

How the Supports Paradigm Is Transforming the Developmental Disabilities Service System

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Abstract

The supports paradigm is based on the premise that the most relevant difference between people with intellectual disability and related developmental disabilities (ID/DD) and the general population is that people with ID/DD need different types and intensities of support to fully participate in and contribute to society. The supports paradigm is changing professional work and public policies in the field of ID/DD by providing a conceptual basis for aligning the work of researchers, policymakers, and professionals at micro (individual), meso (organizational), and macro (jurisdictional) levels. The potential of the supports paradigm to transform the adult service system is discussed.

Key Words: *intellectual disability; developmental disabilities; support needs assessment and planning; resource allocation*

When Urie Bronfenbrenner (1979) developed his ecological theory of human development, he posited that human growth and development is influenced (both positively and negatively) by systems operating at different levels in relation to the individual. Although Bronfenbrenner ultimately proposed five different systems, the three systems most applicable to those interested in human services targeted to people with intellectual disability and related developmental disabilities (ID/DD) are the micro (individual), meso (organizational), and macro (jurisdictional) levels (see Schalock et al., 2010). The focus of this article is on how the supports paradigm conceptually aligns professional work and public policy at all three levels.

Butterworth (2002) described the supports paradigm as follows:

The New Supports Paradigm suggests that individuals should first, without restriction, define the lifestyles they prefer and the environments they want to access. Their goals and priorities then become the basis for intensity and types of support they need to succeed in those environments. (p. 85)

Butterworth wisely draws attention to the connection between the concept of personalized supports and the rights of people with disabilities. The supports paradigm can only be understood within the context of the self-determination and self-advocacy movements of the past 30 years. People with ID/DD seek more than to be passive recipients of services. Additionally, they seek support to live, love, work, play, and pursue their life aspirations just as others do in their community.

In *No Pity*, a seminal work documenting the growth of the disability rights movement, Shapiro (1993) reported on the enigmatic life of T.J. Monroe. Although Monroe had an untidy personal life and clearly was not accessing the personalized supports he needed, his leadership was inspirational. After observing Monroe addressing a crowd of self-advocates at a People First meeting, Shapiro writes that

Monroe and the three hundred people at the hotel ballroom are trailblazers of the self-advocacy movement, a new and spreading crusade of people with mental retardation to make their own decisions about everything

from where they live to what they are called. (p.184)

Shapiro further writes, "As Monroe points out, however, if self-advocacy is a revolt against professionals and the nonretarded world, it also, paradoxically, remains dependent on people who are not retarded" (p. 187). Therefore, there is not a need for people in professional roles to go away and leave people with ID/DD alone. What is needed is for professionals to focus their efforts on supporting people with ID/DD in ways that empower people with ID/DD to lead full and meaningful lives of their own choosing.

Understanding people's dreams, goals, and preferences requires that their voices must be heard (even when a person is nonverbal). Therefore, the supports paradigm is grounded in listening to the voices of people with ID/DD. However, the supports paradigm goes beyond listening to and respecting people with ID/DD. It calls for arranging systems of support that effectively address the mismatch between what people with ID/DD are able to do without extraordinary supports, and the requirements for human performance that are integral to activities and settings in which they want to participate. Effectively arranging supports that are truly personalized is the overarching purpose that coalesces the intent of public policies and funding, the actions of jurisdictional agencies, the missions of community-level provider organizations, the activities of planning teams that are formed around individuals with ID/DD, and the work of direct support professionals.

Paradigms and Paradigmatic Shifts in the Field of ID/DD

Understanding Paradigms

Contemporary use of the term "paradigm" is attributed to the science historian, Thomas Kuhn (1962). Kuhn indicated that a paradigm was the collective set of beliefs and assumptions shared by scientists in a given field. A paradigm provides the basis for scientific progress because it provides the foundation for a collective research agenda. Put another way, a paradigm enables multiple participants to engage in a collective effort to solve problems and develop new knowledge. A scientific revolution or paradigmatic shift occurs when new research findings demonstrate that an existing paradigm does not provide adequate explanations

for what has been observed, and a new paradigm is introduced that provides more satisfying explanations. Often, new paradigms do not so much displace older paradigms as much as they build upon or expand them. For example, Einstein's theory of relativity did not falsify Newton's theory of gravitation, but rather added to it.

Kuhn's (1962) analysis of paradigmatic shifts was focused on the natural sciences. A strong case can be made that social sciences and applied fields (such as ID/DD) do not have the same types of unifying paradigms that are found in the natural sciences. Still, professionals working in the ID/DD field often share common conceptualizations and beliefs that shape their approach to daily work. Therefore, a broader definition of paradigm that is applicable to professional work in applied fields is one that refers to a shared worldview that connects practices at an individual level with priorities and missions of organizations at the community level, and with policies and decision making at the systems level.

We believe that there was a major paradigmatic shift in the field of ID/DD in the 1960s and 1970s with the introduction of the principle of normalization and establishment of a community-based service system, and that today's field is in the midst of another paradigmatic shift associated with the supports paradigm. These paradigmatic shifts have shaped ways in which individuals with ID/DD are understood, ways in which service delivery systems are organized, and the focus of public policies.

From the Medical-Institutional Paradigm to the Normalization-Community Services Paradigm

The first efforts to comprehensively describe and classify people with ID/DD occurred in the early 1900s, and the medical paradigm drove activity at the individual, organizational, and systems levels. According to the medical model, ID/DD is best understood as a defect within the individual. In addition to accepting ID/DD as an internal defect, by the 1920s there was widespread consensus that the extent of the defect could be measured efficiently by an IQ test. Analogous to measuring blood pressure with a sphygmomanometer, defining and measuring intellectual deficit using an IQ test was totally consistent with a medical approach. A troubling offshoot of the medical paradigm was the eugenics movement, which held

that defects within people with ID/DD were not only personally debilitating but also a threat to the health and well-being of the general population. Just as certain diseases are contagious and need to be controlled, the threat to society posed by the menace of the feeble-minded was presented as a cause for alarm (see Gould, 1981; Scheerenberger, 1983; Wehmeyer, 2013).

The medical paradigm dominating the first half of the 20th century provided a unified conceptualization of ID/DD that aligned efforts at the systems, organization, and individual levels. At the systems level, society's obligation was to provide care for people with ID/DD in a manner befitting other chronically impaired patients. Additionally, the medical paradigm justified efforts to protect the general population from people with ID/DD, as well as protect people with ID/DD from themselves. At the systems level during the first half of the 20th century, public funding was almost entirely invested in building and sustaining large, congregate residential institutions, mostly in rural areas. The institutions were designed to be more like prisons or hospitals than like homes. Among the most shameful public policies were mandatory sterilization laws (Scheerenberger, 1983; Wehmeyer, 2013).

At the organizational level, the medical paradigm called for residential institutions to be organized like hospitals, placing medical professionals at the top of the hierarchy and frontline caregivers at the bottom. At the individual level, Wolfensberger (1972) noted that, from a medical perspective, people with ID/DD were "exempted from normal social responsibilities" (p. 23) because they were considered to be incapable. Although not expecting people with ID/DD to hold a job was perceived to be a reasonable approach to take toward people who were chronically incapacitated, this particular implication of the medical paradigm deprived people with ID/DD of opportunities to make contributions to their world. Thus, the net effect was a dearth of opportunities to fulfill higher-order human needs such as the needs for socialization, self-esteem, and self-actualization (see Maslow, 1943).

It is unlikely that paradigmatic shifts in an applied field such as ID/DD will ever occur overnight. Change takes time and vestiges of prior paradigms will remain, sometimes for good reasons. Although the medical paradigm certainly had severe shortcomings, a superficial dismissal of all medical approaches to the ID/DD model can

lead to an unfair characterization of medical doctors and other health care professionals, as well as a devaluation of medical skills and knowledge. Silverman (2009) pointed out that certain causes of ID/DD have been virtually eliminated in industrialized countries due to advances in medical research and interventions (e.g., congenital hypothyroidism is caused by iodine deficiency and can be addressed by the availability of iodized salt; phenylketonuria [PKU] is an inability to metabolize phenylalanine and can be addressed through newborn screening and adherence to a specialized diet; exposure to rubella had severe effects on developing fetuses but has been eradicated because vaccines were developed). Medical research and interventions focusing on curing and/or preventing specific conditions remain relevant to today's field of ID/DD. Schalock et al. (2010) discussed how medical services could be understood and delivered in the context of a system of "health supports" that are part of a broader system of personal supports.

From the Normalization-Community Service System Paradigm to the Supports Paradigm

The normalization-community service system paradigm emerged in the second half of the 20th century as an alternative to the dominant medical paradigm. During the 1950s, a number of factors led to the rapid growth of a community-based service system where the educational, residential, and vocational needs of people with ID/DD were addressed in local communities instead of institutions. The deinstitutionalization movement, fueled by parent advocacy groups such as the Arc, took hold in the United States and throughout the industrialized world (Scott, Lakin, & Larson, 2008; Martinez-Leal et al., 2011). In regard to public policy, the goal of deinstitutionalization was to return institutionalized people to home communities and prevent future admissions to institutions through the availability of community-based service systems (Thompson & Wehmeyer, 2008). During a 20-year period, from 1967 to 1987, the population of citizens living in state institutions dramatically dropped by 81% (from 194,650 to 36,650) despite a growing population (Scott et al., 2008). This fact alone provides compelling evidence that, by the 1980s, the normalization-community service system paradigm had displaced the medical paradigm as the dominant paradigm

for the field of ID/DD in terms of guiding professional work at the individual, organizational, and jurisdictional levels.

Nirje's (1969) and Wolfensberger's (1972) principle of normalization focused on normalizing environments, daily routines, and social roles in society. Two assumptions underlying normalization were: (a) people with ID/DD valued the same types of life conditions and experiences as people from the general population valued; and (b) people's deficits in functioning were exacerbated by environmental factors, particularly living life in an institution.

Although few would argue that the movement away from institutional services to community-based services was a significant step forward, concerns about the primacy of service provider organizations in the lives of people with ID/DD grew as community-based services grew. Community service provider organizations were criticized for creating programs that did not meet the individual needs of people. Group homes, sheltered workshops, and special recreation programs were criticized for promoting segregation from the larger society and establishing organizational control over people's lives. There was a growing concern that many people with ID/DD were physically present in their communities, but were not truly participating in or contributing to their communities (Meyer, Peck, & Brown, 1991; Ferguson, Hibbard, Leinen, & Schaff, 1990).

During the 1980s, a new paradigmatic shift began, one that focused on promoting personalized supports and encouraging self-determination. At first this shift centered within the family support movement whereby family-centered and directed approaches took form, including initiatives to provide families of children with ID/DD direct fiscal support (e.g., cash subsidies) and empower family members to have greater say over the policies and practices that affect them (Agosta, 1989; Knoll et al., 1990).

In the 1990s, this shift expanded to include new approaches to service delivery that provided people with ID/DD choices and promoted people's self-determination. For example, new means emerged where public funds were allocated directly to people with disabilities and their families so that they could direct and manage their services. In addition, people were encouraged to purchase supports that were not available through the traditional systems of service delivery (Stancliffe & Lakin, 2005).

Professional work in the field of ID/DD is becoming more aligned with the supports paradigm every day. At the micro (individual) level, the transformation has focused on supporting people in ways that address each individual's support needs and result in valued personal outcomes. At the meso (organizational) level, the transformation has focused on organizational efforts toward improved effectiveness, increased efficiency, and continuous quality improvement. At the macro (jurisdictional) level, public policies (such as the emergence of individualized budgets) are evolving that are intended to empower people with disabilities to access personalized supports and experience improved personal outcomes.

The Supports Paradigm at the (Micro) Individual Level

People With ID/DD in the Driver's Seat

Aligning the work of planning teams and direct support staff with the supports paradigm can be accomplished by focusing efforts on a straightforward question: "What supports does the person need to be more successful in life activities?" Asking this simple question places professional work in a positive mindset, where energy is devoted to problem solving in order to identify and develop personalized supports. It necessarily moves professional work away from traditional understandings of ID/DD that are based on defectology. Although the question may be simple and straightforward, the work required to plan, arrange, and deliver personalized supports is quite challenging and complicated. In reality, it is work that is very difficult to do perfectly, and is work that is never finished because the context of people's lives is always changing (e.g., people's goals and aspirations change over time, people's health changes, the people who provide key supports change, settings in which people live and work are constantly changing). A person's support needs may be ideally addressed one day, but, in a very short time, the same person's support needs can change and/or the supports he or she uses may change (e.g., a preferred job supervisor might change jobs). When change inevitably happens, planning teams and direct support workers must return to the drawing board and come up with new solutions to address the new context.

Professional work aligned with the supports paradigm at the individual level is characterized by vigilance. Planning teams must truly commit to be as responsive to a person's supports needs as possible and continually strive to improve supports so that the supports in place today are better than the ones that were in place yesterday, but not as good as the ones that will be in place tomorrow. A high level of creativity and problem solving is necessary to arrange and implement personalized supports, and this work can only be accomplished through a team approach. It is simply too big a job for one person.

Although there are multiple ways in which planning teams can be organized and operate, a planning team cannot be aligned with the supports paradigm unless the person with the disability and his or her allies are central to the planning process. In other words, planning activities must be person-centered.

Person-centered approaches refer to methods of providing support to individuals with intellectual and developmental disabilities and their families that place their wants and needs at the center of the supports they receive. Person-centered approaches imply that service organizations should neither predetermine what services are important to people with disabilities nor make the key decisions about the best ways to implement those services; rather, they should respond in individual ways to the needs and wishes of people they support. (Brown, Parmenter, & Percy, 2007, p. 52)

Professional-driven or system-centered planning is incompatible with the supports paradigm.

A Systematic Approach to Planning, Arranging, and Delivering Supports

We are not aware of any successful planning teams that have not adopted a systematic process to guide planning efforts. There are multiple approaches, and a strong case can be made for planning teams (and organizations) to develop an approach that works best for their culture, and to which team members feel a sense of ownership. However, there are certain features of a planning process that are critical to ensure alignment with the supports paradigm. First, it is necessary to include a formal person-centered planning (PCP) process such as MAPS, ELP, or PATH (Employ-

ment and Disability Institute, 2014). Schwartz, Jacobson, and Holburn (2000) identified the following eight "hallmarks" of a PCP process: (1) the person's activities, services, and supports are based on his or her dreams, interests, preferences, strengths, and capacities; (2) the person and people important to him or her are included in lifestyle planning and have the opportunity to exercise control and make informed decisions; (3) the person has meaningful choices, with decisions based on his or her experiences; (4) the person uses, when possible, natural and community supports; (5) activities, supports, and services foster skills to achieve personal relationships, community inclusion, dignity, and respect; (6) the person's opportunities and experiences are maximized, and flexibility is enhanced within existing regulatory and funding constraints; (7) planning is collaborative, recurring, and involves an ongoing commitment to the person; and (8) the person is satisfied with his or her relationships, home, and daily routine.

Support needs assessment is another feature that must be a part of a systematic planning process to help align planning with the supports paradigm. Assessing support needs using a standardized instrument and a uniform procedure, such as the Supports Intensity Scale® (SIS; Thompson et al., 2004), will ensure that a planning team obtains a comprehensive overview of a person's support needs. Informal support needs assessment, such as direct observation and anecdotal logs, runs the risk of overlooking important support considerations but may still be used in conjunction with a standardized assessment. Support needs assessment information in conjunction with information from a PCP process sets the stage for the next essential element of a systematic planning process aligned with the supports paradigm: developing a personalized support plan that is truly responsive to a person's individual needs.

Developing personalized support plans require planning team members to engage in collaborative problem solving focused on seeking ways to align individualized supports, desired life experiences, and personal outcomes. First and foremost, the plans must be workable in relation to a number of factors, including the resources, financial and otherwise, for the plan to succeed. Projected outcomes without a workable support system in place are pipe dreams. Good support plans specify who will provide different supports

(natural supports such as neighbors, family members, coworkers, and friends; paid supports; supportive technologies), what functions different supports will serve (teaching, befriending, financial management, personal safety, behavioral support), where supports will be provided (settings, activities), and what resources will be used to secure them. Although planning teams need to be ambitious, they would be wise to remember the proverb that *the perfect is the enemy of the good*. Very few people, with and without disabilities, are able to get everything they hope for in life right away. Insisting on perfection could result in no improvement at all. A workable support plan is an actionable step in the beginning of a journey, requiring that support plans be updated and improved over time.

The value of striving for consistent improvement leads to the final components of systematic planning processes that are aligned with the supports paradigm. Namely, monitoring and evaluating a support plan that has been put into action. Support teams should schedule a face-to-face, follow-up meeting 30 days after a support plan has been implemented. Although this follow-up meeting can serve multiple purposes, the critical purpose is for people to report back to the team on whether or not they followed through on what was called for in the plan and, if so, how it worked out. When support-planning team members have carried out their responsibilities but were not successful, then the team should assist with problem solving and the support plan may need to be modified. Future follow-up meetings should be scheduled periodically. As was previously mentioned, planning, arranging, and providing personalized supports for a person with ID/DD is difficult work. It requires a great deal of vigilance on the part of team members. In the absence of a structured process to monitor and evaluate how well the plan is working, even the best-laid plans are likely to be abandoned eventually.

The Supports Paradigm at the (Meso) Organizational Level

A Focus on Effectiveness

Effectiveness, which is the degree to which an organization or system achieves its intended results, is significantly enhanced through aligning both horizontally and vertically the input,

throughput, and output components of a service delivery system. At the individual level, horizontal alignment involves assessing personal goals and support needs, implementing a system of supports, and evaluating personal outcomes. At the organizational level, horizontal alignment involves relating value-based policies and resources to organization services, and evaluating organizational outputs impacted by the resources and services. At the systems level, horizontal alignment involves relating value-based policies and resources to the service delivery framework that is consistent with organization services, and evaluating systems-level outputs related to social indicators and systems change indicators.

Vertical alignment involves the juxtaposition of individual, organizational, and systems-level practices at each program logic model component: input, throughput, and outcome/output. Critical indicators associated with each component are summarized in Table 1 (Schalock & Verdugo, 2012a).

A Focus on Efficiency

Efficiency is the degree to which an organization produces its planned results in relation to the expenditure of resources. Over the last decade, three transformational activities have emerged that focus on enhancing an organization's efficiency through: (a) using information from the same support needs assessment instrument in multiple ways, (b) streamlining the supports planning process, and (c) targeting resources to assessed support needs. This section of the article addresses (a) and (b) only. Approaches to resource allocation are discussed later in the article.

Using information for multiple purposes. Efficiency is increased if the same assessment information can be used for multiple purposes. For example, at the individual level, many jurisdictions use information from the SIS to develop an individual profile that shows the pattern and intensity of needed supports, and to integrate SIS information into an individualized support plan (ISP). At the organizational level, SIS information can be used to develop an organization profile that shows the pattern and intensity level of assessed support needs averaged across the organization's clientele, provide a rationale for resource procurement, provide a benchmark for continuous quality improvement, and provide a framework for organization-level evaluation activities. At the systems level, SIS information can be

Table 1
Critical Indicators to Use in Horizontal and Vertical Alignment

Analytic Perspective	Program Logic Components		
	Inputs	Throughputs	Outputs
Individual	Assessed Support Needs	A system of supports	Personal outcomes
Organizational	Value-based policies; Resources	Organizational services; Management strategies	Personal outcomes; Organizational outputs
System	Value-based policies; Resources	Service delivery framework	Service change indicators; Social indicators

used to develop a systems profile (e.g. state, region, province) that shows the pattern and intensity of assessed support needs averaged across the jurisdiction's service providers; develop a providers profile; and provide information for data-based decision making such as strategic and operational planning, organization/service delivery innovations, staff development activities, and resource allocation.

Streamlining the supports planning process. Supports planning with individuals, culminating with the development of a written plan, is a very time-consuming and labor-intensive process that consumes considerable organizational resources. Across multiple jurisdictions, the individualized planning process is being streamlined through the use of the following guidelines (Schalock & Verdugo, 2012b):

- The individual and the person's family lead, to the extent they can, the plan's development and implementation.
- The support team that develops and implements the planning process/approach is composed of people who know the individual well and will be involved in the plan's development, implementation, and monitoring.
- Priority is given to those outcome areas that reflect the person's goals, relevant major life activity areas, and exceptional medical and behavioral support needs.
- A holistic approach is used that reflects the multidimensionality of human behavior within a quality of life framework.
- Support objectives are referenced to specific support strategies composing a system of supports and not to person-specific attitudes or behaviors.
- The planning approach is implemented via multiple entities including the service recipient, one or more family members, direct support staff, and a case manager/supports coordinator.

- The planning approach should be easily understood and easy to communicate so as to facilitate effective implementation.

In addition, such planning increasingly takes place within the context of an individualized budget allocation that sets bounds to the public funds available for implementing the support plan. The planning team may request additional funds if needed or seek additional resources to complement public funding.

A Focus on Continuous Quality Improvement

The purpose of continuous quality improvement (CQI) is to enhance an organization's effectiveness and efficiency through changing organization policies, practices, training, and use of technology within the context of the values guiding innovation: dignity, equality, self-determination, nondiscrimination, and inclusion. Successful CQI requires at least these three features: a framework for viewing a system's structure, processes and results; evidence-based feedback concerning what is done and how; and the implementation of specific quality improvement strategies.

Framework. A balanced framework for CQI is reflected in the concept of a scorecard that reflects four perspectives on the effectiveness and efficiency of an organization: that of the customer or service recipient and the organization's growth (i.e., effectiveness), and the organization's financial status and internal processes (i.e., efficiency).

- The *customer or service recipient's perspective* focuses on the alignment of services and supports to assessed and/or requested support needs and the demonstration that the system of supports used enhances personal outcomes.

- The *growth perspective* focuses on the articulation of the organization's mission and intended results and the development of program options.
- The *financial perspective* focuses on the comparison of unit costs, reporting the percent of budget allocated to individually referenced supports and monitoring the relationship between social capital and agency-based fiscal capital.
- The *internal process perspective* focuses on the alignment of input, throughput, and output components and the employment of an integrated management system that goes across different geographical locations and program types.

Evidence-based feedback. Feedback concerning each of these four perspectives can be obtained by evaluating the level of evidence available within the respective organization or system. Transforming an organization or system requires a balanced approach. In this regard, *the balanced scorecard approach* can be used to replace the traditional performance system that typically focused on assessing only financial performance. Using multiple perspectives on performance evaluation results in a more balanced perspective to an organization's performance and, thus, provides more useful information to organization leaders and managers for reporting and CQI. The results obtained from the measurement of each of the performance-related indicators (i.e., perspectives) summarized above can be reported as a "balanced scorecard." Procedures for doing so can be found in Schalock and Verdugo (2012b).

Quality improvement strategies. In addition to a framework and evidence-based feedback, quality improvement will not occur without specific quality improvement strategies. Although it is beyond the scope of this article to discuss exemplary strategies in detail, they typically involve expanding thinking to include systems, synthesis, and alignment; measuring and using individual, organization, and systems-level outcomes and outputs; creating high performance teams that are organized, informed, empowered, and accountable; employing a system of supports; using evidence-based practices; implementing a performance-based evaluation and management system; and creating value through innovation. A detailed discussion of each of these specific quality improvement strategies—and the literature that provides the rationale and summarizes the results of their use—can be found in Schalock and Verdugo (2012b).

The Supports Paradigm at the (Macro) Systems Level

Arranging Preferred Supports While Applying Disciplined Fiscal Management Practices

The supports paradigm requires that individuals with ID/DD must be free to define the course of their lives. Yet the responsibility for distributing public funds to provide these individuals with the support they need rests with government agencies. In this context, policymakers face pressures to contain, even reduce, spending while accommodating increasing demand for services. As a result, there is growing interest among policymakers to apply public funding in ways to promote increased efficiency and effectiveness and achieve greater equity in spreading funding among individuals. As these dynamics unfold, however, other opportunities for system re-design also exist, such as altering the supports made available to individuals and their utilization of these supports, promoting flexibility in providing supports, and affording individuals access to individualized budget allocations and opportunity to "self-direct" their allocations. In this way, at the macro level, altering the services people receive and their amount could achieve policy outcomes related to improved fiscal management while helping individuals to lead the lives they prefer.

A core value driving change to how public resources are allocated is that higher funding levels should correlate positively with the increased intensity of support needs. That is, all other things being equal, people who have relatively more intense support needs should receive more funding than those with relatively less intense support needs because people with more intense support needs require more resources to live successfully in the community. The challenge, of course, lies in determining exactly how to link support needs to funding, and to do so in ways that promote beliefs over what constitutes best practice in relation to outcomes preferred by individuals with ID/DD and policymakers.

An emerging means for doing so involves a methodology based in formal assessment of support needs, such as that provided by the SIS, whereby individuals are allocated resources based on differences in their needs, circumstances, and/or other factors associated with costs. This approach may provide more explainability than other funding options in terms of justifying the

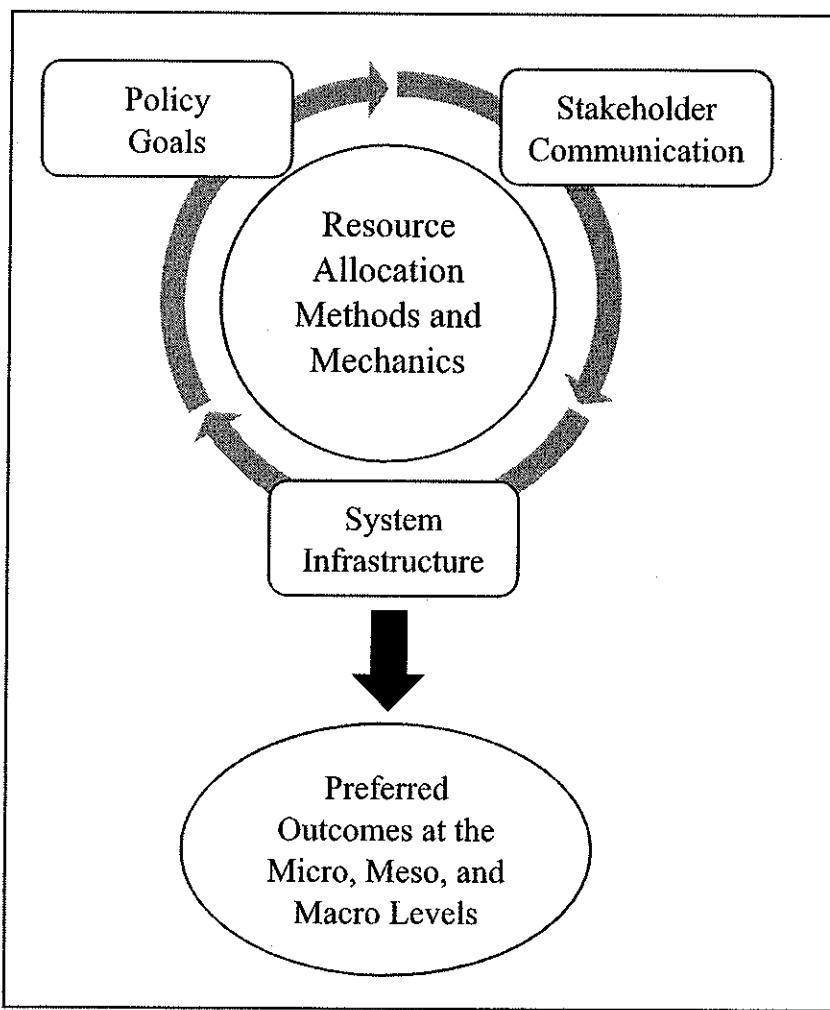


Figure 1. Primary components involved with establishing a resource allocation system based on assessment of support needs.

expenditure of public funds (Agosta, Fortune, Kimmich, et al., 2009; Agosta, Fortune, Melda, & Smith, 2009; Kimmich et al., 2009).

At the center of the approach are well-designed practices for assessing individual support needs and anticipating average service use, and so costs, associated with addressing these needs. As illustrated by Figure 1, however, these practices, although necessary, are not sufficient for ensuring success. In addition, policymakers must be clear about their goals for carrying out planned reforms, must communicate effectively with stakeholders, and implement needed changes to a complementing systems infrastructure. Each of these components is described in the following sections.

Policy Goals to Guide the Effort

Essential to the success are definitive policy goals to guide any subsequent actions taken to redesign methods (i.e., what is done and how) for allocating resources to individuals. Although an overarching intent may be to allocate resources more fairly or efficiently or to promote future system sustainability, there must be other policy goals established to ensure that, at the least, the well-being of individuals will be assured, but, more preferably, to advance the premises of the supports paradigm. For instance, policymakers may seek reforms tied to resource allocation that also maximize opportunities for people with ID/DD to:

- be in charge of the supports they receive to the extent they can be;
- use resources flexibly and in ways that enhance their lives and help them to participate in their communities, including promoting increased opportunities for employment;
- expand on the sources of support received beyond the public sector to include resources available from community service organizations (e.g., civic clubs, religious centers), community businesses, and friends and neighbors; and
- offer support to each other (e.g., as in peer support networks) as well as others in their community to promote community participation and enhance the well-being of all.

Communication With Stakeholders

Given commitment to system reform, policymakers must communicate effectively with stakeholders (e.g., people with ID/DD and their families, service providers, advocates, legislators) to frame policy intentions and actions in ways to explain why planned system changes are needed, what the change process entails, how new protocols will be implemented, and what effects are intended. In addition, the communications effort should also afford stakeholders opportunities to provide feedback to policymakers so that policy decisions may be revised accordingly.

Toward these ends, communication efforts require that policymakers:

- Disseminate information to stakeholders, including service recipients and their families, advocacy organizations, and providers, to describe and gather input about the changes sought.
- Actively engage these stakeholders to speak directly with constituency leaders, gain insight into the impact of the redesign, problem solve perceived issues, and build common cause among stakeholders consistent with the redesign.
- Create a learning community or “community of practice” where all can learn together about the changes underway and how new practices can be best implemented.

Infrastructure Considerations

Implementing an assessment-informed resource allocation system requires that complementing changes be made to other system components. For instance, consider the service planning process. In the past, case managers may have sat with the individual and others to fashion a plan, with budget implications considered later. To contrast, the new approach results in individualized budget

allocations being pre-assigned to individuals based on their assessed support needs. This requires that individuals are informed of their allocations prior to their planning meetings, case managers are trained to facilitate planning meetings when budget allocations are pre-assigned, and means are established to address service needs in excess of pre-assigned budgets. Likewise, changes will also be required pertaining to: (a) the management of information related to individual budget allocations, service utilization and expenditures, and associated outcomes; and (b) quality monitoring and management practices whereby implementation of the resource allocation mechanics can be observed and altered as needed.

Resource Allocation Methods and Practice

At the core of the effort lies the actual means that will be undertaken to establish resource allocation practices. In this regard, policymakers must take several considerations into account. First, they must ensure that accurate, reliable, and valid assessments of individual support needs are completed and appropriately stored to document the relative support needs of individuals. Applying a measure such as the SIS may be used for this purpose, but care must be taken to ensure that data collectors are properly trained and monitored to ensure the accuracy and reliability of the information collected over time.

Additionally, policymakers most typically must decide on the composition of an assessment-level framework whereby individuals assigned to each level are presumed to have a similar amount of support need and are provided a common individual budget allocation. There is no single way to establish a level framework. For purposes of illustration, however, a simple level framework could include several foundational levels based on overall intensity of support needs, as well as additional levels for people with unique support needs. Foundational levels divide the population into groups (e.g., quartiles) based on their assessed intensity of support need. For instance, individuals with the lowest scores (i.e., the least intense support needs) might be assigned to the lowest level while those with the highest scores (i.e., the most intense support needs) would be assigned the highest levels. Additional levels could account for individuals with extraordinary medical conditions and/or significant behavioral

challenges. A framework such as this may be used across jurisdictions to classify a service population, but other level configurations are possible and may be preferable depending on the environment surrounding the decision to move toward the resource allocation system.

When developing an approach to resource allocation, policymakers must also determine whether individual budget allocations will be tied to a past service array that includes historical expenditures and service utilization, *or* to a new array with a rate schedule based on anticipated service use, *or* to a combination of old and new. Note that historical data reflect many of the legacy service use patterns that policymakers may be seeking to alter or eliminate. As a result, although allocations may be made more equitable, using these data to anchor new budget allocations runs the risk of reinforcing past service use patterns. To contrast, policymakers may seek to introduce an altered service array and service reimbursement schedule, and encourage changes in service use. In such instances, resource allocation practices cannot be established based on a regression of need to historical costs, but must be fashioned purposively by considering need in relation to anticipated service use patterns. Another important consideration is the timeframes required and challenges embedded in ending some services and initiating others.

There are two final considerations for those charged with developing public policies in regard to individual budget allocations. First, policymakers must consider other crucial status factors such as where a person lives (e.g., at home with family or in a staffed community residence) and age (i.e., adults versus children). Factors such as these affect service use and corresponding costs. Second, it must be acknowledged that in any service population it is likely that there will be a certain number of people with exceptional needs, (i.e., "outliers"), who have needs for supports beyond what is more typically offered. As a result, a means for identifying and accommodating the needs of these individuals must be established.

Undertaking practices such as these to alter how resources are allocated carry promise for achieving greater system efficiencies and distributing resources with greater fairness across service recipients. Doing so, however, should not be equated with delivering high quality or preferred supports. A fair system that distributes finite public funds efficiently may be a desirable goal

but presents a separate challenge from offering an array of quality supports that service recipients need or want to help them live the life they prefer in the community. Successful macro policy, therefore, requires a reconciliation of the ideals embedded within the supports paradigm with the wise use of public dollars across all planning levels, including the micro and meso levels.

Conclusion

The normalization principle provided a readily understandable, conceptual umbrella upon which to justify the growth of a community-based service system during the 1960s and 1970s. During the past 30 years, however, the field of ID/DD has been pushed to move beyond "normalizing settings/environments" and offer people individualized supports that address personal priorities and lead to meaningful personal outcomes, including full participation in all aspects of community life. In this article we have suggested that the supports paradigm provides a conceptual umbrella for today's field of ID/DD because of its relevance to professional work at the individual (micro), organizational (meso), and jurisdictional (macro) levels.

Like the normalization principle, the supports paradigm is not difficult to explain or to understand. However, arranging individualized supports at the micro level is challenging work, and the work is even more challenging when higher, superordinate systems (i.e., meso and macro systems) are not philosophically or operationally aligned with the supports paradigm. Although it is possible for an individual's planning team to make heroic efforts to secure resources and engage in exceedingly creative problem solving to overcome barriers caused by poorly aligned higher-order systems, heroic efforts that succeed in spite of poor organizational and jurisdictional systems will likely only yield episodic success stories. For those concerned with the lives of people with ID/DD, the goal must be nothing short of widespread opportunities for people to engage in dignified and meaningful life activities that are based on their personal priorities and individual support needs.

In this article, we suggested ways to align professional work that is consistent with the Supports Paradigm at the micro, meso, and macro levels. No pretense is made, however, that the road

to alignment is straightforward or easy. There are many “inconvenient realities” that make absolute alignment difficult, not the least of which is the reality of “finite financial resources.” If financial resources were infinite, there would be no reason to not use public funds to provide personalized supports, no matter what the life activity or what the cost. The reality, however, is that most people with ID/DD need some government funding to access the supports they need. Public funding has never been deemed to be fully adequate, and many jurisdictions today are looking to cut costs. Although we suggested ways to promote efficient distribution of resources at the macro level (e.g., stop funding legacy programs that are no longer viable) and use of resources at the meso level (e.g., use one assessment for several purposes), it would be naïve to believe that greater efficiency alone can fully address the gap between the financial resources that are available and the financial resources that people with ID/DD truly need.

There is no magic solution to the funding problem. The approach taken by most jurisdictions to cope with the problem of insufficient funds is to simply not serve everyone. Today, there are “haves” (people who receive funding) and “have nots” (people who don’t). Those who are denied funding are often placed on waiting lists, which is actually a misnomer because so many people never get off the waiting list until their lives enter into a state of crisis (Braddock et al., 2013).

An alternative approach to insufficient financial resources is to fund everyone at a fixed level. Given the fact that funding is inadequate, such an approach would result in the vast majority of people receiving woefully insufficient funding amounts. Although such a system would be more equitable than the current system (where some are denied funding and others are not), such an approach would severely limit quality. Because people with ID/DD are a heterogeneous population that varies based on intensity of support needed, a “one size fits all” solution would present significant problems.

The supports paradigm is certainly not a panacea for an underfunded adult service system. However, to paraphrase the Rolling Stones, we believe that, although efforts to align micro, meso, and macro systems with the supports paradigm may not enable everyone to *always get what they want*, it may come closer to ensuring that many more people are able to *get what they need*. The

argument to repeat to elected representatives is that, with proper supports, people with ID/DD can lead successful lives in their communities. Any suggestion that an “order of selection” is necessary because government can only afford to serve the “most severe” needs to be countered with the prospect of the wasted human potential that results when people with ID/DD are denied supports that they need to contribute to society.

People with ID/DD and their families want to define and identify desired life activities, experiences, and personal outcomes for themselves. They want individual planning teams, local support provider organizations, and government agencies to facilitate the arrangement of individualized supports. Supports should effectively address whatever obstacles (i.e., person-environment mismatch) stand as barriers to full participation and inclusion. As Thompson et al. (2009) stated, personalized supports provide a “bridge between ‘what is’ (i.e., a state of incongruence due to a mismatch between personal competency and environmental demands) and ‘what can be’ (a life with meaningful activities and positive personal outcomes)” (p. 136). Funding should be tied to individual support plans and the use of public funds should be sufficiently flexible to address individual priorities. The challenge before us is to build sustainable systems that are aligned with the supports paradigm at the micro, meso, and macro levels, and to continue to work toward the day when everyone with ID/DD can access the supports they need.

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DDS / PROVIDER TRADES MEETING:

Tuesday, July 15, 2014 | 10:00 AM – 11:30 AM

DDS Central Office - 460 Capitol Avenue, Hartford | Commissioner Macy's Office

1. Trades Meetings Moving Forward – Meeting Format:

- 2014/2015 Draft Meeting Schedule of Venues
- Perspectives Re: Alternating Regions, Discussion Re: Meeting Content

GOVERNOR'S I/DD WORKING GROUP:

2. DDS Wait List:

- How will the Provider network fit into the process in the future?

3. Timeframe, Expectations: Establishing priorities within the initial scope of topics for discussion:

- 3a. Concerns over the most efficient use of state and federal funds and the ability to look at the system as a whole
- 3b. The difficulty in looking at the waiting list in isolation without examining other factors such as less expensive settings, federal requirements, etc.
- 3c. Re-examination of the PRAT process
- 3d. Understanding the current delivery system and numbers of individuals served at what cost
- 3e. What is happening to families while they remain on waiting lists including what supports they may be receiving
- 3f. The focus on person-centered planning and integrating people into the community

4. DDS Project/Initiative Updates:

- DDS Rate Transition – Overview, Updates
- DDS Process Re: Clinical-Behavioral Provider Oversight
- Community of Practice
- Mentoring Group
- Risk Mitigation

Upcoming Trades Meetings:

8.06.14: Summer Recess (Unless mutually determine to meet)

9.03.14: CCPA – South Region - Venue TBD

10.01.14: Arc Connecticut – West Region - Venue TBD