

**Defining and Measuring Systems Change for State and
Territorial Councils on Developmental Disabilities:**

A Concept Paper with Embedded Recommendations



May 2011

The 2000 reauthorization of the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act) directs State Developmental Disabilities Councils (DDC) to engage in advocacy, capacity building and systemic change activities that contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system that includes community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families. [Section 101(b)]. The key DD Act goals for Councils are to advance independence, productivity and inclusion of people with developmental disabilities. These broad and vital mandates form the core of what Councils seek to do, and why their work is so important.

However, the DD Act does not include definitions for the prescribed activities. The lack of definition and a science behind the concept of systems change has posed persistent limitations for the DDCs to provide appropriate, consistent, standardized performance information that can be aggregated across states and territories. A concomitant problem is that systems change, capacity building and advocacy are processes " not outcomes " which is contrary to the current outcomes-focus in performance measurement. With increased focus on program evaluation and systems change in the federal arena, the body of information on systems change, while still small, is beginning to emerge.

Thus, as a starting point, the National Association of Councils on Developmental Disabilities (NACDD) proposes the following definitions of systems change, capacity-building and advocacy:

- **Systems change**¹ is a process that shifts the way that an organization or community makes decisions about policies, programs, and the allocation of its resources . and, ultimately, in the way it delivers services and supports its citizens and constituencies (modified from Comprehensive Community Change Initiatives - http://www.ccitoolsforfeds.org/systems_change.asp).²

¹ **Systems change** is defined in the Family Support title of the DD Act as: The term "systems change activities" means efforts that result in laws, regulations, policies, practices, or organizational structures-

- (A) that are family-centered and family-directed;
- (B) that facilitate and increase access to, provision of, and funding for, family support services for families of children with disabilities; and
- (C) that otherwise accomplish the purposes of this title.

A comparable definition is found in the Technology Act with bullets that fit the intent of that particular legislation.

² While not elaborated in this definition, this also includes intangible community resources that include acceptance, encouragement and support for participation of individuals with developmental disabilities and their families in their communities.

- **Capacity building** activities expand and/or improve the ability of individuals with developmental disabilities, families, supports, services and/or systems to promote, support and enhance self-determination, independence, productivity and inclusion in community life (FL DDC).
- **Advocacy** is active support of policies and practices that promote self-determination and inclusion in the community and workforce for individuals with developmental disabilities and their families (DD Act).

Current Trends in Measuring Performance

The focus of DDC work is consistent with current federal stewardship guidelines circulated by the federal Office of Management and Budget (OMB/ Metzenbaum, 2010) that require program managers to:

- focus on achieving ambitious performance goals
- use a constructive performance review process
- look at trends, causal factors, and alignment of action to outcomes within a detailed analysis; and
- share resultant information with the public.

More discretely, the work done by DDCs is compatible with federal stewardship guidelines which call for (OMB/Metzenbaum, 2010):

- setting specific outcome-focused goals,
- measuring progress,
- tracking completion of key milestones,
- comparing programs across peers,
- looking for factors that can be influenced,
- contributing to identification and development of promising and evidence-based strategies,
- confirming achievement of intended outcomes,
- quickly adjusting ineffective strategies,
- encouraging adoption of effective strategies, and
- sharing lessons learned in useful and accessible ways.

This illustrates a clear focus on outcomes and impact to inform policy development, refinement, and change. As a result, ongoing analysis of evaluative information for all activities focused on achievement of a given objective is used to identify trends, causal factors, alignment of actions to outcomes, and prepare resultant information for sharing with relevant stakeholders and the general public.

The recent enactment of the GPRA³ Modernization Act of 2010 (P.L. 111-352) incorporates program improvement and sustainability as a focal area. Furthermore, the American Evaluation Association (2009), in its *An Evaluation Roadmap for More Effective Government*, calls for strengthening the connection between evaluation, performance measurement and the laws that Congress enacts. Thus, a careful balance must be maintained between attaining outcomes with documenting the systems change process in changing conditions for our work to be truly sustainable, with the latter being the crux of DDC work.

In summary, there is a critical need to tie performance measurement for DDCs to the spirit and intent of the DD Act. Specifically, the DD Act calls for increased choice and control; increased consumer involvement in decisions that affect their lives; prevention of abuse and neglect, and increased independence, productivity and inclusion of individuals with developmental disabilities and their families in their communities. This framework extends beyond actual provision of services and supports to the mindset and practices of communities in accepting, encouraging, and supporting participation.

By design, DDCs are not direct service providers nor are DDCs directly responsible for the life outcomes of individuals with developmental disabilities but we are vitally concerned about those life outcomes. Using the work of Deming (1982) as guidance, State Councils on Developmental Disabilities would not be viewed as a part of the general flow of human services programs. We perform supplementary activities that improve and refine those processes " a research and development function, a human resources function, etc. Using this conceptualization, a two stage process, possibly a circular process, is envisioned. The outcomes of the broader service delivery system (i.e., NCI, CMS and other national data systems) are used as the inputs in the systems change logic model. DDCs are then responsible for making appropriate changes to the system. When those changes come to fruition in a sustainable manner, ' our job is done" (so to speak). Those efforts and those of a multitude of other players feed into national data sets and trend analysis over time. When properly monitored, the resultant outcomes, once again, become inputs into the DDC logic model for yet another change effort. Overall, this approach is consistent with current thinking about performance measurement for programs, like Councils on Developmental Disabilities, with a mission directed toward improving system policy and practice.

We must pay close attention to the data systems that define and track individual outcomes, but they are not an appropriate measurement tool for Council work. Careful monitoring of national data and trend analysis would more appropriately be an Administration on Developmental Disabilities (ADD) function as they monitor progress of the national mission and purposes of the DD Act " as illustrated below.

³ Governmental Performance and Results Act of 1993

The Big Picture

Performance measures demonstrating the impact of the DD Act are best designed, developed and reported through ADD, where all DD Act programs converge and through their collective and collaborative contributions implement the overall national mission and purpose of the DD Act. Currently, performance measures citing individual State Councils on Developmental Disabilities, Protection and Advocacy Programs (P&A) and University Center for Excellence in Developmental Disabilities (UCEDD) initiatives and accomplishments do not form a cohesive and accurate picture of the impact of the DD Act programs.

As noted above, performance measures for DD Act programs and for ADD should be based on:

- The specific purposes included in the DD Act - increased choice and control; increased consumer involvement in decisions that affect their lives; prevention of abuse and neglect; and increased independence, productivity and inclusion of individuals with developmental disabilities and their families in their communities;
- The success of state-administered federal programs⁴ in achieving these principles across the lifespan; and
- The impact of the DD Act programs toward increasing the success of federal funds and programs to promote the independence, productivity, and inclusion of individuals with developmental disabilities in their communities.

We propose that State Council performance measures tie directly to individual Council State Plans. The Council State Plans emerge from the comprehensive state assessment, a critical component of our work specified in the DD Act. State Plans should be structured similar to a logic model that lends itself to measuring, at the state level, long term systemic change and critical milestones.

An important component of the systems change support needed from ADD is proactive guidance that provides coaching on key policy issues, and expected goals and outcomes. Another component might be formative and summative evaluation assistance that examines whether and how specific activities contribute to systems change goals and outcomes (i.e., self-advocacy). Also, assistance and feedback from ADD can help states sharpen their focus on how best to achieve the changes in policies and institutional practices that can best benefit individuals with developmental disabilities and their

⁴ This could also include state level programs where that is appropriate.

families. The need for consistent messages to all DDCs about expectations and ongoing constructive support toward helping them achieve their systems change goals is inherent.

The ADD role should include designing, developing and issuing a national report that effectively demonstrates the impact of the DD Act and its programs. We recommend that this process be conducted by independent evaluator(s) working together and using multiple sources of information and data, such as:

- Focus groups, or other appropriate data collection strategies, with people with developmental disabilities and their family members to illustrate impact on constituents;
- Community and government partner interviews, or other appropriate data collection strategies, to illustrate impact on disability and non-disability community groups and state programs;
- Illustrations from state DD Act program sites and initiatives; and
- Sustainability assessment, specifically have DD Act programs contributed to lasting improvement to federally funded programs for individuals with developmental disabilities.

Historically, the national report about the work and impact of Councils was based on state generated data using the existing performance measurement system. Both NACDD and ADD agree that this approach has not effectively demonstrated the impact and success of the DD Act, Councils and the DD Network, nor has it been an accurate representation of the role, purpose and successes of Councils. A national frame of reference is critical, with State program performance tied to the national goals in the DD Act; additionally, State data and examples can be used to show impact.

An example of this approach was used by the Substance Abuse & Mental Health Services Administration (SAMHSA) for a national evaluation project for systems change (Hodgdon, 2011). SAMHSA used three different independent evaluation contractors evaluating discrete programs and then asked them to work together on a national effort to evaluate the impact of the overall program. State level programs contributed to the evaluation by carrying out specific objectives on the local/state level and all contributed to the overall national program goals and provided examples of impact on citizens and local community institutions.

Performance Measurement vs. Performance Management

Performance measurement and/or performance monitoring is not the same as performance management. The concept of performance management encompasses a

diversity of data collection and reporting strategies which are matched to the needs and questions of stakeholders (which can include auditing, evaluation, monitoring, etc.). It also includes structures and processes for actually having people think about the data and integrate findings into their work. Current conceptions of data use tend to focus only on the production of measures and reporting of results via dashboards in the name of "data-driven decision-making;" thus, we are recommending that the broader performance management perspective be developed and used as described above.

With that in mind, the National Association of Councils on Developmental Disabilities (NACDD) asked its members for contributions which resulted in the following proposed logic model for systems change that can be used to guide the work of DDCs and feed into an ADD performance management system.

A Proposed Logic Model for Systems Change

Systems change is a complex process. It involves a dynamic set of inter-relationships and multiple dimensions. Councils are positioned in the DD Act to set in motion a unified process that will lead to far reaching results. DDCs are concerned with modifying large community and government systems for two purposes: 1) to turn marginalized and fragmented approaches into a comprehensive and effective system; and 2) to integrate that system into the larger community of services and resources. Our work can and will be sustained if, and only if, it is meaningful to all who are affected by the changes in policy and/or practice.

The method that we propose for improving the documentation of Councils..work is based on strands of several frameworks have been combined into a global logic model for guiding systems change initiatives:⁵

- The Route to Success framework (PA DDC, 2009) for effecting systems change is a conceptualization that includes improving the knowledge base, selecting social strategies, engaging stakeholders, support for policy entrepreneurs, and effectively using unexpected events (or 'tipping points' " see Gladwell, 2000, 2008);⁶
- The four areas of change that occur when systems change activities have been successful " policies and procedures, infrastructure, design and delivery of services, and expectation of consumer outcomes and experiences (Newman, 2001, 2002);⁷

⁵ These are consistent with the Comprehensive Community Initiative framework and toolbox for federal staff working on systems change which is described in Appendix A.

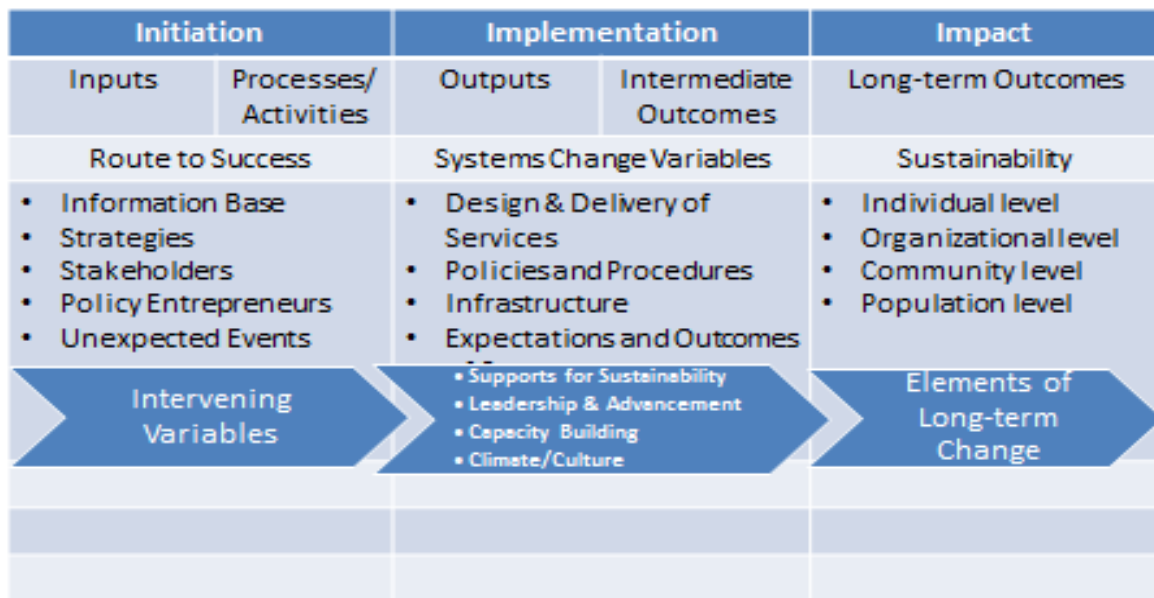
⁶ See Appendix B for a description of the Routes to Success.

⁷ See Appendix C for a description of these areas of change.

- A recent delineation of the dimensions of sustainability of funded work that differentiates sustainability at the individual, organization, community and population levels with an emphasis on sustainability of concepts rather than maintenance of funding for specific programs or projects (Scheirer, 2010).⁸

Taken together, these frameworks comprise the following logic model for systems change. This approach assumes each state DDC chooses their systems change goals with activities and strategies to achieve them. The *logic model* provides the structure so that state level systems change is viewed as tangible and concrete and that the proposed activities are designed to achieve the intended objective. This level of focus and connectedness is critical to moving systems change initiatives forward so that the various components are directed to coherent and meaningful long-term outcomes. Explanation of each element of this logic model follows in the appendices to this paper.

An Example: Logic Model for Systems Change



From Newman and Lobosco, 2010

Performance Measurement

A common problem in evaluating programs with systems change intents is the need to move the focus of the evaluation from documenting individual outcomes (e.g., benefits

⁸ See Appendix D for a discussion of dimensions of sustainability.

received from a particular program by members of a target audience) to systemic outcomes that affect multiple dimensions - fiscal strategies, public policies, service coordination, cultural competence, and that include all stakeholders as decision-makers. Although individual outcomes may still be a part of the documentation effort, a systems change initiative extends beyond individual outcomes and programs to multiple entities and often the entire community. While most performance measurement systems are a 'snap shot' in time, in order to be effective, systems change must be measured over a longer period. Consequently, the program planning, initiation, performance measurement and program evaluation processes for systems change initiatives need to:

- Define the complexity of the system and identify and define systems parts and their relationship across and within the system that is to be changed;
- Envision the desired outcomes and define the steps necessary to effect the desired change;
- Identify relevant inputs and resources including funding, personnel, organizational structures, policy and procedural factors, and interactions needed to facilitate or support the desired changes; and
- Clarify the purpose of the evaluation, the sphere of stakeholders, and how the evaluative information is to be presented, at what points in the evaluation process, and to what audiences.

Recognizing that DDCs, historically and persistently, have been held to service provision standards despite their work being more akin to Research and Development and process-driven, as is the nature of systems change, a reasonable and effective performance measurement system needs to be developed that takes into account the DD Act mandate as well as those related to Office of Management and Budget mandates " with far less of a reliance on individual outcomes. This includes a focus on:

- a) increased choice and control (DD Act);
- b) increased consumer involvement in decisions that affect their lives (DD Act);
and
- c) efficiency/economy in use of taxpayer funds (OMB).

Within these three focal points, consideration must also be given to key concepts in the DD Act which define the desired outcomes of DDC work in terms of benefits to individuals with developmental disabilities and their families:

- increased independence;
- increased productivity;
- increased inclusion in community life; and
- prevention of abuse and neglect.

There is reasonable agreement among State DDCs that the following reflect the DDC systems change intent.⁹ While there is agreement that these are areas of focus for a performance measurement system, the actual dimensions of each category need to be further clarified, operationalized and possibly, though not necessarily, quantified - for example, developing a defensible standardized list of elements, program components, or benchmarks for each area.

- **Policy and Program Changes** - Formal and informal operational and organizational policies and procedures that guide the everyday work of a system or community and may be tied to authorizing legislation.
- **Service Design and Delivery** - Processes that envelop program content, formal communication, supporting theories and knowledge base, design delivery, capacity, outreach, and how the above are arranged/configured to address service needs of the constituency, and expected outcomes.
- **Infrastructure** - The underlying foundations or basic framework of a system or organization (i.e., resource allocation and organizational structure; it includes the resources that are devoted to its existence including, most notably, funding, personnel, equipment, space, partnerships and collaborations) and how they are configured, prioritized and deployed.
- **Attitudes, Experiences and Expectations of Consumers** - The expectations of program consumers and providers (i.e., a redefinition of what should be expected and delivered from a program, not just more of the same).¹⁰
- **Engagement and Empowerment of People with Developmental Disabilities and their Families** as active participants in decision-making, including serving in elected, appointed or other official capacities, on advisory and planning boards and participation in leadership development activities.
- **Sustainability** – Assessment of the success of sustaining Council work beyond its immediate funded activity and into the future, including sustainability of programs, funding or concepts/principles. To date, DDC performance indicators have not addressed the ultimate intent of sustainability of our work; thus, carefully thought out measures of sustainability need to be devised that consider

⁹ *These are concepts, not specified wording, that will need to be operationally defined.*

¹⁰ There are three major reasons for systems change in human services programs: 1) to improve participant outcomes (i.e., higher achievement); 2) to promote greater efficiency (i.e., serve more people with the same resources or serve the same with fewer resources); or 3) to employ a different guiding philosophy (i.e., provider-directed vs. consumer-directed services).

sustainability not just at the project level but at the individual, organizational, community and population levels.

Our recommendation is that the emphasis be placed on developing a broader performance management system for ADD; Appendix E includes a list of current or slightly modified performance measures which can be looked at for compatibility within that broader performance management system. Though, we caution, once again, aggregation of these performance measures has not and will not be an accurate reflection of the quantity and/or quality of DDC work. While the regular collection and reporting of data to track project performance and results serves DDCs internally, the usefulness of this data at the federal level needs further examination.

Recurring Themes

There are several recurring thoughts that have permeated discussion of DDC performance measurement that need to be fully considered as a performance management system is devised and the performance measurement system is refined so that the resultant product provides both an accurate and fair assessment of the work being done by DDCs.

Differences Across States - Integral to this discussion is the intent of the DD Act to allow latitude for states to differ in their approach to effecting systemic. States have very different human services delivery systems, resources (DDC and other), and cultures which affect the process and content of their work. The State context is essential to explaining and understanding the significance of actions taken and their impact over time. Two points for consideration:

1. While in some cases, acknowledgement of State differences can be accommodated by absolute and clear definitions of performance indicators, it also means that latitude is necessary to account for those state differences;
2. Provide allowances for state defined performance indicators (that may be more qualitative in nature) based on the specific work they are doing and the desired outcomes.

Annual Performance Versus Long-Term Sustainability - A consistent theme raised in discussion of performance measurement for DDCs is the disconnect between annual performance indicators and the long-term impact and sustainability for DDC systems change work. While the accountability framework for federal programs is likely to maintain a reliance on annual assessment of progress, stewardship guidelines are also looking for information that can only be obtained with a long-term view of DDC work. The current performance measures are a 'snap shot' in time and not necessarily reflective of, nor do they measure, change over time. Using a performance management framework, it has been suggested that it would be useful to use a performance measurement system that includes long-term performance measures related to Council state plans and allows

DDCs to collect baseline information and monitor long-term impact of DDC efforts would be useful.

Quantitative Versus Qualitative Information " Given that the intent of the DD Act is to do work that results in improved quality of life for people with developmental disabilities and their families, greater allowance for assessment and presentation of the qualitative aspects of DDC work has been suggested.

Collaborations and Partnerships - While the knowledge base, or science, surrounding systems change is relatively modest, a key theme throughout the entire body of knowledge is the integral importance of collaborations and partnerships as essential to successful systems change efforts. Each strand of the above logic model contains some recognition of the importance of collaborations and collaborative efforts " citizen participation and engagement, building trust, and forging common purposes are essential to transformative and change efforts. However, this also raises the persistent question of ' when can we take credit for?' Current guidance suggests that ' if you can see your paw print in the change, you can claim credit.'" While DDCs are in the best position to determine when and where they can claim credit, there needs to be consensus on more definitive decision criteria in this area.

Support and Educating Communities - The DD Act concept of supporting and/or educating communities needs elaboration. A key DDC activity is helping people and communities to get and use the information they need to make informed decisions and promote change efforts, i.e., improved knowledge and/or skills, however, this indicator (or set of indicators) needs to be framed in a way that allows DDC to measure and report without undue drain on resources.

Using Logic Models - While the above logic model is a reasonable map for the national programs and each of our state programs, a word of caution is needed on how to use logic models in DDC work. ' Logic models illustrate the causal relationships among program elements and define program success'" (OMB guidance to program managers, 2006) and program logic models have been ' warmly embraced'" by the Office of Management and Budget (OMB) (Julnes & Rog, 2007). Thus, for several years, there has been a heavy reliance on logic models - and **fidelity to those logic models** - in federal programs.

For programs which are evidence-based and have a well-tested program theory, this is a valid requirement which should increase effectiveness and efficiency of the program. However, for programs intending to promote systems change and build the evidence-base, the **function of the logic model needs to be different** with less reliance on fidelity to the logic model and more of a focus on use of logic models to document the **evolution of an emerging programmatic framework** as elements are tested for effectiveness and efficiency in DDC demonstrations. Using a well thought out logic model to initiate a program with routine revisions to that logic model as the program is

implemented and moves toward greater maturity will do just that and provide the evidence-base for replication and scaling up efforts (which are generally beyond the purview of DDC demonstration efforts).

Use of National Data and Databases - While there is some expressed desire to use national data sets, such as the National Core Indicators (NCI) in a performance measurement system for DDCs, there are difficulties and challenges with this concept. For the most part, the link between DDC work and the national data sets is not immediate and it may take years for that data to move significantly enough to be used to assess systemic performance and, thus, would not be useful in an annual assessment of DDC performance. While DDC efforts certainly contribute, they are one of several contributory factors to systemic movement with too many intervening variables to be used fairly in an annual assessment of performance. Furthermore, not all states participate in NCI which would definitely limit the ability to aggregate data and do trend analysis.

There are some elements in the systems and administrative data of the National Core Indicators, for instance, which might be useful in the state plan evaluation over a longer period of time. NCI provide valuable data in nearly half the states, including data from consumer and family surveys that offer information on experiences, outcomes and perceptions of people with developmental disabilities and their families. On the whole, NCI data offers a good measure of where states stand in terms of services and supports for people with developmental disabilities and their families, and how states are changing over time. Expanding the NCI to all states could be beneficial and increase the value of core indicators. As previously noted, NACDD recognizes the challenge of linking NCI data to Council work; however, we also believe that there could be a legitimate way to use NCI data as a component of evaluating the long-term effectiveness of the broader developmental disabilities networks in the states.

What This Means:

This document explores the framework for and underpinnings of system change as it relates to performance measurement for DDCs. It defines system change as a process that shifts the way that an organization or community makes decisions about policies, programs, and the allocation of its resources . and, ultimately, in the way it delivers services and supports its citizens and constituencies.^{11,12} It, then, provides the three major compartments for the different stages of system change:

¹¹ While not elaborated in this definition, this also includes intangible community resources that include acceptance, encouragement and support for participation of individuals with developmental disabilities and their families in their communities.

¹² This point is modified from Comprehensive Community Change Initiatives - http://www.ccitoolsforfeds.org/systems_change.asp

- **Initiation** (or planning) which addresses what to think about and include in order to achieve system change as the council is initiating its goal;
- **Implementation** including where to look for and measure changes that will lead to system change (i.e., outputs - these measures are not unlike some of those we have used historically); and
- **Impact** including categories to measure the sustained shift in the way an organization or community makes decisions about policies, programs, and the allocation of its resources -- and, ultimately, in the way it delivers services and supports to its citizens and constituencies.

Any effective evaluation and measurement of systems change must loop back to the definition of systems change. Did what we defined as 'system change' actually occur? Effective measurement of system change, within a broader performance management effort, should then be based on whether the shift was sustained at the individual level, organizational level, community level and/or population level. More specifically:

- for the individual level outcome - was there a sustained shift in the benefits or outcomes for an individual with developmental disabilities because of what decisions were made, how an organization made those decisions, and in the way services/supports were delivered;
- for the organizational level - was there a sustained shift in the specific program activities because of how an organization made decisions and in the way services and supports were delivered;
- for the community level - was there a sustained shift in enhanced community or organizational capacity because of how a community or organization made decisions and in the way services/supports were delivered;
- for the population level - was there sustained attention to the issue or problem via dissemination or replication because of how a community made decisions and in the way services/supports were delivered.

NACDD and its member Councils acknowledge and appreciate the challenges of defining and measuring systems change. We also appreciate the need for accountability, including illustrating program effectiveness, particularly in this era of limited resources and budget cuts. Now more than ever, it is imperative that Councils be measured on what they actually do, and how this work affects people with developmental disabilities, their families and communities in the long term.

We look forward to working with ADD, our DD network partners, and relevant others to strengthen meaningful program evaluation that results in stronger Councils doing more good for more people.

Background Information

Appendix A: Using the CCI Conceptualization of Systems Change

Appendix B: Routes to Success

Appendix C: Areas of Change

Appendix D: Dimensions of Sustainability

Appendix E: Performance Measures

Using the CCI Conceptualization of Systems Change

Recent emergence of a Toolkit for Federal Staff Who Work With Comprehensive Community Initiatives (2009) highlighted the difficulties of working on a systems change mission that paralleled those experienced by DDCs over the last two decades. Its compatibility with the spirit and intent of the Developmental Disabilities Assistance and Bill of Rights Act Title B Programs makes it a valuable resource.

This website was developed by an outside evaluation/technical assistance consultant using data and information from the funded programs and their work over time. As such, a useful outcome of the Westat Study of DD Act Programs might be a similar toolkit for DDCs.

A Comprehensive Community Initiative (www.ccitoolsforfeds.org) is defined as an effort to better the lives of children, youth and families through systems change work. It recognizes the systems change as different from a conventional service-delivery and as challenging to plan and implement. Several characteristics set CCI apart from conventional service delivery programs; they:

- **take a broad view of community problems** (Step back to see the problem in its entirety and take into account the range of factors that impact a problem. social, economic, political, and geographic);
- **engage all sectors of the community** (Reach beyond traditional agencies to engage members of nontraditional and natural networks);
- **use long-term strategies** (Systems change takes time requiring long-term projects, extending beyond typical Federal funding cycles of 1 to 5 years);
- **build trust and forge common purpose** (Systems change ultimately comes down to collaborative working relationships . along with the drive and collective purposes that sustain them);and
- **encourage participatory decision-making** (Requires that all stakeholders - community members, grant staff, evaluators, technical assistance providers, and funders - come together to make decisions and carry out the work in structures that tend toward the nonhierarchical and form a learning community).

When funds are spent just to deliver services, their impact is limited to the people who receive those services. But when funds are devoted also to systems change, their impact can extend beyond a single program . to multiple programs, agencies, and service recipients, or to the entire community . and far into the future. For this reason, funders are more and more interested in systems-change efforts. Even when funding provides for the time to build collaborative relationships and structures, day-to-day pressures divert

energy and focus from the long-term, systems-change work, to the immediacy of service delivery. It takes vigilance to maintain the vision of the initiative. Thus, funds from the federal Office of Juvenile Justice and Delinquency Prevention were used to develop a toolkit for federal staff overseeing systems change endeavors.

In the CCI conceptualization, **systems-change** is a change in the way that a community makes decisions about policies, program services, and the allocation of resources. It enlarges who participates in decision making to include families and others affected by decisions. As a result, decisions reflect a larger, better-informed perspective on family and community needs and priorities. To undertake systems change, a community must build collaborative bridges among multiple agencies, community members, and other stakeholders. (Comprehensive Community Change Initiatives/
http://www.ccitoolsforfeds.org/systems_change.asp)

A system is a collection of components that interact with one another to function as a whole. Systems change may involve.

- Shifting system components and/or their sequence
- Shifting interactions between system components
- Altering the "whole" through shifts in underlying choices, as well as.
- Shifting the manner in which the system provides feedback to itself.

(Adapted from Foster-Fishman et al., Using a Systems Change Approach to Evaluate Comprehensive Community Change Initiatives)

Systems change takes place in multiple dimensions. These dimensions are interconnected so that a change in one supports change in all the others. To truly transform community systems, shifts are required that rely on:

- Joint governance and shared decision-making " including all affected by decisions in the decision making so those decisions reflect a larger, better-informed perspective on needs and priorities;
- Cultural competence - knowledge and skills to help understand, appreciate, and communicate with people whose culture and life experience differ from others;
- Service coordination and integration - looking at the total service-delivery system, identifying gaps, duplication, and overlaps in services to ensure that a person seeking help encounters a seamless path through the services they need;
- A unified fiscal strategy - looking collectively at all the funding streams and other resources already devoted to solving the problem, they may be able to reconfigure these multiple streams to use funds more efficiently and /or identify new sources of funding to fill gaps and expand services;
- Supportive public policy " looking beyond formal written laws, regulations, procedures, and protocols to the unwritten, informal culture of agencies and organizations and the way people are accustomed to doing things to identify and rectify barriers and contradictions.

Because systems change is complex, involves diverse stakeholders, multiple programs and wide ranging activities drawing resources from many sources over a long period of time, logic models are viewed as an essential foundation and tool for all aspects of the change effort throughout the life of the project.

Appendix B

Routes to Success

The Pennsylvania Developmental Disabilities Council funded a project, called **Route to Success**, with the Human Services Research Institute (HSRI) and the Temple University Institute on Disability to identify indicators for DDC funded projects that are likely to result in positive systems change for people with developmental disabilities. In this conceptualization, systems change involves making changes in the way major parts of community service systems are linked together and how they function (Center for Civic Partnerships, 2001); focus on goals or outcomes; is usually a result of small steps taken over time; typically is spurred on by a dedicated group of advocates and/or an individual champion, working in collaboration; and see individual advocacy as essential.

The conceptualized model is based on the work of John Kingdon (2003) and Julius Richmond (1983) who both posit that system change results when a number of activities addressing different parts of a system come together. System change is not the direct result of one of these kinds of activities but rather results when efforts in each of the areas converge to bring about system change. These efforts do not need to be sequential; rather, regardless of sequence, efforts in several areas together are more likely to result in change. This conceptualization was tested with funded projects and the following five (5) activities are necessary for systems change to occur and define the work of systems change:

1. **Improving the knowledge base:** System change is more likely when people representing a wide range of stakeholders have common information, detailed information, and reliable information about the nature of the problem, possible solutions, and the impact of various courses of action. Projects that focus on the following kinds of activities are addressing the area of improving the knowledge base:
 - Identifying the specific problems, collecting data about population trends or unmet needs, identifying or examining potential solutions, best practices, or discovering the social determinants that exist
 - Disseminating the information or data gathered in a variety of formats, to a range of stakeholders

2. **Selecting clear social strategies:** Accomplishing a particular goal is more likely when activities have been planned to account for a range of social points of view. Projects that focus their efforts on the following kinds of activities are addressing the area of using clear social strategies:
 - Identifying the constraints around a particular course of action, documenting contributions (in terms of activities, support, resources) toward a particular cause, establishing clear, simple to understand goals, identifying and recruiting key players to the effort, developing a plan of

action in which players, responsibilities, outcomes and evaluation strategies are detailed, organizing institutional support for a course of action, and celebrating the successes of particular efforts

- Establishing a need for a particular data set and then going about gathering data to address concerns or barriers
- Sharing this information broadly, so that a range of stakeholders can become involved and informed
- Building coalitions, formal or informal, to address a problem

3. **Obtaining stakeholder involvement:** Broadly defined, stakeholders come from a variety of backgrounds and have unique experience and capacity to become involved in system change. The force and energy that can be brought to a problem is greatly increased when many stakeholder positions are involved. Persons with disabilities, families, providers, agency managers, politicians play powerful roles in all system change. Projects that examine or seek to influence the climate in which a project is undertaken are directed at obtaining stakeholder involvement and creating the momentum within different stakeholder groups to take action. Such projects are often engaged in some or all of the following:

- Identifying who cares about the project/problem/situation, describing how this problem with this population relates to other problems with other populations, connecting this particular problem with greater, more broadly experienced problems, building on already existing or already successful efforts of others, analyzing the complexity, difficulty, or urgency of the problem
- Bringing like stakeholders together to share experiences and ideas and to build an action strategy
- Bringing different stakeholders together to foster coordination and collaboration among them
- Developing common content so that all stakeholders can be part of building the same case for change

4. **Supporting policy entrepreneurs:** Policy entrepreneurs are those people who become champions of a cause, those who are willing to take a public stand about the importance of an issue or a possible solution to a problem. While projects do not necessarily have to have a policy entrepreneur, those that have them use them and celebrate them. ' Policy entrepreneurs'(1) were rated as very or somewhat important in 15 out of 23 case studies of critical factors in policy change; further, they were seen as the key to sustainable change.

5. **Using unexpected events:** There are those times when events, that cannot be anticipated, have a significant impact on the success of an activity. Projects cannot anticipate the occurrence of such events; by definition, they are

unpredictable, accidental. However, projects must be prepared and ready to seize opportunities that these unexpected events offer. Sometimes the event celebrates a wonderful new step toward a goal; sometimes the event highlights a crisis or a terrible problem for the services system. In either case, these unanticipated opportunities should be seized for the additional momentum they may give.

The conceptualized model has since been applied to DDC process in a variety of ways to clarify purposes of the work and its connections to ongoing efforts inside and outside of the DDC with an eye to meeting the mission, including:

- Grantee applications:
 - Thinking about projects as they are planned for strategic identification of needed work and project scope of work as well as clarifying the larger context of project work
 - Applying the model while projects are in process to review progress, promote the project, and look for unexpected events
 - Using the model at the end of a project to identify alliances, champions, next steps, directions and lessons learned with an eye to the broader context.
- DDC applications:
 - Drafting Requests for Proposals (RFPs)
 - Working with funded projects and connecting those projects to one another
 - Planning long-term and building on past work

Appendix C

Areas of Change:

Newman (2001, 2002) and colleagues developed and piloted an evaluation model where systems change is viewed as an active process that is developmental in nature " not an outcome but actions that lead to incremental steps or progress. The model assesses systems change according to three developmental levels " initiation, implementation and impact " that can occur in a cyclical fashion. As the organization changes, it is important to document activities, learning, uses and outcomes that are occurring at each phase. This evaluation model has been used in education, substance abuse, technology, mental health and developmental disabilities venues in over 100 program evaluations (Newman, 2008; Newman, Smith, Geehan, & Viamonte, 2004); a meta-evaluation of these studies revealed four key factors as occurring when true systems change has occurred:

- **Policies and procedures** " formal and informal operational and organizational policies and procedures that guide the everyday work of the program/organization/system;
- **Infrastructure** " underlying foundations or basic framework of a program/organization/system (i.e., resource allocation, organizational structure, communication systems);
- **Design and delivery of services** " processes that envelop program content, formal communication, supporting theories and knowledge bases, design, delivery, capacity, outreach and the like; and
- **Expected outcomes/experiences** " the expectations and experiences of program consumers and providers (i.e., redefinition of what would be expected and delivered from a program not just more of the same).

Following are a brief definition and an overview of each of the above described ' legs" of systemic change, some examples of successful practice, and key indicators for when documenting systems change. Wherever possible, the examples are framed in terms of participation of critical stakeholders, but especially program consumers.

Operational and organizational **policies and procedures** guide the everyday work of most, if not all, programs. It is a rare program that does not have a ' policies and procedures manual" for its staff. Since policy and procedure changes can be minimal or pervasive, minor or major, the difficulty arises in measuring the magnitude of change in terms of actual impact. There is also a comparable difficulty in measurement of efforts that prevent a ' bad" (albeit well-meaning) policy or procedure change that would have a detrimental effect upon the lives of real people. If policy/procedure changes are being tallied, a ' bad" change and a ' good" change are counted equally and there is no indicator of magnitude. Similarly, government funded programs are guided by legislation and regulation " all work done under that funding must be consistent with the letter and intent of those policies. Examples of changes to policies and procedure systems change might include:

- Major or pervasive change: new or amended legislation at any level of government that creates, deletes, or expands a service option used by many people (i.e., changes in age at which social security can be tapped).
- Minor or minimal change: a minor wording change in current program regulations or forms that may change a select type of service for a select group (number of minutes allowed in a mental health 'hour').

Of note - These examples do not qualify the change as 'good' or 'bad;' rather, it is noted that a component of the supporting systems has been changed.

Key indicators of participatory systems change in policies and procedures include:

- Initiation: 1) involvement of all stakeholders in the identification of the policies and procedures that are needed to support the changes and in discussions of how these policies and procedures will be developed; 2) involvement of all stakeholders in identifying which policies and procedures work and which need to be restructured; and most importantly, 3) acknowledgement of the need for, and subsequent placement of, all stakeholders on any policy and procedures decision making teams.
- Implementation: 1) an acknowledged role for all stakeholders in overseeing the implementation of policies and procedures; and 2) the development and assessment of outputs and outcomes that encompass policies related to all stakeholders; all stakeholders have a voice in modifying these policies as they are examined via formative evaluation.
- Impact: 1) Changes in policies and procedure that impact the organization's regulations for all stakeholders including rights and responsibilities for all groups; and 2) The rights of all groups are weighed equally in the planning and implementing summative evaluation and the subsequent decision making process.

The **infrastructure** of a system represents the underlying foundation or basic framework that holds it together and allows it to function; it includes the resources that are devoted to its existence including, most notably, funding, personnel, equipment, space, partnerships and collaborations. These resources can be prioritized and deployed in various configurations to attain differing results; consequently, there are as many infrastructure arrangements as there are programs and systems. Examples of changes to systemic infrastructure change include

- Special education: moving from self-contained classrooms to inclusive classrooms (changes in space, staffing requirements, classroom equipment, and partnerships).
- One-stop access to services: moving from insulated, hierarchical access to complimentary coordinated services (inter- and intra-agency collaboration, funding, personnel training/knowledge).

Key indicators of participatory systems change in infrastructure include:

- Initiation: 1) All stakeholders are part of the planning process and in identifying which components of the infrastructure need to be supported, enhanced, added or removed. 2) When envisioning the new or enhanced infrastructure, resources necessary to support all stakeholders e.g., staff, administrators, consumers, parents, advocates, and community members, are considered.
- Implementation: 1) The needs identified above are prioritized and decisions in support of their acquisition are made based on a ' democracy' policy. 2) While not all needs may have equal weights, the implementation of all resources is considered with justifiable reasons, accepted by a consensus building process, used to prioritize the implementation process.
- Impact: 1) Changes in infrastructure are assessed and valued based on the needs of all stakeholders, not just on ' economy' or ' efficiency'. 2) All stakeholders continue to have a voice in the summative evaluation and in revising the goals of the project. 3) Values of different stakeholders are included in the discussion of needs and continue to be a supporting process for the delineation of future changes in resources.

It is within the **service design and delivery** processes where the program becomes most evident and where most traditional program evaluation occurs. Key system concepts include program content, formal communication systems, supporting theories and knowledge base, design delivery, capacity, outreach/advertising, etc. How all of this is arranged and configured to address one or more service needs defines the program, its constituency, and its expected outcomes. What many program implementers forget is that a change in design and delivery of services generally requires a change to the supporting system that supports the delivery. Examples of changes to the design and delivery of services include:

- Technology integration: Moving from stand-alone curriculum on how to use technology and the use of technology labs to curriculum and instructional practices that view technology as a tool for teaching and learning (change in content, communication, supporting theories of pedagogy, and design and delivery of information)
- Person centered planning: Moving from top-down expert referent decision making to purposeful consumer involved information sharing and decision making (changes in communication, supporting approaches, design and implementation of service delivery, and capacity to serve).

Key indicators of participatory systems change in design and delivery of services include:

- Initiation: As is typical in participatory processes, representatives of all stakeholder groups should be part of the design and delivery of services. During this stage, there should be a sharing of visions and values of what constitutes services and, if resources are limited, in prioritizing who gets what services and to

what degree. The development of service outcomes is key at this phase and should represent all groups.

- **Implementation:** Implementation activities should reflect the appropriate services to stakeholders, and from a systems change viewpoint, should reflect meeting outputs that will lead to outcomes and associated indicators. Key to this stage is formative evaluation; this process should match the general tenets of participatory evaluation. Program modifications should be based on consensus building among the stakeholders and a re-clarification of visions, strategies, or indicators as needed to promote sustainability.
- **Impact:** The impact stage of delivery and services further extends traditional participatory evaluation of the program to examination of the outcomes from the viewpoints and values of all stakeholders. The delineation of significant changes, their impact on stakeholders, and the valuing of the impact should represent a collaborative process of data analysis, interpretation and reporting. The presentation of the final summative report should convey the voices of all participants along with information on the weight of those voices in design, implementation, and analysis.

In looking at **expected consumer outcomes and experiences**, there are three major reasons for seeking systems change in education and human services programs: 1) to improve participant outcomes (i.e., higher student achievement); 2) to promote greater efficiency (i.e., serve more people with the same amount of resources or serve the same number with fewer resources); or 3) to employ a different guiding philosophy. (i.e., move from provider-directed to consumer-directed services, or teacher-centered to student-centered practices). In each instance, the experiences and outcomes for program participants will be different " receipt of new, more or higher quality services, greater improvement in learning or physical well-being, greater responsiveness or satisfaction, increasing capability, and the like.

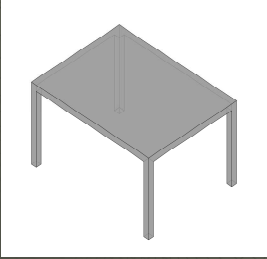
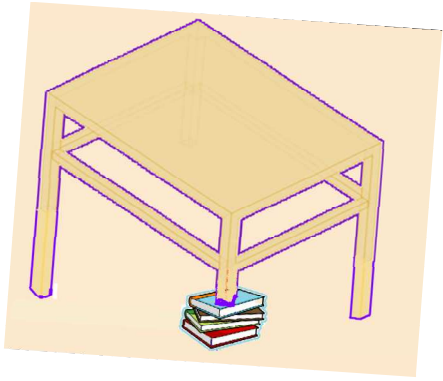
- **Deinstitutionalization:** Providing family supports (respite, home modifications, service coordination, sibling programs, counseling, etc.) to families of children with significant disabilities allowed families to keep their children living at home rather than admitting them to an institution. In this instance, more families receive needed assistance, it is done for a lower cost, the children are more functionally capable, and it maintains families in communities (rather than growing or maintaining segregated institutions).
- **School Counseling:** Moving from a ' silo" approach to treatment of K-12 social, behavioral and academic issues where parents and teachers meet with different service teams to a ' braided" approach that recognizes that the three are interrelated and must be addressed in a unified approach (Change in parent expectations of services, counselor expectations of their role in providing services, and student expectations of their role as learner).

Key indicators of participatory systems change in expected consumer outcomes and experiences include:

- Initiation: 1) all stakeholders or their representatives are involved in a discussion of what the new expectations will be for the end consumers (e.g., better incoming skills, more exiting knowledge and abilities, etc.); 2) expectations (and objectives) reflect changes in all stakeholders perceptions of their own skills and planned interactions; and 3) strategies are developed that include ways to transfer expectations for all parties including in-depth communication of visions, sharing of needs, and a discussion of different philosophies.
- Implementation: 1) all stakeholders receive active learning or assistance in sharing expectations and the verbalizations of expectations and indicators. Other activities include sharing of values as a part of the process. 2) formative evaluation assesses an understanding of these new expectations and the degree to which they are accepted and 3) program modification and revisioning is used to reinforce these new expectations and their acceptance.
- Impact: 1) summative evaluation documents sustainable, integrated changes in expectations of consumers and the perception of all stakeholders on what the consumers can do; 2) these expectations continue to 'fuel' further growth in expectations and the search for ways that involvement can be increased.

Newman and Lobosco (2007) and Lobosco and Newman (2007) have conceptualized these four factors as table legs that support a systems change platform¹³. When the systems change effort is initiated, all four legs do not have to be perfectly balanced. A wobbly table can still serve its intended purpose though the wobble may be annoying, at best, or an impediment, at worst. If the legs are too far out of balance, however, the table may become non-functional or hazardous and not serve its purpose as a secure platform. Thus, attention to all four legs is essential as the systems change effort proceeds and " from a formative perspective, help program managers to see where work still needs to be done.

¹³ *There is another set of concomitant factors which brace the systems change table legs though their exact placement has not yet been defined. Those factors are climate and culture, capacity building, support for sustainability, and leadership and advocacy.*

<h3 style="text-align: center;">“Legs” of Systems Change</h3>  <ul style="list-style-type: none"> ◆ Policies & Procedures ◆ Infrastructure ◆ Design & Delivery of Services ◆ Expected Outcomes/ Experiences 	<h3 style="text-align: center;">A “WOBBLY” PLATFORM</h3> 
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This point is especially important because, rarely, do systemic change efforts intend to totally overhaul or replace a program or set of programs; it is more likely that systems change efforts will be explained as programmatic refinement. It is also more likely that those refinements and change efforts will begin by focusing on one of the four ' legs of the systems change table' " those key areas of change that occur when systems change efforts are successful. It is important to keep the dynamic nature of systems change firmly in mind because changes to one table leg will inevitably have an impact on the other three. For example, one cannot simply change policies or procedures without assessing what concurrent changes may need to be made to the infrastructure, the design/delivery of services/supports, or people’s expectations of and experiences with the program.

Appendix D

Dimensions of Sustainability

The term sustainability (Shulha, Lee, & Van Melle; 2001) also includes the concepts of usability,¹⁴ maintainability,¹⁵ replicability,¹⁶ and transferability.¹⁷ These concepts are particularly important to funders who see them as key indicators of change, including systems change, because of their link to: 1) the ability of a grant funded demonstration or pilot program to sustain and maintain itself once the demonstration period and grant funding is exhausted, and 2) the ability to take the change that has occurred under grant funding and disseminate to, and replicate in, other settings. The emphasis is on stimulating integral and pervasive change that withstands the test of time " while also acknowledging the continuous and cyclical nature of systems change.

For purposes of DDC work, sustainability is what happens to a program or intervention after external funding ends. It is the capacity to endure; development that meets the needs of the present without compromising the ability of future generations to meet their own needs; equity over time, being fair and sensitive to future generations as we play out the present.

Sustainability is more than making sure that there is a funder after our project funds are exhausted and it needs to be considered from the very outset of our work. We want the ' concepts" that we are working on to survive, to grow and flower, and to take on a life of their own - in some way, shape or form - that may or may not mean the specific project gets an infusion of funds to continue. However, there are states that have laudable service systems, or laudable elements of the service system, but it has grown at an unsustainable rate and it is being increasingly threatened as money gets tight. There are those who have said that the system is fundamentally flawed because it is creating huge dependency on public funding when it should be creating less dependence on and greater independence from the system and considering how to create capacity and a sense of responsibility in the community for support of all citizens.

Scheirer (2010) notes that sustainability is important to funders, to community partners, and to the program itself as the focus moves from program outcomes to longer term effectiveness and ability to scale up or replicate the program more broadly. This perspective is developmental in nature as sustainability is affected by all the earlier stages of problem identification, solution specification, implementation, achievement of outcomes, and the question of future use. Four levels of sustainability are identified:

¹⁴ *Having utility and especially practical worth or applicability*

¹⁵ *To keep in an existing state - preserve from failure or decline*

¹⁶ *Capable of being duplicated or replicated*

¹⁷ *To convey from one person, place, or situation to another*

- Individual/client-level outcome " sustaining the benefits or outcomes for consumers;
- Organizational-level outcome " sustaining specific program activities;
- Community-level outcome " sustaining enhanced community or organizational capacity (coalition, partnership);
- Population-level outcome " sustaining attention to the issue or problem via dissemination or replication.

While it is laudable to identify sources of funding to keep specific projects going beyond the DDC funding stream, the focus is largely on maintaining and building on the concept that was demonstrated. A few key questions arise:

- How is sustainability measured?
- What about unintended and negative consequences?
- When to assess sustainability and maintenance or deterioration over time?
- Is there a threshold that can be used to determine sustainability?
- How much adaptations can occur and still be the same program?
- Does continued existence mean it was caused by the initial funding source?

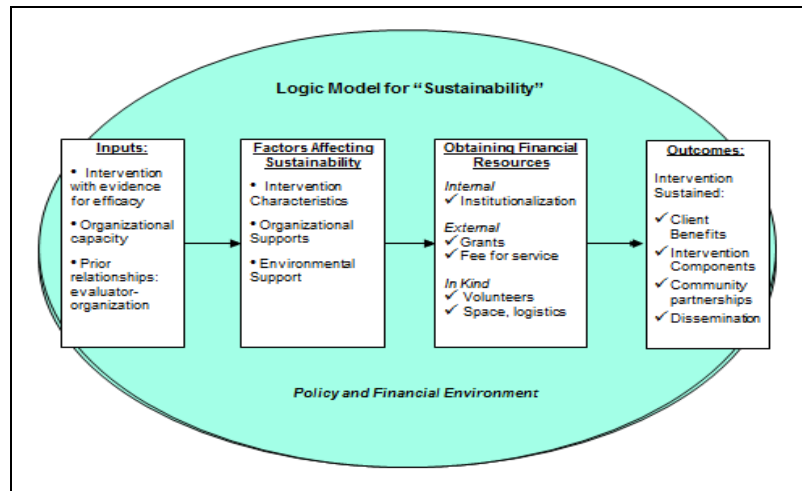
Unfortunately, like many other areas of systems change, the knowledge base is sparse as most sustainability studies did not look at a uniform set of factors, used retrospective data collection and relational analysis, focus largely on health programs, and had relatively small samples. However, those studies did identify the following factors influencing sustainability:

- Project design/characteristics
 - The intervention is flexible and adaptable enough to be modified from its original form
 - Low personnel cost or volunteer-driven
 - Evaluation was done and showed effectiveness (or had a reputation for effectiveness)
- Organizational factors:
 - Good fit between program and host agency mission, objectives and operating routines
 - Presence of an internal ' champion"
 - Organization has strong existing capacity
 - Benefits ' felt" by agency and/or staff
- Community involvement or environment
 - Presence of external funding
 - Non-monetary support by other community organizations

Additionally, sustainability of evidence-based programs includes four (4) major processes/levels of decision making and/or support:

- Information dissemination based on the demonstration, including how the change agents work

- □ Decision to adopt/use the program based on program attributes and adaptability
 - □ Implementation processes in each adopter organization, including an implementation support system; and
 - Sustainability based on active or passive rejection of the innovation
- Using this information, a logic model for sustainability was developed:



From Scheirer, M.A. (2010)

The NYS DDPC (2010) has, in turn, taken this and other information on sustainability and developed a compendium to guide its work. This compendium identifies 5 critical points, or phases,¹⁸ for doing work toward conceptual sustainability of its funded efforts. This compendium is supplemented by a delineation of roles and responsibilities for the DDPC and its funded programs as related to sustainability. The compendium also includes questions to answer and potential activities for each phase. The five points are:

1. **Design Phase** (Initiation, Pre-Start Up) where extensive information gathering and analysis is conducted to assure that the program is designed to take into account all relevant programmatic factors;
2. **Delivery Phase** (Implementation, Funding Cycle) where possible resources and assistance to funded projects are identified and provided;
3. **Diffusion Phase** (Scaling Up, Replication, Expansion) where strategies are identified for disseminating information and encouraging conceptual sustainability in the field;
4. **Time Out and Turn Around** (Your decision points. ' If this does not happen by____, then what turnaround strategy or what last resort will you use?") where alternatives for assisting unsuccessful endeavors are identified; and
5. **Exit Phase** where potential activities for assuring long-term sustainability are considered as the focus of funded effort move to other concerns.

¹⁸ The assistance of Jon Vogelsang is noted with appreciation in the identification of the five phases of sustainability work identified in this Compendium.

This compendium, while having a very short life thus far, is viewed as a valuable asset to maintain a focus on sustainability of DDC work from identification of the problem and programmatic concept through the entire life of the funded program and beyond.

Appendix E

Performance Measures

There are some key factors which can provide a reasonable start towards developing a set of performance measures for DDCs once the broader performance management system is identified. This is, by no means, exhaustive in scope " nor, is it recommended. However, if it is necessary to have a fairly limited and discrete set of performance indicators, supplementing that data with information that is more qualitative in nature is viewed as desirable though aggregation of that data across states does not provide a valid assessment of DDC work. There is reasonable agreement amongst DDCs that the following outputs (or, at best, initial outcomes) reflect the DDC systems change intent:¹⁹

- policies/procedures created/improved/refined/deleted;²⁰
- programs created/improved/refined/deleted;²¹
- use of funds - leveraged/allocated/reallocated/dedicated;
- individuals/family members participating in policy/advisory/planning/ governing bodies;
- people trained in content areas/systems advocacy/self-advocacy;²²
- people involved in self-advocacy;
- people engaged in systems change efforts;
- organizations engaged in systems change efforts, including best practices developed, implemented and replicated;
- organizations involved in coalitions/networks;²³
- policymakers reached²⁴

It is possible that the identified performance measures (and others to supplement them such as measures of supporting/educating communities, infrastructure elements, sustainability) might fit into an overall framework such as:

¹⁹ *These are concepts, not specified wording, that will need to be operationally defined.*

²⁰ *possibly with an eye to impact at the individual/organizational/community/population levels*

²¹ *possibly with an eye to impact at the individual/organizational/community/population levels*

²² *These are all separate types of training and should not be aggregated – however, training was felt to be a critical activity to systems change*

²³ *This needs to be supplemented with a measure of citizen participation.*

²⁴ *While there is a feeling that reaching policy makers is an essential activity, there is also concern about its use as a performance indicator so refinement in wording or definition is needed.*

Area of Change	Definition	Implications for Performance Measurement
Policies & Procedures	Formal & informal operational & organizational policies & procedures that guide the everyday work of the system and maintain consistency with authorizing legislation.	<p><u>Increased choice/control (i.e., more self-determining)</u></p> <ul style="list-style-type: none"> • Policies/procedures created/improved/refined/ deleted <p><u>Increased consumer involvement in decision making</u></p> <ul style="list-style-type: none"> • self-advocates trained (or individuals trained in self-advocacy) • individuals/families on policy/advisory bodies • policymakers reached • individuals/family members engaged in policy change or systems improvement <p><u>Efficiency/economy (i.e., collaboration & decreased reliance on Medicaid)</u></p> <ul style="list-style-type: none"> •
Infrastructure	The underlying foundations or basic framework of a system or organization (i.e., resource allocation and organizational structure; it includes the resources that are devoted to its existence including, most notably, funding, personnel, equipment, space, partnerships and collaborations " and how they are configured, prioritized and deployed.	<p><u>Increased choice/control (i.e., more self-determining)</u></p> <ul style="list-style-type: none"> • use of funds - leveraged/allocated/ reallocated/dedicated <p><u>Increased consumer involvement in decision making</u></p> <ul style="list-style-type: none"> • individuals/families on planning/ governing bodies <p><u>Efficiency/economy (i.e., collaboration & decreased reliance on Medicaid)</u></p> <ul style="list-style-type: none"> • dollars leveraged/saved • organizations involved in coalitions/networks
Design and Delivery of Services	Processes that envelop program content, formal communication, supporting theories and knowledge base, design delivery, capacity, outreach and the like; it includes program content, formal communication systems, supporting theories and knowledge base, design delivery, capacity, outreach/ advertising, etc., and how they are arranged/configured to	<p><u>Increased choice/control (i.e., more self-determining)</u></p> <ul style="list-style-type: none"> • programs created/improved/refined/deleted • individuals/families/providers trained in content <p><u>Increased consumer involvement in decision making</u></p> <ul style="list-style-type: none"> • individuals/families/providers engaged in change efforts • organizations engaged in change efforts (including best practices developed, implemented and replicated) <p><u>Efficiency/economy (i.e., collaboration & decreased reliance on Medicaid)</u></p> <ul style="list-style-type: none"> •

	address one or more service needs defines the program, its constituency, and expected outcomes.	<u>Other:</u> <ul style="list-style-type: none"> • Products developed • Products disseminated • General public reached
Expected Consumer Outcomes/ Experiences	The expectations of program consumers and providers (i.e., a redefinition of what should be expected and delivered from a program not just more of the same). ²⁵	<u>Increased choice/control (i.e., more self-determining)</u> <ul style="list-style-type: none"> • people trained in self-advocacy • people involved in self-advocacy • people benefitting • families benefitting • consumer satisfaction survey data <u>Increased consumer involvement in decision making</u> <ul style="list-style-type: none"> • trained in systems advocacy • individuals/families engaged in systems change efforts. <u>Efficiency/economy (i.e., collaboration & decreased reliance on Medicaid)</u> <ul style="list-style-type: none"> •

²⁵ *There are three major reasons for systems change in human services programs: 1) to improve participant outcomes (i.e., higher achievement); 2) to promote greater efficiency (i.e., serve more people with the same resources or serve the same with fewer resources); or 3) to employ a different guiding philosophy. (i.e., provider-directed vs. consumer-directed services).*

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*1660 L Street, NW, Suite 700
Washington, DC 20036
202.506.5813 (Phone)
202.506.5846 (Fax)
www.nacdd.org*