A National Gateway to Self-Determination

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# A Series of Papers on Scaling-Up Efforts to Promote Self-Determination

## Paper 4: Lessons Learned in Scaling-Up Effective Practices: Implications for Promoting Self-Determination within Developmental Disabilities

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# The National Gateway to Self-Determination

The National Gateway to Self-Determination (SD) is a consortium of University Centers for Excellence in Developmental Disabilities (Missouri, Kansas, Oregon, New York, Illinois) in partnership with a National Self-Determination Alliance (including self-advocates, families, and numerous national partners). The overall goal of this project is "***to establish a sustainable, evidence-based training system that enhances self-determination training programs that lead to quality of life outcomes for individuals with developmental disabilities throughout the lifespan."***

There are a number of important beliefs upon which this SD initiative is founded. They include:

- SD is best considered in the context of a ***social-ecological framework***
- Development of SD is a ***lifelong process***
- Scaling-up SD training activities must occur within an ***evidence-driven*** framework
- The development of SD is a means to obtaining an ***improved quality of life***
- People with developmental disabilities ***must be equal partners***

The purpose of this Paper and the others in the series is to fill existing gaps in the SD literature related to these beliefs. If you would like to see a complete listing of the White Papers in this series, please visit the National Gateway to Self-Determination website: www.aucd.org/ngsd.

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Over the past two decades, there has been a surge in professional activity associated with the promotion and adoption of effective practices with an adequate evidence base to support their use (Detrich, Keyworth, & States, 2008). The pressures that have been building for greater accountability and increased cost efficiencies across government agencies over the past decade are also now reflected in the public's demands for a better return on its investment in research and development by federal funding sources. Congressional budget hearings for federal agencies, whose mandates focus on such areas as health, education, disability, and child mental health, for example, are often characterized by a strong press for documenting the impact of public funding in preventing destructive outcomes, in transforming lives, and enhancing overall quality of life.

Examples of frequently asked questions in these hearings include, "What difference will this research make in a person's life?", "What will be the impact of this work on our society in five, ten or fifteen years?", and "How do targeted consumers access this information?" The answers provided in response to these concerns have often been judged unsatisfactory by those who raise them. On a positive note, however, they have prompted a strong interest in addressing the gaps between research and practice in these fields and in translating research findings into useable, cost-effective, and acceptable practices that more directly impact people's lives.

Experts have estimated it can take up to twenty years for a new innovation in the education field to be broadly adopted and integrated into routine school operations (Detrich, et al., 2008; Walker, 2004). In fairness to educators, however, many of these practices have not been broadly or effectively disseminated within venues that school-based personnel can typically access. The *What Works Clearing House* and the *Practice Guide Series* of the Institute for Education Sciences are both direct attempts to address this ongoing problem, and they have proved to be very popular with professional and non-professional consumers alike.

Fixsen and Blasé (2009) have argued that broad-based dissemination and diffusion are necessary but not sufficient conditions for supporting implementation efforts to solve national problems. There is broad agreement among human services and educational professionals that implementation science is the missing link that connects research outcomes to the delivery of effective practices. The knowledge base on implementation science informs the scaling-up of effective practices and addresses such critical variables as social marketing processes, adoption decisions, capacity building, training, technical assistance, consumer participation and satisfaction, and long-term impact (See Dunst, Trivette, Masiello, & McInerney, 2006; Fixsen, Blasé, Horner, & Sugai, 2009a; Horner & Sugai, 2006; Simmons & Shiffman, 2006).

The purpose of this paper is to address the complex issues involved in the promotion and scaling-up of self-determination. It will do this in part by applying the knowledge base on scaling-up processes and procedures that has been developed in such allied fields as education, delinquency prevention, health education,

child mental health, and behavioral interventions for use with challenging at-risk youth. In the past several decades, some remarkable advances have occurred in the above subspecialties that have also produced a cohesive body of knowledge on scaling-up. We now know a substantial amount about the conditions under which successful scaling-up of effective practices occurs and can access valuable lessons learned from the experiences of others (See Fixsen, Naoom, Blasé, Friedman, & Wallace, 2005).

As discussed in Paper 2 of this Series, self-determination is highly valued by people with disabilities, their families, and professionals in the field of developmental disabilities (Lachapelle et al., 2005). (Readers should refer to Paper 2 for a discussion of the definition of the self-determination construct and Paper 1 for an overview of the social ecological framework with which the NTI project approaches the task of scaling-up.) Scaling-up efforts to promote self-determination will deliver to more people and families the many benefits deriving from its effective promotion and implementation. While there has been a relative dearth of evidence-based scaling-up efforts in the field of developmental disabilities generally, and particularly in relation to self-determination, there now is a strong need to address this issue in our field. Analysis of the strategies and challenges that have emerged in the diverse scaling-up efforts in the areas cited above can provide useful guidelines for our own activities in this regard. The remainder of this paper addresses the following topics: 1) definition and overview of scaling-up targeted practices; 2) seminal examples of the types of practices that have achieved successful scaled up outcomes; 3) levers and incentives for scaling-up self-determination; 4) generic scaling-up issues, processes, and procedures, 5) the NTI template for scaling-up efforts to promote self-determination; and 6) concluding remarks.

**Definition and Overview of Scaling-Up Targeted Practices**

*Scaling-up* incorporates the features and required procedures for the planned transfer and expansion of promising practices from initial demonstrations of their efficacy to large-scale adoptions. There are four generally recognized phases of implementation in scaling-up a practice (Dunlap, Sugai, Lewis, Goodman, & Horner, 2009). These are: 1) *emergence, 2) demonstrating capacity, 3) elaboration, and 4) system adoption and sustainability.* *Emergence* refers to the initial design phase of a scaling-up initiative and involves deciding whether a targeted practice is actually scalable, whether the organizational capacity exists to support scaling-up and the implementation process, and whether the scaled up practice would be more efficient, cost-effective, and acceptable to consumers than what currently exists. The *demonstration* phase of scaling-up is designed to determine whether the practice can be implemented locally with acceptable fidelity and with sufficient impact on target outcomes. This phase also involves analyzing state policies, assessing capacity, and building a consensus around the infrastructure and resources needed to support scaling-up requirements. *Elaboration* shifts the focus of scaling-up efforts from demonstrations to broad implementation and a) uses demonstration

site trainers to accomplish training and technical assistance with multiple stakeholders (i.e., administrators, agency staff, policy makers, families, and implementation team leaders) and b) records and disseminates outcome data on the results of implementation. Finally, *system adoption and sustainability* involve integration of the innovation or practice into organizational policy and normal routines, the regular reporting of essential data (especially on fidelity of implementation), and continuous evaluation, adaptation, and reinvestment in the innovation so that it is sustained over the long-term.

**Seminal Examples of Successfully Scaled-Up Practices**

Menter, Haaria, Johnson, & Ashby (2004) distinguished between two primary types or forms of scaling-up: *Vertical and Horizontal.* Vertical scaling-up involves the *depth* of scaling-up activities, which means all elements or levels of a given system are addressed and impacted by the scaling-up process (e.g., human services state agency, school system, mental health network). Horizontal scaling-up, in contrast, refers to the *breadth* of scaling-up efforts and involves the broad-based diffusion and adoption of a practice and its sustained use over time (Dunst et al., 2006). Such adoption need not involve all layers of a bureaucratic system. Horizontal scaling-up is characteristic of programs and practices that meet a compelling need and solve a high-priority problem in a cost-efficient manner, such as the early identification of problem readers. Some examples of horizontal scaling-up program practices and seminal research findings are provided in Appendix A. These examples involve 1) two seminal studies whose results have profoundly impacted policy and practice in a range of important social, educational, and political contexts (Hawkins, Catalano, Kosterman, Abbott, & Hill, 1999; Hawkins, Kosterman, Catalano, Hill, & Abbott, 2008; Hart & Risley, 1995), 2) a comprehensive, ecological intervention that effectively impacts the lives of at- risk youth and their families (Henggeler, 1998), and 3) a brief diagnostic-assessment procedure that allows for the accurate, early detection of those students in kindergarten and grade one who will become struggling readers by the end of third grade (Dynamic Measurement Group, info@dibels.org).

The brief profiles of the successful horizontal scaling-up examples provided in Appendix A illustrate a) the diversity of practices that have been replicated numerous times and adopted by many agencies and systems as standard practice (DIBELS, MST) and b) the role of powerful research findings in influencing legislation, policy, practices, and public acceptance of new innovations (Hart & Risley, 1995; Hawkins, et al., 1999; 2008). These critical findings and associated program practices have been adopted and implemented by a broad array of agencies and service systems; they have also heavily influenced policies that drive the adoption of similarly effective approaches. In many ways, the adoption and integration of a practice or seminal findings into a system's ongoing operations and routines is the ultimate test of consumer acceptance and satisfaction. Collectively, these scaled up practices have huge implications for solving vexing problems that continue to plague our

society, lower our quality of life, and cost billions in revenue annually.

**Levers and Incentives for Scaling-Up Self-Determination**

The developers of the above profiled practices and findings have amply demonstrated that each is eminently "scalable" and that there are clear advantages for doing so (i.e., meeting individual needs on a broad scale, increasing the skills of professionals, improving the effectiveness of organizations, systems, and agencies, and so forth). However, the primary reason they have achieved such robust horizontal scaling-up status and outcomes is that they provide a cost-effective solution to high-priority problems.

A major goal of the National Transition Initiative in Self-Determination (NTI SD) is to analyze, integrate, codify and make available to a range of stakeholders the knowledge base on self-determination. A number of venues are being developed to accomplish this outcome including: 1) a resource website; 2) publications, including peer reviewed journal articles, chapters, and books; 3) ecology-based tools and products for use in assisting persons with developmental disabilities to evaluate their own life experiences and quality of life; 4) curricula review guidelines and formats; and 5) state-by-state summits that bring together individuals from all levels of the system(s) serving persons with developmental disabilities and their families. As such, the initiative's overall approach represents a blending of both vertical and horizontal forms of the scaling-up process. That is, the NTI SD will vet and make available information on best practices and key findings that are accessible through a range of national outlets and information sources (horizontal). In addition, the initiative will use state summits to mount scaling-up initiatives that involve statewide resource teams and representatives from local, state, and, in some cases, regional configurations as appropriate (vertical). A major goal of the state level summits will be to develop a statewide plan for the quality implementation and delivery of policies, practices, and activities that promote self-determination. Dunst et al. (2006) have developed a similar framework or model process for scaling-up literacy practices and concepts within early intervention instructional contexts.

The levers that will guide our overall approach involve: 1) recognizing the National Core Indicators (Human Services Research Institute, 2009) as a valid method for establishing operational definitions and standards based on the values and outcomes that scaling-up efforts to promote self-determination embraces and promotes; 2) informing policies and standards regarding self-determination within systems that serve people with developmental disabilities and their families, including schools and a range of national, state, and local agencies; 3) responding to the letter and spirit of legislative mandates regarding self-determination contained in federal and state-level legislation; and 4) promoting best practices in promoting self-determination that have an adequate empirical base, are grounded in acceptable values, and that lead to enhanced consumer outcomes and satisfaction.

**Generic Scaling-Up Issues, Processes, and Procedures**

The generic knowledge base on scaling-up results primarily from two sources: 1) the reflective analysis of an array of horizontal scaling-up efforts conducted across fields as diverse as agriculture, medicine, and delinquency prevention; and 2) planned scaling-up studies in which vertical approaches are used that impact all individuals served by the different levels of a service system, from direct care providers, stakeholders, and partners, to key policy makers, agency heads, and leaders at the state level (Fixsen, Blasé, Horner & Sugai, 2009b; Menter et al., 2004). Fixsen et al. (2009; 2009a) argued that states often merely dabble in the use of evidence-based practices and tend to fund pilot and demonstration sites for the targeted practice rather than design and conduct a truly vertical scaling-up initiative. These efforts usually result in unsatisfactory outcomes since they tend to focus on targeted practices or interventions without sufficiently taking into account the systemic and infrastructure variables that actually determine the implementation capacity to accomplish scaling-up effectively.

**Transformation Zones to Accomplish Scaling-Up Outcomes at a State Level.** Fixsen et al. (2009a) recommended identifying transformation zones that can be thought of as a vertical slice of an organization or system that is large enough to contain all necessary elements to accomplish scaling-up but are sufficiently small to be manageable. These transformation zones address: *1) creation of a state management team; 2)consideration of issues related to sustainability, quality improvement, and scalability with the future in mind; 3)anticipation and planning for policy, funding and regulatory exceptions in relation to capacity building; and 4) formalizing of practice-level feedback that are built into communication and monitoring protocols.* The operation of each of these elements is carefully monitored and assessed against implementation fidelity standards. Self-reported and externally recorded data are used to inform decision-making at all levels of this transformation zone.

Horner, Sugai, and associates have built this transformation zone innovation into the scaled up model they have successfully implemented in a number of states to support scaling-up of their School-Wide Positive Behavior Support Model (See Sugai et al., 2005; Sugai & Horner, 2006). Currently, SWPBS has been adopted by approximately 9,000 U.S. K-12 schools. The impact of SWPBS has been extensive and the contributions of these professionals to the knowledge base on how to scale up at state and national levels are widely recognized in the literature (Dunst et al, 2006; Fixsen et al., (2005).

**Criteria for Scaling-Up a Targeted Practice or Innovation.** A practice refers to a procedure, or set of procedures, that is designed for use in a specific context by individuals having certain skills/features in order to produce valued outcomes (See Fixsen, et al., 2005). Practices can vary in size and scope and one should scale up practices only when they are sufficiently aggregated and have developed to a point where they have the ability to impact on a core social outcome (e.g., enhanced quality of life). Analysis of diverse horizontal

scaling-up efforts has identified four critical issues or big ideas in scaling-up. They are: 1) *selecting what to scale up; 2) determining how to implement a new innovation or practice so that it actually produces the intended benefits to consumers; 3) defining how to scale up effective practices so they are available to all individuals who can derive benefit from them; and 4) identifying how to align system structures and functions to fully support scaling-up efforts as part of their normal operating procedures.* Additional questions that need to be addressed include: Is the innovation evidence-based? Is it conceptually coherent? Why is it effective? How is it more efficient than what is currently practiced? The Fixsen et al., (2005) handbook and the work of Horner, Sugai, and colleagues provide a valuable roadmap for professionals to use in addressing these important questions (Spaulding, Horner, May, & Vincent, 2009).

We (the NTI consortium) developed a two-level set of criteria for use in selecting targeted practices that can be scaled up in promoting self-determination (See Table 1). These criteria are based on an analysis of the self-determination literature. The Level 1 criteria in Table 1 describe the best, currently available practices for promoting self-determination as they are carefully referenced to persons with developmental disabilities and the DD field (e.g., Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007). Level 2 criteria in Table 1 present features drawn from our social ecological model for enhancing self-determination through addressing social and environmental factors that impact quality of life (see Paper 1 in this series). We will use these criteria to inform the design of our NTI state summit initiative on scaling-up self-determination and in vetting, synthesizing, and integrating the existing knowledge base.

**Figure 1. Criteria for Identifying Scaleable Practices and Innovations**

| **Evaluation Criteria to Determine Best Available Practices to Promote Self-Determination** |
|---|
| **Level One: General Factors** |
| 1. Intervention/practice grounded in theory/research. (Low to High)<br>2. Level and quality of evidence, taking into account issues pertaining to research design, validity of measures, size of sample, and so forth, of efficacy of intervention or practice in promoting the self-determination of people with intellectual and developmental disabilities. (Weak to Strong)<br>3. Current Level of Adoption, Availability, or Utilization. (Low to High)<br>4. Affordability/Cost of Implementation. (Low to High)<br>5. Acceptability of treatment or intervention or delivery method among stakeholder groups. (Low to High)<br>6. Breadth (e.g., is intervention limited to one population, age, or topic, or could it be implemented across ages, populations, and topics?). (Limited to Wide)<br>7. Expertise, training, or cost required to implement intervention. (Low to High)<br>8. Replicability of intervention. (Low to High)<br>9. Degree to which persons with disabilities and/or family members participated in development and evaluation of the intervention or practice. (Low to High)<br>10. Degree to which intervention or practice is valued, recommended, or perceived as positive by people with disabilities. |
| **Level Two: Factors Drawn from Social-Ecological Approach** |
| 1. Intervention/practice motivating to target audience (which could be direct support staff, teachers, parents and family members, people with disabilities, agency administrators, etc.).<br>2. Intervention/practice takes into account moderating variables such as gender, ethnicity, cultural context, and others.<br>3. Intervention/practice addresses person-specific variables. (Low to High)<br>4. Intervention/practice addresses environment specific variables. (Low to High)<br>5. Intervention/practice integrates both person-specific and environment specific variables. (Low to High)<br>6. Intervention/practice includes mechanisms to involve the mediating effect of social effectiveness, social capital, and social inclusion.<br>7. Intervention/practices lead to improved quality of life outcomes. |

**Critical Elements of Successful Scaling-Up.** Simmons and Shiffman (2006) reported a detailed conceptual model for successfully scaling-up targeted practices and innovations within the health services field. They advised that the critical elements which have to be addressed, carefully planned, and organized in successful scaling-up efforts are: *1) identification of a targeted practice (innovation) that meets scaling-up criteria; 2)availability of technical experts (resource teams); 3) identification of end-user individuals, programs, and organizations; and 4) effective mounting of scaling-up strategies.* The supporting attributes that undergird these elements include target practices that are observable, supported by empirical evidence, and that have a relative advantage over existing practices; technically skilled advocates or champions who understand the political, social and

cultural environs in which scaling-up efforts occurs; end-user organizations that have the capacity to accommodate scaled up programs; and use of scaling-up practices and strategies that incorporate the best available knowledge about how to make the process work effectively. Other important issues in this context include determining when a program, approach, or practice is ready to be scaled up, the type of scaling-up that needs to occur (i.e., breadth vs. depth), sources of resistance and obstacles, and methods for assessing the impact of scaling-up efforts. The Simmons and Shiffman (2006) model also illustrates the generic and overlapping nature of scaling-up processes across diverse fields. The elements and indicators of their successful model for scaling-up health services are nearly identical to that used in successful horizontal scaling-up efforts within education and in delinquency prevention.

**The NTI Template for Scaling-Up Efforts to Promote Self-Determination**

The Centers for Medicaid and Medicare Services (CMS) have articulated a vision for quality in Medicaid-funded Home and Community-Based Services (HCBS) waiver programs that assures that individuals have choice and control to achieve independence, health, and a satisfactory quality of life. Funding available through the HCBS waiver programs led many states to develop new and innovative community service programs based on the idea that enhancing self-determination and improvement in the quality of services were related issues. One approach to increasing self-determination options within HCBS waivers is the inclusion of a specific section of waiver applications and renewals devoted entirely to state practices that allow for participant direction of services. Participant direction can empower waiver enrollees with either "employer authority" (the participant exercising control over the selection, training, and scheduling of his or her support staff), "budget authority" (the participant exercising control over an individualized portable budget or amount of service), or both.

Models of self-directed services can provide an important support to facilitate the self-determination of people with intellectual and developmental disabilities. Numerous demonstrations of self-directed services (Robert Wood Johnson Foundation, 2007) have found that consumer-controlled services lead to improved quality of life and satisfaction while costing less than agency-managed care. When self-directing, people with developmental disabilities almost universally report a greater sense of choice and control, increased community participation, higher levels of satisfaction with staffing arrangements, and enhanced social networks (Wehmeyer et al., 2007). It is noteworthy that outcomes leading to enhanced social networks and community connections build "social capital," which has been consistently linked to enhanced quality of life, mental and physical health, and economic security (CQL, 2007).

The NTI SD efforts to scale-up self-determination can be informed by existing approaches and strategies used to promote and measure how the principles of consumer-controlled funding lead to improved supports, enhanced consumer satisfaction, and increased quality of life. CMS and its partners have developed the HCBS Quality Framework, requiring that

states applying for HCBS waiver funding include in their waiver application a description of the quality management systems they would put in place to assure that waiver services achieve participant-centered desired outcomes and meet specific system performance standards. This HCBS Quality Framework provides states with a set of domains by which to assess system performance and HCBS waiver service improvement resulting from federal funding.

In addition to the HCBS Quality Framework, two sets of performance measures have been developed that also have the potential to capture the extent to which people with intellectual and developmental disabilities are achieving important personal outcomes related to self-determination. The first approach is based on the use of the National Core Indicators (NCI) (Human Services Research Institute, 2009), which were initially developed to provide states with the ability to measure performance and outcomes in state developmental disabilities systems. The second approach was developed by the Council on Quality and Leadership (1997) and focuses on measuring personal outcomes achieved by human service organizations.

The NCI project began in 1997 as a collaboration of the Human Services Research Institute (HSRI), the National Association of State Directors of Developmental Disability Services (NASDDDS), and member state agencies to systematically measure performance and outcomes in a state developmental disabilities service system. Today, 30 states participate in the initiative, with each state using surveys of consumers, families, providers, and the state's service system data to monitor system performance, systemic changes over time, consumer outcomes, and satisfaction. The "Consumer Survey" portion of the NCI is of particular interest to the NTI SD. It measures indicators related to quality of life and consumer satisfaction, and includes domains related to home, health, community inclusion, friends and family, rights and privacy, and satisfaction with services. The Consumer Survey is an open-ended standardized instrument consisting of questions that are answered by individuals receiving services as well as items that may be answered by a proxy. Its psychometric properties were established using test-retest reliability and estimates of face validity provided by a panel of experts. Various indicators have been developed from subsets of items, such as scales for choice and community inclusion. Additional indicators that tap into complex variables like "individualization of services" and "person-centeredness" are under development. The NTI SD project will critically examine these scales to determine their usefulness in measuring the systemic implementation of evidence-based practices in self-determination over time, and their impact on quality of life outcomes for individuals with intellectual and developmental disabilities. There are several advantages to using the NCI Consumer Survey and relevant scales for the purposes of this project. As noted, the measurement system has been adopted in 30 states to date, the psychometric properties of the instrument have been established, and the survey is administered annually in each state, allowing for year-by-year and state-by-state comparisons.

The approach taken by CQL led to the development and publication of the *Personal Outcome Measures* assessment. This instrument is designed to measure quality in services and supports for people with developmental disabilities in terms of personal outcomes for the service recipients (rather than compliance with organizational process). Since 1993, CQL has maintained a database of information collected during Personal Outcome Measures interviews with over 6,500 individuals having disabilities. The current version of the Personal Outcome Measures instrument contains 21 personal outcomes, many of which are specifically related to self-determination, such as "*People choose where and with whom they live*" and "*People choose where they work*." CQL has published findings from the data and has demonstrated the validity of the instrument and the reliability of the review and interview methodology.

Together these measurement tools offer two key methods for assessing how well developmental disabilities service systems support the development of self-determination, and how that relates to improved quality of life for service participants. Using these instruments to track system performance and consumer outcomes will ensure that the proposed NTI strategy for scaling-up self-determination builds on evidence from different state systems and results in meaningful changes in the end stage users' (i.e., consumers') lives.

Despite the supportive national policy context and the creation of new state infrastructures to promote self-determination, people with intellectual and developmental disabilities continue to experience limited choices in services, work options, and living arrangement, and are not fully included in the community. The NTI approach to scaling-up existing policies and practices supporting self-determination is designed to address this reality. Whenever possible, it will build upon the scaling-up conceptual model by Dunlap et.al. (2009) that describes four sequential phases: emergence, demonstration, elaboration, and system adoption and sustainability. The NTI approach has three components, each of which may support activities in one or more of the four sequential phases: 1) the compilation of relevant content and creation of a knowledge dissemination website; 2) state summits to create participant buy-in and develop state-specific strategies for scaling-up efforts to promote self-determination; and, 3) a program of ongoing technical assistance, information and support to strengthen the capacity of key stakeholders in each state in their scaling-up activities.

**Knowledge Dissemination Website.** A major goal of the NTI SD project is to vet, codify, and integrate existing knowledge and evidence-based practices to promote self-determination, as well as to develop new products and tools. This information will be collected and organized so as to focus the existing "implementation science" related to the successful scaling-up of efforts to promote self-determination. It will then be disseminated through a project website, which will include a searchable, electronic resource guide of approaches, strategies, resources, and curricula that promote self-determination and have been used successfully by people with developmental disabilities, their families, or support professionals.

**State Summit Framework.** The NTI SD State Summits will be designed to scale up efforts to promote self-determination through the adoption of policies, practices, and implementation of strategies that promote widespread, sustained use of evidence-based practices that promote self-determination and lead to improved quality of life outcomes across the lifespan. The NTI SD project plans to sponsor these Summits as a vehicle for scaling-up self-determination, in which stakeholders can come together to develop a common understanding of system gaps and best practices related to self-determination, as well as potential strategies to promote self-determination. The Summit Framework will be based on an approach developed in 2009 by the Association of University Centers on Disability (AUCD), in which regional (multi-state) Summits were used to help states address issues of early identification of autism.

The NTI SD project will work with up to six states per year over three project years to conduct state summits on promoting self-determination. States will be recruited to participate in the project through the AUCD network and will be provided mini-grants from the NTI-SD project to cover some costs. A state leadership team will be formed composed of key stakeholders, including the UCEDD, state DD councils, state DD agencies, other state agencies, self-advocacy groups, parent and family groups, workforce representatives, and service providers. With support from the NTI SD project, the state leadership team will conduct pre-summit planning activities and will: 1) conduct an initial needs assessment or environmental scan using NCI data or other state data analyses; 2) decide on a focus area or areas for the summit (e.g., self-advocacy and leadership, community living, work and contribution, relationships and community participation, health and safety, transition, person-centered planning, self-directed services and supports, future planning), as well as potential "transformation zones" for vertical scaling-up; 3) recommend a preliminary strategy to measure the impact of the summit; and 4) identify other stakeholders who should be invited to participate.

The state summit agenda will facilitate "buy-in" to the goal of the summit through the participation of state and national policy leaders. To provide a venue for shared learning, the summits will include: a) the perspective of people with developmental disabilities and families on the importance of self-determination; b) research findings and practices of experts who have developed evidence-based self-determination models; and c) systems experts who understand vertical scaling-up and how to institutionalize the policies and infrastructure needed to support self-determination practices. Finally, summit participants will have opportunities for sharing and collaborating on exercises designed to develop a statewide action plan and priorities. The development and implementation of this plan will serve as an important outcome of the NTI SD.

**Follow-Up for Sustainability.** Scaling-up is a complex process, and its strategies and processes are implemented within the context of complex, bureaucratic, service delivery systems. A state summit can be an effective means to develop a state plan that identifies priorities and produces a roadmap to guide action. It can also be used

to build linkages, partnerships, and strategic alliances with stakeholders, both vertically and horizontally, who are focused on extending evidence-based practices to support self-determination. But ongoing support and follow-up are needed in order to sustain these efforts. The NTI SD project plans to provide small implementation grants to states through UCEDDs as a follow-up to the state summits to assist with implementation of the state's action plan. The NTI SD project will provide ongoing technical assistance, information, and support to strengthen the capacity of key stakeholders within each participating state in order to scale up self-determination effectively.

**Conclusions**

The challenges to scaling-up efforts to promote self-determination are not insignificant. Sufficient rigor exists within the knowledge base on the effects of promoting self-determination to justify its scaling-up and broad-based diffusion (Rogers, 1995). The pathways for doing so have been clearly demonstrated by professionals in other disciplines and their important work will be used as guideposts in adapting these strategies for effective application(s) within the developmental disability field. The work of Dunst et al. (2006) provides an especially compelling example of how this goal can be conceptualized and achieved successfully within the closely allied field of early intervention. The state summit approach to the vertical scaling-up of SD within developmental disabilities provides an exceptional opportunity for collaboration and the forging of working partnerships among important elements of the national DD service delivery network (e.g. UCEDDs, DD Councils, the U.S. Administration on Developmental Disabilities, state and local agency personnel, individual and family consumers, the U.S. Administration on Developmental Disabilities, and key advocacy organizations on behalf of persons and their families with developmental disabilities). It will also provide a venue for the identification of obstacles and sources of resistance to scaling-up practices in self-determination so that proactive strategies can be developed and planned. The NTI consortium on SD looks forward to participating in and coordinating these activities over the next four years.

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## Appendix A

## Seminal Examples of Horizontal Scaling-Up

**Example 1:** ***Meaningful Differences in the Everyday Experiences of American Children***

**Description**: This book reports a remarkable 2 ½ year study of the language environments provided by 42 families who were categorized as professional, working class, or welfare. For each month of a 2 ½ year period, one full hour of each spoken word between parents and child was recorded in the homes of these families. The study revealed that between professional and welfare families, there was a difference of almost 300 spoken words per hour and by age three, the children of professionals had larger vocabularies than the parents in the welfare families. By age nine, the dramatic differences in the children's language experience predicted large differences for them in schooling outcomes favoring the children of professional families. The publication of the findings of Hart and Risley had a profound impact on the thinking of professionals regarding the relative advantage and disadvantage that educational and SES levels make in the lives and prospects of children. The policy and practice implications of this research have been widely felt and it has influenced professionals in a number of disciplines and a range of federal and state agencies. This study's results received widespread coverage in the national media and they were also presented before the U.S. Congress.

**Source**: Hart, B., & Risley, T.R. (1995). Meaningful differences in the everyday experiences of young American children. Baltimore, MD: Paul H. Brookes.

**Example 2: Longitudinal Study of the** ***Social Development Intervention in Children***

**Description**: This comprehensive, longitudinal investigation of the Social Development Intervention was conducted in 15 elementary schools in Seattle, WA., serving at-risk neighborhoods. The overall goal of the study was focused on preventing mental health, sexual risk, drug abuse, delinquency and school problems of at risk youth through early intervention in school contexts. Its goal was to prevent long-term destructive outcomes among study participants; the intervention was developed by researchers in the school of social work at the University of Washington (Hawkins and colleagues, 1999; 2008). The intervention procedure involved three major components: 1) teacher training in classroom instruction and management strategies, 2) child social and emotional skills instruction, and 3) parent training. This intervention was remarkably successful in preventing a host of health risk behaviors in late

adolescence and early adulthood and fostering more favorable adjustment, educational attainment, and mental health. This longitudinal study provides one of the most compelling demonstrations of the efficacy of high quality early intervention. It has been highly influential in shaping national policy as well as state and local practices, and is one of the most often cited pieces of research in justifying prevention through early intervention during the early school years.

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**Example 3: *Multisystemic Therapy* (MST)**

**Description**: MST is an ecological family intervention that addresses tertiary-level children and youth who are severely at-risk for a host of destructive outcomes (i.e., delinquency, drug abuse, neglect, school failure, and so forth). MST is based on nine core principles and is a carefully manualized intervention that focuses on family preservation and support to promote positive adjustment of at risk youth and reduce emotional and behavioral difficulties. MST is included as one of the "Blueprint" violence prevention programs validated at the Center for the Study and Prevention of Violence at the University of Colorado. It is a highly cost-effective program and has been carefully researched. For each dollar invested in the cost of implementing MST, an average of $13.36 is returned in benefits. MST has been widely disseminated and adopted by many communities across the U.S. MST is one of the most widely used and effective interventions for preventing delinquency and in reducing risk factors and enhancing offsetting protective factors among vulnerable children and youth.

**Source**: Henggeler, S.W. (1998). Multisystemic therapy. In D.S. Elliott (Ed.), Blueprints for violence prevention. Boulder, CO: Center for the Study and Prevention of Violence.

**Example 4: DIBELS (Dynamic Indicators of Basic Early Literacy Skills)**

**Description**: DIBELS is a formative early literacy assessment created by Roland Goode, Ph.D., and Ruth Kaminski, Ph.D. of the Dynamic Measurement Group. DIBELS is used by kindergarten through sixth grade teachers in the U.S. to screen for whether students are at risk for reading difficulty and failure. It can also be used to monitor student progress and guide instruction. The DIBELS procedure is composed of a developmental sequence of one-minute timed measures of the following literacy skills: recognizing initial sounds, naming the letters of the alphabet, segmenting the phonemes of a word, reading nonsense words, oral reading of a passage, retelling and word use. DIBELS makes it possible to identify struggling readers very early in their school careers. Currently, DIBELS is used in approximately 15,000 U.S. schools and continues to be in very high demand by educational professionals.

**Source**: Dynamic Measurement Group, 132 E. Broadway, Suite 136, Eugene, OR, 97401, email: info@dibels.org.