of Life Outcomes Using a Statewide Tiered Implementation Approach: The Missouri Experience

by Teresa Rodgers, Julie LePage and Rachel Freeman

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Many state agencies supporting people with intellectual and developmental disabilities (IDD) have relied on reactive approaches to address the challenges that arise, resulting in out-of-home or institutional placements. This article describes how the Missouri Division of Developmental Disability (MO DDD) has been changing statewide policies to improve quality of life (QOL) outcomes for people with IDD by establishing positive and proactive strategies that naturally prevent challenging behavior. Two types of statewide strategies have been employed: 1) changes in policies, procedures, funding mechanisms, and evaluation systems; and 2) a three-tiered training and technical assistance infrastructure for supporting people with IDD by improving QOL and preventing challenging behavior.

## Tiered Model for Improving Quality of Life Outcomes

The statewide changes and technical assistance strategies implemented by MO DDD were based on a three-tiered model used widely in schools, public health, early childhood, juvenile justice, mental health, and other settings (Freeman et al., 2014). In this model, each prevention level increases along a continuum of intensity, with a focus on increasing QOL outcomes for people with IDD by promoting positive social interactions. These prevention levels are referred to as Primary Prevention, Secondary Prevention, and Tertiary Prevention.

### Primary Prevention in IDD Organizations

The Primary Prevention level emphasizes the importance of implementing universal interventions for improving the QOL of everyone within the organization, including staff members and the individuals they support (Putnam, George, LePage, Rodgers, & Freeman, 2014). Organizations implementing Primary Prevention strategies use a team-based approach to assess broader social policies, training, resource allocation, and environmental or service issues that impact QOL. Primary Prevention includes teaching, practicing, and

reinforcing universal social skills; creating positive and predictable home and work settings; and promoting person-centered environments that encourage meaningful participation within the community. Staff members learn to encourage people with IDD to express themselves, make choices, and engage in self-determined actions. Figure 1 shows the tiered model with examples of strategies used at each level.

THE STATEWIDE CHANGES AND TECHNICAL ASSISTANCE STRATEGIES IMPLEMENTED BY MO DDD WERE BASED ON A THREE-TIERED MODEL USED WIDELY IN SCHOOLS, PUBLIC HEALTH, EARLY CHILDHOOD, JUVENILE JUSTICE, MENTAL HEALTH, AND OTHER SETTINGS.

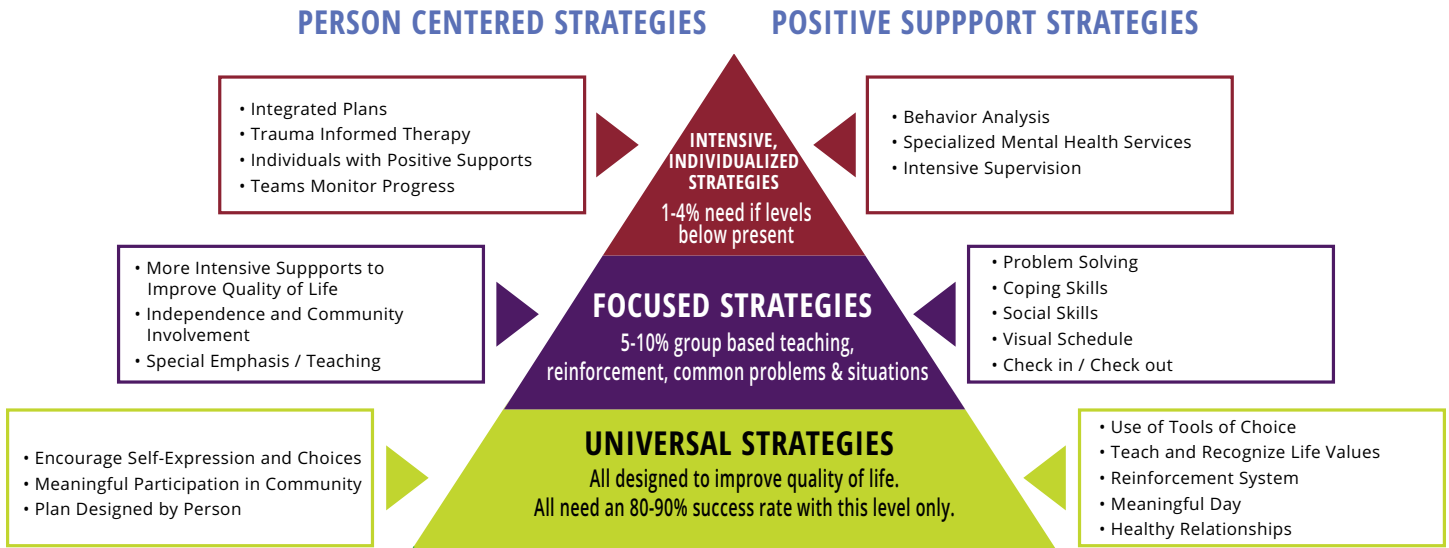
### Secondary Prevention in IDD Organizations

Interventions at the Secondary Prevention level include screening and early identification of individuals who need additional social, emotional, or communication supports, and increases in reinforcement within an environment. Group or individualized interventions are used in Secondary Prevention to support people with IDD by providing acquisition strategies for home and work-related skills, counseling and mental health services, communication and coping strategies, relationship and friendship building, and sexuality education. Simple interventions are used to address development and encouragement of new social, communication, emotional skills that will improve QOL. Data systems are utilized to monitor progress through established and regular feedback loops within an agency.

### Tertiary Prevention in IDD Organizations

The goal of Tertiary Prevention is to reduce and prevent severe and chronic challenges for a smaller number of people who may need more intensive individualized supports to help improve QOL.

**Figure 1: Implementing a Prevention-based Model in Organizations Supporting Individuals with IDD**



Individualized positive behavior support (PBS) plans are implemented at the tertiary level within the context of person-centered planning with primary and secondary prevention supports. Interventions at the tertiary level involve a more highly intensive assessment and technically complex strategies to address challenging behavior.

### Statewide Self-Assessment and Action Planning

The MO DDD team began the systems change process with a statewide self-assessment and action plan to consider the most efficient and effective ways in which to proceed with implementation efforts. Elements that were considered within the self-assessment included:

- › The types of data systems that were already in place for services.
- › The practices that were used to prevent problem behavior.
- › Policies and procedures related to behavioral services and QOL enhancement for individuals with IDD.
- › The state staffing patterns and job positions.
- › Training and technical assistance for organizations.
- › The systems that would need to be modified as part of a comprehensive statewide model for preventing challenging behavior.

At the time of the self-assessment, the Missouri state legislature had recently established a licensure mandate for the practice of applied behavior analysis (ABA), and limited this practice to licensed behavior analysts and professionals with documented experience in behavior analysis. As a result of this action, 20 Behavior Resource Team (BRT) state employees were providing the unregulated behavior therapy intervention in approximately 50% of the 11 state regions. Only one of these

staff members met the new licensure requirements, suggesting that the state team might need to utilize BRT members differently within statewide planning efforts. The self-assessment of the state's tertiary resources also indicated the state had fewer than 70 licensed behavior analysts and approximately 50% of these individuals were designated providers for the IDD system through the state's Medicaid Waivers. The lack of capacity for behavioral support services provided a greater sense of urgency on the part of

**Table 1. State Level Action Plan Elements**

<b>Data Analysis</b>	Data indicators were determined at all implementation levels including agency, regional and state. Access of information along with ongoing coaching and established feedback loops are being implemented with the intention to increase data analysis skills.
<b>Preventative Practices</b>	Emphasis at the state level has shifted from individual crisis resolution to preventative problem solving with resources allocated accordingly.
<b>Policies and Procedures</b>	Policies and procedures are being aligned including Medicaid waiver service definitions, state rules, directives and guidelines. These policies require that positive supports and least restrictive environments be used to promote individual choice.
<b>Systems Modifications</b>	Systems modifications beyond the shift of focus from individual to agency include additional regional clinical staff with the expertise to analyze data indicating high-risk situations for individuals, and facilitate regional problem-solving, preventing crisis.
<b>Training and Technical Assistance</b>	Framework for training and technical assistance is provided through regional staff trained by state-level staff to implement and coach Tiered Support efforts to fidelity.



the state team to develop and implement primary and secondary prevention strategies.

The information gathered during the self-assessment process was used to establish activities supporting five major objective areas. Table 1 summarizes each of the following areas: 1) data analysis, 2) preventative practices, 3) policies and procedures, 4) systems modifications, and 5) training and technical assistance.

### Establishing a Technical Assistance Infrastructure for Tiered Supports

The data, systems, and practices used in school-wide PBS efforts were adapted by the MO DDD team to design a technical assistance infrastructure for supporting IDD organizations. Figure 2 provides a

visual comparison of the two statewide PBS training systems.

Although the statewide planning processes used in Missouri’s PBS efforts in schools and IDD organizations include different goals, members, and data systems, both teams employ similar systems-change methods to address funding, policy, political support, infrastructure, and issues related to visibility of implementation efforts across the state. Coordinators train and support regional coaches, communicate with the statewide team, and summarize data for decision-making at the statewide level.

For evaluation purposes, the unit of analysis for school-wide PBS is at the building level while the unit of analysis for

organizations supporting people with IDD varies depending upon each organization’s characteristics. Larger organizations may be responsible for a wide range of services for people with IDD and, therefore, the organization-wide team may start implementing PBS within a specific type of service. These larger organizations begin implementation in residential settings, supported employment or with families. Gradually, PBS is expanded across of the different types of services an organization provides. Both state teams design strategies for recognizing and celebrating the exemplary work of participating organizations.

### Piloting Organization-wide Planning

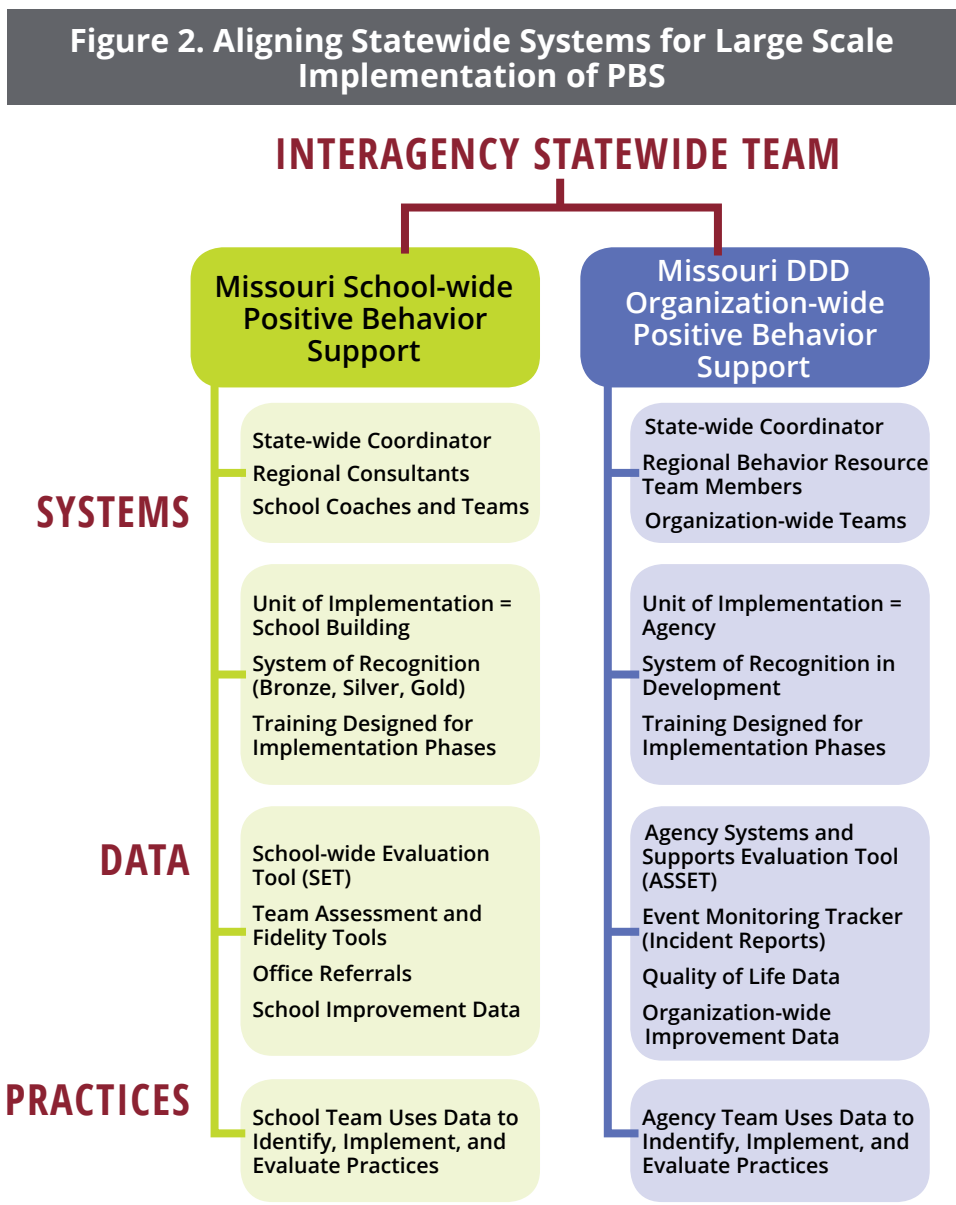
Over a two-year period, 33 organizations were recruited by the MO DDD team to participate in PBS training and technical assistance. Each organization formed a team with members who represented staff from different areas: supported employment, residential supports, management and administration, people with IDD, family, and other community members. During the first year of the pilot, teams met regularly to identify the organization’s strengths and needs and to create an action plan for implementing primary prevention.

### Regional Coaching, Training and Facilitation

Behavior Resource Team (BRT) members served as coaches for organization-wide teams on an ongoing basis as these teams implemented primary prevention. The role of the regional coach included providing ongoing technical assistance, recommending best practices, evaluating progress, and assisting teams in problem-solving during meetings throughout the year. Interventions were implemented using a consensus-based approach with the involvement of all stakeholders. Teams learned how to use data to guide action planning.

### Establishing Comprehensive Data-based Decision Making Systems

Organization-wide teams learned to use the following data for decision-making purposes:



- › Individual QOL measures.
- › Incident reports and other related documentation (e.g. use of restraints, human rights committee referrals).
- › Observations recording the ratio of positive and negative interactions occurring during specific routines.
- › Satisfaction, stress, and climate surveys.
- › Organizational data related to staff attrition, injury, sick days.
- › Overall improvements in the efficiency of staff development and performance management.

An important goal in data-based decision making was to establish a fidelity-of-implementation measure. The School-wide Evaluation Tool (SET), used to evaluate fidelity of implementation in school-wide PBS implementation efforts, served as a model as the MO DDD team developed a plan for evaluating organizations implementing primary prevention. Since initial research on the SET indicated psychometric soundness (Horner et al., 2004), the MO DDD team modified the SET for use in organization-wide implementation efforts. The modified version of the SET was then piloted with the 33 pilot organizations implementing PBS.

### Agency Systems and Supports Evaluation Tool (ASSET)

The new fidelity-of-implementation tool, referred to as the ASSET, was used in evaluating the extent to which organizations were implementing person-centered environments that promoted independence, self-determination and community inclusion. The ASSET included reviews of permanent products, onsite observations, and staff and individual consumer interviews or surveys. Regional Coaches (BRT staff members) and agency team members conducted the ASSET in order to:

- › Assess features of person-centered thinking and PBS that were in place before and after implementation.
- › Determine goals for action planning.
- › Evaluate the impact of organization-wide tiered supports.
- › View an organization's progress implementing PBS over time.

### Quality of Life (QOL) Data

The MO DDD team considered QOL to be an important outcome measure, with data collection needed across all three prevention tiers. At the primary prevention level, QOL measures were already gathered as part of individual service plan (ISP) outcomes. However, since most organizations traditionally have not used data for decision-making, the team felt

WHILE MANY STATES ALREADY IMPLEMENT SERVICES THAT ADDRESS PRIMARY AND SECONDARY PREVENTION, FEW, IN OUR EXPERIENCE, HAVE ALIGNED AND COORDINATED THESE SERVICES ALONG A CONTINUUM OF INTERVENTION INTENSITY USING EVALUATION DATA FOR PROGRESS MONITORING AND EARLY INTERVENTION TO PREVENT BEHAVIORALLY-RELATED CRISES.

that additional technical assistance would be needed to ensure organization-wide teams would be prepared to use QOL data for decision making at primary and secondary prevention levels. A task currently underway involves introducing these new primary and secondary QOL evaluation procedures into the training process.

### Event Monitoring Tracker (EMT)

The main system already used by the state of Missouri for reporting purposes is called the Event Monitoring Tracker (EMT). In the past, any EMT analysis required a tedious review process for each incident report. The new EMT system that was modified by the MO DDD team made access to data easier at the organizational level and provided graphic displays including the frequency of incidents occurring by month, types of incidents reported, day of the week the incidents occurred, and the time of day that an event occurred. Regional coaches shared the EMT data with their assigned organization-wide teams, assisted these teams in analyzing data during planning meetings, and facilitated the active use of data for evaluation purposes.

### Conclusion

It is no longer sufficient for organizations supporting people with IDD to rely exclusively on tertiary behavioral support systems. A more proactive approach is needed for improving QOL using data for both progress monitoring and early screening and intervention at local, regional, and state-wide levels. While many states already implement services that

address primary and secondary prevention, few have aligned and coordinated these services along a continuum of intervention intensity using evaluation data for progress monitoring and early intervention to prevent behaviorally-related crises. The state of Missouri has reinforced the idea that coordination of a three-tiered model of PBS can occur, not only within the IDD field, but across agencies using the data, systems, and practices.

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## A Model for Building a Statewide Infrastructure for Person-Centered Practices and Positive Supports: Minnesota's Approach

by Joe Timmons, Rachel Freeman, Mark Olson, Claire Benway, and Anab Gulaid

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In November, 2015, Federal Judge Donovan Frank approved Minnesota's Olmstead Plan. According to the Minnesota Department of Human Services (2015) the Olmstead Plan is:

*...a broad series of key activities our state must accomplish to ensure people with disabilities are living, learning, working, and enjoying life in the most integrated setting. The Plan will help achieve a better Minnesota for all Minnesotans, because it will help Minnesotans with disabilities have the opportunity, both now and in the future, to live close to their family and friends, to live more independently, to engage in productive employment, and to participate in community life.*

Collaborating state agencies are expected to build a statewide training infrastructure for implementation of the plan. This infrastructure includes tools and training opportunities for any individual or organization supporting people through Home and Community Based Services (HCBS) that are funded by the Centers for Medicare and Medicaid Services. In Minnesota Statutes, the standards for HCBS are found in what is known as "245D" (see the statute text for the standards at <https://www.revisor.mn.gov/statutes/?id=245D>).

A major part of Minnesota's Olmstead Plan includes a multi-tiered system of positive supports for children, youth, and adults with disabilities. In Minnesota, positive supports refer to all practices that include the following characteristics (Young, Anthony, Flint, & Freeman, 2016):

- Person-centered interventions that demonstrate cultural competence and respect for human dignity.
- Evidence-based or "promising" practices.
- Strategies for ongoing assessment and monitoring at individual and organizational levels.
- Approaches that are implemented in combination with more than one practice.

Positive supports are driven by the values inherent in person-centered thinking and

planning. Examples of programmatic models with all four criteria include applied behavior analysis, assertive community treatment, cognitive behavior therapy, and school-wide positive behavioral interventions and supports.

To implement positive supports systematically, state agencies in Minnesota are designing training and technical assistance

TO IMPLEMENT POSITIVE SUPPORTS SYSTEMATICALLY, STATE AGENCIES IN MINNESOTA ARE DESIGNING TRAINING AND TECHNICAL ASSISTANCE EFFORTS THAT FOCUS ON GATHERING DATA TO DRIVE THESE EVIDENCE-INFORMED PRACTICES.

efforts that focus on gathering data to drive these evidence-informed practices. The Minnesota Department of Education (MDE) has been implementing positive behavior support (referred to as school-wide PBIS) since 2004 (Fixsen, Naoom, Blase, Friedman & Wallace, 2005; Sugai et al., 2010). This article describes how the Minnesota Department of Human Services (DHS) is working with MDE to adapt this model to implement a training and technical assistance infrastructure in person-centered practices and positive supports for providers supporting people with disabilities, county systems, and mental health organizations.

### Piloting a Positive Supports Training and Technical Assistance Project

The Minnesota Department of Human Services, in partnership with the Research and Training Center on Community Living at the University of Minnesota, has launched a layered person-centered practices and positive supports training system that builds regional capacity of



human service organizations. The goal of this training and technical assistance effort is to build capacity within regions by establishing internal expertise and plans for sustainable practice over time. A variety of training strategies are used including onsite action planning, webinars, technical assistance sessions, coaching, mentoring, and other collaborative efforts.

## Person-centered Practices

Person-centered practices include a) person-centered thinking, b) organization-wide practices for promoting person-centered policies and systems change, and c) person-centered planning.

Support Development

Associates (SDA), a

specialized consultation and training organization,

has been providing training and technical assistance to the State of Minnesota in person-centered practices. Within SDA's model, *person-centered thinking* is a universal strategy taught to staff working within counties and human service organizations. This strategy begins with a shift in thinking to a focus on what is important *to* and important *for* a person. Balancing the *to* and *for* requires an understanding of what make a person happy and content with what makes them healthy and safe. This balance starts with the person being supported and not with the "system."

At the organizational level, coaches within counties and human service organizations learn to support other staff as they learn person-centered thinking and make systems changes that embed the values and vision of person-centered practices into practice. Additionally, person-centered practices call for developing or enhancing "valued social roles" (O'Brien & O'Brien, 1998) and providing more opportunities, if desired, to participate in the community. Friend, employee, neighbor, volunteer, student, spouse, parent, advocate, and voter are examples of valued social roles. *Person-centered planning* is used in individualized planning to build a partnership between the person who is supported and the people who provide support.

## Positive Behavior Support (PBS)

*Positive behavior support* (PBS) is a positive support practice that is included in the organization-wide training and technical assistance effort in Minnesota. PBS refers to a set of tools and strategies for improving quality of life and creating positive social environments. PBS is a value-driven practice that incorporates the principles of

PERSON-CENTERED PRACTICES CALL FOR DEVELOPING OR ENHANCING "VALUED SOCIAL ROLES" AND PROVIDING MORE OPPORTUNITIES, IF DESIRED, TO PARTICIPATE IN THE COMMUNITY. FRIEND, EMPLOYEE, NEIGHBOR, VOLUNTEER, STUDENT, SPOUSE, PARENT, ADVOCATE, AND VOTER ARE EXAMPLES OF VALUED SOCIAL ROLES.

behavior and biomedical research with an emphasis on empowering people to identify strategies that are the best fit for each social context. Two other key elements that are included within PBS – organizational design and workforce and practices for ensuring cultural competence – are included in the curriculum for teams to consider. As mentioned earlier, the overall model used in this statewide training has been adapted from the research and technical assistance in school-wide positive behavioral intervention and supports (Sugai et al., 2010) and implementation science principles described by Fixsen and his colleagues (2005). Three prevention tiers were adapted for human service settings including Universal Strategies for staff and people supported, Secondary Prevention interventions that include early intervention when quality of life is not optimal for a person, and Tertiary Prevention involving individualized PBS processes.

Layers of training are provided in both person-centered practices and PBS. These layers include team-based training, person-centered thinking and planning trainers, person-centered thinking coaches, and PBS Facilitators. These trainings are all tied to organization-wide team planning efforts.

## Organization-Wide Planning

Each participating organization begins the organization-wide planning process by assessing readiness of all stakeholders to begin implementing person-centered practices. Administrator buy-in and active leadership is an important factor as well. An organization-wide team includes administrators, middle management, frontline staff, people receiving supports, family members, board members, and individuals from the community. Five training events are scheduled to deliver information to teams and provide time for discussion and planning.

Teams complete a self-assessment to evaluate strengths and needs related to person-centered practices and PBS including

reviewing policy and practices, completing surveys, and reviewing organizational data. This self-assessment process leads to strategic (action) planning to improve policies and procedures, establish staff development including mentoring and performance management, implement specific positive support strategies, and build data-based decision-making systems for continually improving quality of life outcomes for people receiving support.

## Evaluation

Each organization-wide team learns strategies for data-based decision making to guide implementation. At the universal organization-wide level, the following types of data are collected:

- › Impact of training (numbers of staff involved in implementation, number of people impacted by practices).
- › Individual quality of life (QOL) measures.
- › Incident reports and other indicators of challenging interactions (e.g. use of restraints, 911 calls, injury documentation).
- › Direct observations of positive social interactions.
- › Climate, satisfaction, stress, and surveys.
- › Staff retention/tenure, sick days.
- › Improvements in staff and team-based performance.

Technical assistance includes onsite evaluation by project staff who conduct interviews with key stakeholders, review documents used in programming, observe program activities, and support data collection and analysis. An important focus of evaluation is on changes in quality of life. Quality of life domains identified by Schalock and his colleagues (2002) include:

- Emotional well-being: Feeling empowered and experiencing positive emotions.
- Interpersonal relations: Opportunities for friendship and intimacy, quality of interactions with others.
- Material well-being: Ownership of possessions, meaningful employment.
- Personal development: Opportunities for education and habilitation.
- Self-determination: Setting personal goals, making decisions about important life choices.
- Physical well-being: Optimal health care and nutrition, mobility and general wellness.

- Social inclusion: Natural support networks, inclusive and integrated environments.
- Rights: Experience of ownership of key items and property, allowed due process, privacy and barrier free environments are available.

THE MINNESOTA TEAM IMPLEMENTATION  
 CHECKLIST WAS CREATED FOR TEAMS TO ASSESS  
 FIDELITY OF IMPLEMENTATION AS IT APPLIES TO  
 MULTIPLE POSITIVE SUPPORT STRATEGIES.

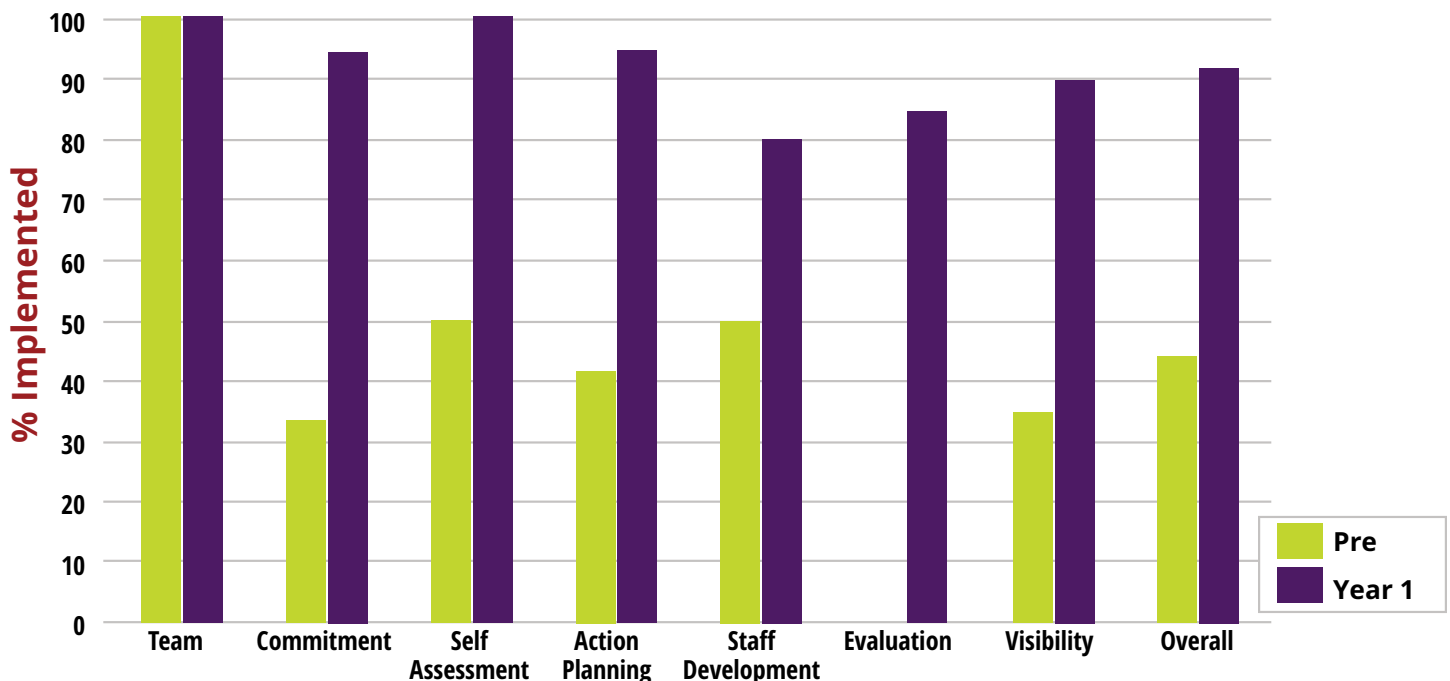
An important evaluation strategy for organization-wide planning includes measuring the fidelity of implementation efforts. The *Minnesota Team Implementation Checklist* was created for teams to assess fidelity of implementation as it applies to multiple positive support strategies. Two subscales are added to the fidelity tool: person-centered practice and positive behavior support. Teams use the self-assessment checklist during meetings

two to four times a year. Data are summarized so teams can assess progress (see Figure 1). Each item is scored with a “0” when no actions have been taken yet; “1” indicates action planning is occurring to complete the item on the checklist; and “2” reflects a fully completed item. Items reflect important steps that are considered part of implementation (e.g., “Team assesses readiness of people to participate in each person-centered and positive support practices”). A team that has completed all fidelity self-assessment items would, therefore, receive two points for each of the 36 items on the checklist. Figure 1 shows

how team progress would be summarized by tallying total number of points obtained divided by total points possible.

Once a year, an onsite evaluation conducted by someone with expertise outside the organization provides objective information about how well person-centered practices and PBS are being implemented. This external evaluation process is used to help teams:

**Figure 1: Results of the Minnesota Team Checklist**



**Subscale Items on the Checklist**

**Table 1: Summary of Evaluation Questions and Tools**

ORGANIZATION-WIDE EVALUATION	RELATED EVALUATION DATA/ TOOLS
<b>What impact did the training have on capacity building?</b>	<ul style="list-style-type: none"> <li>• Number of coaches, key contacts</li> <li>• Number of staff involved in implementation</li> <li>• Number of people supported</li> </ul>
<b>What are the strengths and needs of the organization?</b>	<ul style="list-style-type: none"> <li>• Person-centered organizational tool</li> <li>• Quality of social and physical environment survey</li> </ul>
<b>How well are the practices implemented?</b>	<ul style="list-style-type: none"> <li>• Fidelity of implementation checklist (Quarterly)</li> <li>• Onsite evaluation</li> </ul>
<b>Are there improvements in the conceptual knowledge of the staff?</b>	<ul style="list-style-type: none"> <li>• Pre/ post tests for staff using Direct Course/College of Direct Support</li> </ul>
<b>Are there changes in behavior of staff and people living and working in a setting?</b>	<ul style="list-style-type: none"> <li>• Direct observation of staff person-centered practices (Quarterly)</li> <li>• Direct observation of people supported (Quarterly)</li> <li>• Incident reports, restraint, 911 calls, etc. (Quarterly)</li> <li>• Organizational data (retention/ tenure, etc.)</li> </ul>
<b>Are there changes in universal quality of life?</b>	<ul style="list-style-type: none"> <li>• Quality of social and physical environment interviews</li> </ul>

- › Assess progress implementing features of person-centered thinking and PBS over time.
- › Identify goals that will be included in the team action plan.
- › Assess the impact of the organization-wide team training.
- › Celebrate success as teams make progress.

Table 1 summarizes the evaluation and data collection tools used by teams participating in the training.

## Conclusion

The State of Minnesota is using implementation research outlined by Fixsen and his colleagues (2005) to move away from the “one-shot workshop” approach towards ongoing coaching and capacity building at the regional level. The emphasis on person-centered practices provides a

value-based foundation for implementing positive supports to improve quality of life, encourage self-determination and independence, and establish valued social roles for people in the community. Data-based decision making strategies help guide systems change and contribute to sustainable implementation over time.

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## Positive Strategies to Support the Mental Health Needs of People with IDD

by *Melissa Cheplic and Daniel J. Baker*

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**People with** intellectual or developmental disabilities (IDD) encounter many factors across their lifespan that increase their risk for mental health challenges. Restricted opportunities, negative labels, rejection, exclusion, and other negative experiences can lead to feelings of inferiority and loneliness, as well as poor self-concept and low self-esteem. Consequently, research shows that people with IDD are more vulnerable to stress, anxiety, and other mental health problems than people who do not have IDD. According to NADD, an association for persons with intellectual/developmental disabilities and mental health needs, 30-35% of persons with IDD also have a psychiatric disorder (NADD, 2016). These challenges can interfere in several areas of the individual's life, including social relationships, finding and keeping work, their home environment, and participating in recreational activities. Lack of coping skills and insufficient communication skills can also make life difficult for people with IDD and contribute further to stress and anxiety. Recognizing and supporting mental health needs in individuals with IDD is essential to providing quality supports and addressing wellness.

### Mental Health Strategies for Specific Needs

Services and practices that are available for people with mental illness also should be offered to people with IDD, recognizing how an overlap in strategy can be applied, with emphasis on modifying to the specific needs of an individual. These include strategies that can be incorporated in both formal plans and everyday supports.

Behaviors viewed as problematic may be a sign of a mental health disorder, or can be indicative that the individual is experiencing discomfort or dissatisfaction with his or her surroundings. However, the interventions used to address these issues can sometimes be more isolating and anxiety-provoking for the person, rather than therapeutic. For example, if someone experiences challenging or aggressive behaviors in the community, they are

sometimes excluded from community involvement. Since tension or anxiety can serve as contributing events for problem behavior, creating a supportive, calming environment that addresses specific triggers is key to addressing wellness and to prevent challenging behavior. Considering what tools can support the person when he or she encounters a potential trigger or discomfort is a more positive way to encourage community involvement.

For some people with IDD, lack of opportunity to engage in meaningful experiences can lead to anxiety based in unfamiliarity with events common to the general population. For example, meeting new people or trying a new hobby can be a chance to try something new, but this can be stressful for someone with IDD. Provide a person with IDD more information about unfamiliar situations. For some, this may include a social story about what to expect from a setting or interaction, and a clear description of the appropriate behavior to reach a decided outcome. Other individuals may benefit from teaching on interpersonal relationships and the social skills required to interact with others.

People with IDD are less likely to report having friends, significantly more likely to report feeling lonely, and also identify developing meaningful relationships as difficult (NASDDDS and HSRI, 2014, 2012). If we consider that interactions that can potentially lead to friendships can be stressful, we realize that mental health challenges can be both a cause and an outcome of lack of meaningful relationships and social support. It is essential to support people in ways in which they can cultivate relationships. This can be accomplished at school, at work, in the community, at recreational programs, as well as in therapy. Friendships are a significant source of mental wellness in the general population.

Promoting choice about the types of activities in which people with IDD participate has been shown to decrease anxiety and increase interest in said activities (NASDDDS and HSRI, 2014, 2012).

Providing individuals with choice and control over their lives has been central to person-centered planning and self-determination. Empowerment helps individuals overcome powerlessness, recognize capacity, and gain control. This is of particular importance in the lives of people with IDD, who often do not play an active role in their own wellness.

RECOGNIZING AND SUPPORTING MENTAL HEALTH NEEDS IN INDIVIDUALS WITH IDD IS ESSENTIAL TO PROVIDING QUALITY SUPPORTS.

### Using Wellness Strategies

Promoting relaxation can help an individual self-manage stress, tension, worry, anger, discomfort or other feelings that can interfere with enjoying quality of life. Relaxation strategies are also effective in distracting the person from the cause of the potential anxiety and focusing him or her on an alternative activity or behavior. For example, if someone is very stressed about being in an elevator, he or she can participate in a relaxation exercise involving a combination of deep breathing and counting while closing his or her eyes and visualizing a calming setting, for the duration of the elevator ride. The key to successful implementation of relaxation exercises is practicing with the person when not in the presence of the stressor/stressful environment and providing prompts as needed during rehearsal. Deep breathing for individuals who require more structure can be encouraged by using balloons, bubbles, party favors, and other instruments. Additionally, everyday activities such as baking bread and gardening will stimulate muscle involvement, resulting in an analogous effect seen in the more methodical technique, Progressive Muscle Relaxation. Sometimes knowing the person's interests and being creative alongside him or her is the best strategy to help through stressful situations as well as build enduring coping skills.

A more expanded visualization strategy is Guided Imagery. By using words and/or music, the person is invited to create a positive image of a setting or scenario in order to generate a calming effect. During this exercise, the person is directed to focus on an image in his or her mind while given a set of instructions to reach a therapeutic goal. This practice can aid in relaxation, distraction from a stressor, potential de-escalation during behavioral crisis, and have an overall improved effect on the person's state of mind while he or she is disoriented or uncomfortable.

Supportive communication is another therapeutic mental wellness strategy to ensure positive interactions. People need to be heard and understood. Choosing the right words and maintaining a supportive tone of voice is important. Provide an opportunity for reflection through active listening and show the person you understand. A verbal strategy called Validation helps to communicate to others that we are interested and supportive. Validation is particularly helpful with disoriented people, those suffering from disordered thinking (personality disorder, psychosis), traumatic brain injury, or those experiencing escalating behaviors. When we validate individuals with IDD, it's important to remember that the person is grounded in his or her feelings and use those feelings to guide your responses. If problem solving or further intervention may be needed, distracting the person to a less stressful topic and promoting a calming response first will be more constructive. Validate the feelings and use the feelings to guide them towards more useful and calming activities.

When most of us think about mental health intervention, we think of speaking to a therapist. Therapy can be individual or group. Many forms of traditional therapy rely on advanced verbal skills, but may not be within the skill set of some people with IDD. Therapy can be adapted to meet the learning profile of people with different ability levels, however, and can be very effective. Common adaptations can include use of concrete instruction or providing an increased number of examples. For persons who have trouble remembering past events, frequent reminders may be helpful,

as may be use of pictures or other visual aids. Helping a person develop self-awareness about his or her feelings and identify ways to respond to those feelings is a common goal of therapy, as well as a valuable skill in approaching stress that inhibits wellness.

RESEARCH SHOWS THAT PEOPLE WITH IDD ARE MORE VULNERABLE TO STRESS, ANXIETY, AND OTHER MENTAL HEALTH PROBLEMS THAN PEOPLE WHO DO NOT HAVE IDD.

### Conclusion

Persons with IDD are vulnerable to mental health challenges as well as a lack of mental wellness opportunities. In recent years, there has been a much greater level of awareness around these concerns, and a wealth of interventions have been identified. In this pursuit, we should always be aware of how the general population promotes mental wellness, and adapt as necessary for persons with IDD, focusing on building skills and meeting the learning style of the person. These considerations should always be foremost as we plan and arrange for supports and include people in the selection of what works best for them.

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## Developing and Supporting Leaders: The Key to Creating Person-Centered Organizations

by Steven M. Eidelman

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**The question** we hear all the time is “Are great leaders born or made?” The answer is in three parts:

- 1) Yes
- 2) All are born
- 3) Most are made

Leadership is a skill set that can be nurtured, trained, developed, and improved. As Kouzes and Posner (2012) point out:

- › Leadership is an observable set of skills and abilities that are useful whether you are in the executive suite, on the front lines or in between. You can be a leader in an organization (or from outside an organization) without being the CEO, top dog, Executive Director, President, etc.
- › The instrument of leadership is the self. Leadership is an affair of the heart more than it is an affair of the head. And, as I said above, with practice, mentoring, training, coaching and development, the skills to be a leader can be honed, improved and refined.

To see my favorite video about leadership, go to “Drew Dudley - Leading with Lollipops” (<http://www.youtube.com/watch?v=hVCBrkrFrBE>). Drew Dudley demystifies leadership. We have a tendency to think there is some magic, some formula, some innate ability that makes some people leaders and other people not. It isn’t so. Leaders are as different from each other as you would expect in any other way that we classify people...with a few exceptions. Good leaders clearly communicate, through words and/or actions, what they stand for, who they are, and compel us to pay attention to what is important.

Leaders create and “sell” the vision for their organization, but they don’t (or shouldn’t) create the vision by themselves. The most effective leaders work with their organization and community stakeholders, specifically including people they support and families, to create a vision based on the values we find in the Convention on the Rights of Persons with Disabilities (CRPD) and in IDEA, the ADA, the *Olmstead* decision, Section 504 of the Rehabilitation Act, the Developmental

Disabilities Act, and in both the Declaration of Independence and the U.S. Constitution as well as state-specific laws and regulations. We have magnificent laws and policies and every day leaders strive to uphold them. Alas, others disregard and block them on a regular basis.

For so many people with disabilities, their days are spent doing things they do not like, or that bore them, or both. We all need a reason to get out of bed in the morning. Something to look forward to. The leadership task is to help create these opportunities and offerings. If the leader is successful in creating such environments, helping people find what they want to do, what they are good at and what they enjoy, the need to express oneself with “behaviors” is greatly diminished.

People with disabilities may live with people with whom they did not choose to live and live in a place that is not where they might want to live. Or they may live with their families, as adults, but are still treated as they were when they were a child. In all these circumstances, the situations in which they find themselves cause them to express their discomfort, displeasure or boredom by doing things that are euphemistically called “behaviors.” Far too often we react to challenging behaviors with strategies that do not promote quality of life, are not person-centered, and end up using procedures that restrict people in an attempt to produce a change in behavior and control the person.

One of the most important things a leader can do is to create, within the context of the organization in which they work, a culture and climate of dignity and of respecting the rights and humanity of people with disabilities with whom the organization works. The leadership task is finding and removing the obstacles to creating such an environment, working with people supported, staff, boards and volunteers. Leaders work to remove barriers, overcome obstacles, and employ creative tension within the organization to help it change, adapt, and modify itself to meet the needs of those who count on



## THE LEADERSHIP CRISIS IN THE INTELLECTUAL/DEVELOPMENTAL DISABILITIES FIELD

*Effective leadership is critical to the quality of supports people with disabilities and their families receive. A study by the University of Delaware that was specific to community intellectual/developmental disability agencies found that over 50% of the chief executive officers of these service agencies did not have a succession plan for their organization (Eidelman & Brady, 2006). Because the vast majority of community agencies serving people with intellectual and developmental disabilities were established in the late seventies or early eighties, many are still led by the individuals who founded these organizations. Many leaders of disability organizations are reaching retirement age and there is not a "next generation" of leaders ready to move into these positions. As one CEO put it, "I'm ready to think about retirement, and we've got no one on the bench."*

*A study by the American Association on Intellectual and Developmental Disabilities found a significant gap at the executive level in training programs on leadership and management in the developmental disabilities field (AAMR, 2005). When professionals in the field were surveyed about the need for a comprehensive program in leadership for developmental disabilities executives, the response was overwhelmingly positive. Ninety-four percent of respondents indicated that such a program is needed. Almost without exception, the leadership crisis has been a major topic of focus at recent conferences for developmental disability professionals.*

*An additional problem that threatens the quality of developmental disability services nationally is the lack of top-level leadership training and support for the directors and executive staff of state departments*

*Adapted and reprinted with permission from The National Leadership Consortium, University of Delaware, <http://www.nlcdd.org/leadership-crisis.html>.*

*of developmental disabilities. These departments in each state are responsible for setting funding priorities, establishing public policy, and overseeing the quality of the services that are delivered. The turnover is great. The National Association of State Directors of Developmental Disabilities Services has stated that the average tenure of a state director of developmental disabilities services is about two years and that there is over 20% turnover annually in the top position in state developmental disabilities departments across the country. When the directors of these departments change, top-level staff often change as well. As a result there is a need for knowledgeable support and training for new chiefs of state departments of developmental disabilities and their executive level staff on an ongoing basis.*

*While the disability field is rich with effective and creative leaders, almost all achieved their skills through some combination of luck and opportunity – they fell into a great job, formed a relationship with a forward-thinking mentor, or arrived at effective leadership approaches through trial and error. An important focus of The National Leadership Consortium is to conduct ongoing research into exactly what it takes to create top-level leaders in the intellectual/developmental disabilities field and to make those skills and opportunities available to people across the country with demonstrated leadership potential.*

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them for support. Good leaders obviate the need for practices that are restrictive, aversive or deprivative.

So how do we find these leaders? Do they exist in my community? I think they do, though as a professional field we spend far too little effort mentoring, developing, training, and supporting future leaders. Most of the federal support for training leaders is in Special Education and Maternal and Child Health, mostly for historical reasons. Yet most people with disabilities are adults, not children.

We know from the research on non-profit and government leaders that the majority of existing organizational leaders see retirement on the not too distant horizon. To respond to the need for effective leaders we created the National Leadership Consortium on Developmental

Disabilities at the University of Delaware (see <http://www.nlcdd.org>), a consortium of a dozen national organizations interested in addressing this looming shortage. We offer a week-long, industry-specific executive development program to enhance the effectiveness of people working in disability organizations. Our leadership development work is focused on three major components: values and vision, skills necessary to make those values and vision real, and personal leadership development strategies and techniques. To date 1,000+ people have participated in our week-long leadership institutes from 45 states, two Canadian provinces and 20 countries worldwide. But affecting change with a handful of people at a time is not enough.

Disability and other human services organizations and state governments need to pay attention to the issue of leadership.

There needs to be a formal effort in each state to grow the next generation of leaders focused on inclusion, self-determination, positive approaches, and person-centered practices. It cannot be left to chance and does not happen by accident. It takes resources, but the resources needed are a very small percentage of overall budgets. There are many graduate programs to train organizational managers and leaders. Any decent program will do for the basic skills. But generic leadership programs won't focus on managing change to provide person-centered, inclusive services. Local, field-focused efforts are needed to supplement such programs.

One of the skills we need to assure that people have is ways to use data to manage services and how to assure that data collection and analysis is built into programs, not tagged on as an afterthought.

We also want people to have access to the best research available on practices in person-centered planning and supports, positive approaches, inclusion, self-determination, and full participation in the community. Sadly, most published research

is not read by those leading service organizations.

Developing and supporting leaders is vital to creating organizations, policies, and programs that help people get the lives

they want. We need to take this issue on positively, proactively and affirmatively. It is too important to leave to chance.

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## RESOURCES

*Below are resources from around the country that readers of this Impact issue may find useful.*

### Kansas Institute for Positive Behavior Support ([kipbs.org](http://kipbs.org))

Among the extensive resources created by this institute, which is based at the University of Kansas, is a set of 10 free modules for professionals on topics including applied behavior analysis, functional behavior assessment, emotional and behavioral health, and designing positive behavior support plans (see [kipbsmodules.org](http://kipbsmodules.org)). Also available is the KIPBS Toolbox (see [kipbs.org/new\\_kipbs/fsi/toolbox.html](http://kipbs.org/new_kipbs/fsi/toolbox.html)), which provides easy access to brief summaries, troubleshooting guides, tools, and links that can assist in the problem-solving process in positive behavior support and person-centered planning. And another resource is the Kansas Mental Health Positive Behavior Support Project Web site ([knhpbs.org](http://knhpbs.org)), which helps professionals in mental health services implement a positive behavior support training system that uses evidence-based approaches to create outcomes that are effective and sustainable.



expert in person-center thinking and practice, discusses what is meant by person-centered approaches, thinking, and planning; person-centered plans that make a difference; how to get started making person-centered planning mainstream; and more. Useful for organizations, individuals, families, these free podcasts, as well as a person-centered thinking toolkit and many other resources (see [sdaus.com/resources](http://sdaus.com/resources)), are available online from Support Development Associates (SDA).

### Impact: Feature Issue on Supporting Wellness for Adults with Intellectual and Developmental Disabilities ([ici.umn.edu/index.php?products/view/739](http://ici.umn.edu/index.php?products/view/739))

Wellness is a rapidly growing area of focus for Americans. But, for people with intellectual and developmental disabilities, access to wellness activities and programs can be limited. How can disability service providers, health and wellness professionals, community recreation programs, and others open up participation? Find out in this issue of *Impact* published by the Institute on Community Integration and the Research and Training Center on Community Living, University of Minnesota. Available in PDF and HTML, or for a complimentary print copy contact the Institute's Publications Office at 612/624-4512 or [icpub@umn.edu](mailto:icpub@umn.edu).



### Positive Supports Minnesota (<https://mnpsp.org>)

Offering tools in the areas of Community Living in Action ([mnpsp.org/community-living/](http://mnpsp.org/community-living/)) and Positive Behavior Support in Action ([mnpsp.org/pbs/](http://mnpsp.org/pbs/)), this Web site assists disability and mental health service providers, social workers, educators, and others in helping professions, as well as people receiving services and their families, to successfully implement positive supports. Among additional areas of focus for this resource from the Research and Training Center on Community Living, University of Minnesota, are tools in mental health, person-centered practices, families, aging, and applied behavior analysis.



### Association for Positive Behavior Support ([apbs.org](http://apbs.org))

APBS is an international organization dedicated to promoting research-based strategies that combine applied behavior analysis and biomedical science with person-centered values and systems change to increase quality of life and decrease problem behaviors. It's Web site has resources for community agencies, statewide leadership, education, families, and early childhood professionals, including case studies, research, and links on implementing positive behavior support in a variety of settings.



### SDA Person-Centered Practices Podcasts ([sdaus.com/podcasts](http://sdaus.com/podcasts))

This set of short video podcasts by Michael Smull, nationally-known





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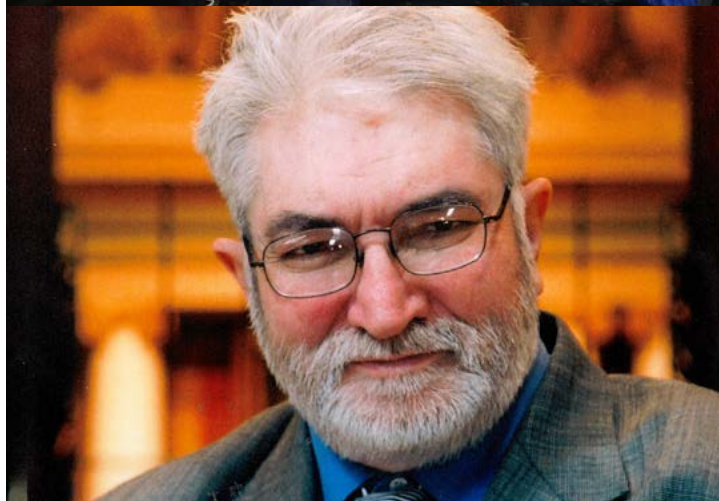
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## Impact

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**Feature Issue: Person-Centered Positive Supports and People with Intellectual and Developmental Disabilities**

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