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How Support Needs Can Be Used to Inform the Allocation of Resources and Funding Decisions

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Authors' Notes

This white paper focuses on how the assessment of support needs can be used to inform the allocation of public funds. A discussion of values that should underlie funding decisions is followed by consideration of the ways in which the structures and purposes of funding streams affect the distribution of funds. A seven-level approach to allocating resources is described. Finally, ways support needs assessment information can inform the development of individualized budgets are considered.

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The expression “no man is an island,” originally coined by the 16th-century poet John Donne, provides an eloquent means to express a basic truth about the human condition. Namely, humans do not thrive in isolation from one another. The human experience is one of interdependency—each person contributes some things that benefit others, and all people profit from the collective contributions of the group. In a modern society, everyone needs support from others in all aspects of their lives, including getting food to eat, moving from place to place in the community, learning new information and developing new skills, and satisfying basic social needs for human contact and interaction. All human beings have support needs, which Thompson et al. (2009) defined as “the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning” (p. 135). People with intellectual and developmental disabilities (IDD), however, have more intense support needs than most others in society and, therefore, require supports that are qualitatively and quantitatively different than most others. Put another way, what distinguishes people with IDD from the general population is their need for extra support to fully participate in school and adult life.

The Supports Intensity Scales (Adult Version [*SIS—A*], Thompson et al., 2015; Children’s Version [*SIS—C*], Thompson et al., 2016) were created to provide a reliable and valid means to assess the support needs of children and adults with IDD. These assessments are administered through a uniform procedure (i.e., a semistructured interview) and generate norm-referenced standard scores. Standard scores distinguish people by their relative intensity of support needs and are provided for each subscale, as well as for the scale as a whole (i.e., the Support Needs Index).

Although information from a SIS assessment can be used for multiple purposes related to supports planning, the standard scores have proven to be particularly useful to those seeking to establish an evidenced-informed and logically defensible basis for estimating the distribution of public funds (i.e., resource allocation) that are available to provide services and supports for people with IDD. Historically, throughout the United States and in many other parts of the world, most of the public funding targeted to people with IDD was apportioned to support care in large congregate facilities. Later, as increasing numbers of people with IDD were served in community settings, an amalgam of factors influenced how funding was distributed, including historical funding levels; advocacy efforts by people with disabilities and their families, professional groups, and service provider organizations; negotiations between government officials and service provider organizations; operating costs and cost caps; and diagnostic categories. The upshot of unsystematic and fragmented approaches to funding were resource allocation systems that paid “little specific attention to the individual needs and characteristics of service recipients beyond basic eligibility requirements” (Stancliffe & Lakin, 2005, p. 9).

Today, people with IDD have diverse lifestyles and life circumstances. They live in a wide range of residential settings, are employed in diverse work settings, have different interests in terms of recreation and leisure pursuits, and, therefore, receive supports and services that differ considerably from one another. Clearly, aligning public funding decisions with an objective measure of “support need,” such as that provided by the SIS scales, has provided jurisdictions with the opportunity to develop more evidenced-informed and logically defensible alternatives to allocating resources than their legacy

approaches. SIS scales are currently being used, or are under consideration, to inform the allocation of resources in nearly 20 U.S. states and Canadian provinces, as well as three European countries (American Association on Intellectual and Developmental Disabilities, 2017).

The purpose of this white paper is to provide an overview of ways in which information from assessments of people's supports needs has been used by jurisdictions to address issues of funding and resource allocation, and the considerations that accompany their use. First, a discussion of the values that should underlie resource allocation algorithms and funding decisions will be presented. Next, ways in which the structures and purposes of funding streams affect decision making regarding the distribution of funds will be considered. This will be followed by a description of a seven-level approach to resource allocation that makes use of support needs assessment data, variations of which have been adopted by multiple jurisdictions. This paper concludes with a discussion of individualized budgets, and how budget development can be informed by the support needs assessment results.

Values-Driven Resource Allocation

Anyone who has vested time and energy into developing algorithms for allocating resources has had to wrestle with issues of fairness and justice. Distributing public funds requires prioritization, and prioritization stems from the relative emphasis placed on different values and considerations. No matter the jurisdiction in which one is operating, the following parameters apply when developing approaches to distributing funds:

- Society, in the form of the government, must decide who is deserving of public funding among many competing interests (e.g., funding for the military, for efforts to protect the environment, to build and maintain infrastructure);
- There is never sufficient funding to fully satisfy advocates for all competing interests; thus, when budgetary decisions are made, it is very rare for any entity to get everything that was requested, but it is also unusual for a cause/interest that has had a long history of public support (e.g., human services to people with IDD) to be completely shut out;
- Regardless of the proportion of funding that was received to the funding that was sought, the total amount of available funding is finite;
- Because funding to support people with IDD is finite, decisions must be made to allocate resources in ways that do the most good and/or are most consistent with the intent of policy makers who crafted the laws and regulations pertaining to how funding should be spent;
- Answering the question “Who receives funding?” requires a decision to be made about criteria for eligibility;
- Because the total amount of money is capped, there is an inverse relationship between the number of eligible people and the average amount of funding provided per person; and

- Once eligibility parameters are established, decisions must be made about differentiating funding among eligible persons: Does everyone who is eligible receive the same amount of funding? Are some people deserving of more or less funding than others? If there is not sufficient funding for all eligible people, should people for whom there is insufficient funding be placed on waiting lists? How is the decision made regarding who is funded and who is on a waiting list?

Developing an approach to funding at the jurisdictional level requires a “big picture” perspective. How can funding be arranged to maximize the benefits to the greatest number of people? Or, in times of budget restrictions, the operative question may be, “How can funding be managed to minimize its negative impacts while maintaining adequate benefits for the greatest number of people?” The decision maker at the jurisdictional level who is charged with determining how public resources should be allocated must focus on the collective well-being of everyone whose quality of life is at least partially, and in some cases significantly, tied to having access to finite resources.

Those whom a jurisdiction charges with making decisions about the distribution of resources must balance competing interests and strive to be as fair as possible to everyone. The following values should drive their efforts:

- **Equity** – this value refers to evenhandedness. An equitable system is one where everyone with IDD is treated equally, and is evidenced by all people receiving funding that leads to their needs being met (or unmet) to the same extent. An inequitable system is characterized by one person having access to relatively greater amounts of funding than another person with similar support needs. The well-funded person has access to better options for addressing his or her support needs than the poorly funded person. Because people with IDD are a heterogeneous population with differing intensities and patterns of support needs, providing everyone the exact same amount of funding is likely to result in an inequitable system. To paraphrase the words from an old Rolling Stones’ song, in an equitable system, people may not always get what they want, but they have an equal opportunity to get what they need.
- **Efficacy** – this value refers to producing the desired result, and it is closely related to the concept of effectiveness. An efficacious system is one where the funds that are distributed produce the desired outcomes. Regardless of the jurisdiction, policy makers set aside funding for people with IDD with the intent that the funds be used to enhance people’s quality of life. One factor that has been long recognized as an influence on people’s quality of life is size (i.e., number of housemates) within a residence (see Lakin & Stancliffe, 2007). Thus, efficacious resource allocation systems should encourage the expansion of relatively smaller-sized residential options, as well as other factors that are associated with enhanced quality of life. In contrast, funding patterns that are unlikely to lead to better outcomes for people should be abandoned. An example of an effort to use public funding to create more efficacious vocational supports in the IDD service system was evident in the United States with the passage of the Workforce Innovation and Opportunity Act (WIOA) in 2014. By placing restrictions on the distribution of public funding to organizations providing vocational services where people with disabilities were paid subminimum wages, the WIOA

discouraged funding for sheltered workshop services and encouraged the expansion of integrated employment options (The Arc, 2015).

- **Efficiency** – this value refers to distributing funding so as to maximize the most favorable cost-to-benefit ratio (i.e., getting the biggest “bang for the buck”). Balancing the amount of funding that is directed to overseeing how funds are spent with the amount of funding that is made available to directly support people with disabilities is often the key to increasing efficiency. On one extreme, public funding distributed with no oversight may have very little administrative expense associated with it and, therefore, may be appealing in terms of efficiency at face value. However, the potential for fraud and abuse (intentional or otherwise) is untenable when there is no monitoring of how public funds are spent. The fraudulent use of funds is the most inefficient, wasteful use of funds possible. In the other extreme, the displacement of funds can occur when the *costs of administrative oversight* outweigh any *benefits of improved quality*. Every jurisdiction’s goal is a straightforward, efficient system that fully accounts for the public’s expenditures while ensuring that funds are spent wisely and as intended.
- **Transparency** – this value refers to opportunities for others to clearly see how funding is spent, including what actions have been initiated and what decisions resulted from those actions. Transparency fosters confidence in the algorithms used to allocate resources because it provides a means for accountability. If a person is unhappy with the funding that is allocated to them, they should be able to verify that the rules applied to their allocation were not applied arbitrarily or capriciously. Also, transparency provides a basis on which to build a case for changing approaches to resource allocation to include additional considerations or weighing various factors differently. A transparent system is one that is neither difficult to explain, nor difficult to defend.
- **Flexibility** – this value refers to having multiple ways in which to use funding and providing people with choices as to how to spend the funding that has been allocated to them. People with IDD are a heterogeneous population, and if funding decisions are justified based on assessing differences in people’s needs, it only makes sense that spending would also be tailored to people’s needs. Additionally, funding should be adaptable as people’s needs change over time. Allowing flexibility in ways that funds are spent is a hallmark of a system that strives to be responsive to individual unique and changing needs.
- **Redressability** – this value refers to providing people the opportunity to appeal decisions regarding the funding they are allocated. No funding algorithm is perfect, and no process for determining who gets what amount of resources is foolproof. People must have the opportunity to appeal decisions about their funding level, which might include the introduction of information outside of what was considered in the process that was established to assign funding. Appeals should be relatively easy to initiate, and final decisions on the merits of an appeal should be made by an impartial third party (i.e., not made by the same people who initially established the funding amount). No matter how well-conceived an approach to allocating resources might be, in a jurisdiction serving thousands of people, there are bound to be a few outliers or exceptional cases. That is, there are going to be people whose needs are not being met

to the same extent as others. An approach to allocating resources may work quite well for most people, but very poorly for a few. The “few” must have the opportunity to explain why their situations are unique.

Funding Streams and Decisions Involving the Allocation of Resources

Funding Streams

There are multiple federal, state, and local sources for funding disability-related services and numerous budget categories. The specific funding streams one can access are dependent on where one lives and the purpose for which funding is sought. Any discussion of approaches to allocating resources must take into consideration the context of the situation, including the population being targeted and the regulations pertaining to a funding stream. In particular, funding ramifications are different for services that people are legally entitled to under the law compared to those for which people may be eligible, but are not legally guaranteed.

Developing algorithms for allocating resources is not necessary for services that people have a legal entitlement to receive. For example, in the United States, public funding for the purpose of providing special education services to children with IDD is required by the Individuals With Disabilities Education Act (IDEA, 2006). A child’s education must be provided at the public’s expense without any charge to the family, and there is no limit/cap on educational costs. In 1975, when IDEA was originally passed, Congress authorized the federal government to pay 40% of each state’s excess cost associated with educating students with disabilities. Although the federal government has never come close to actually providing the 40% that was promised (percentages have gone up and down over time, but typically have been around 15%), the congressional mandate is clear—states are legally required by IDEA to provide each child who meets eligibility requirements (which includes children with IDD) with a *free and appropriate* education that is specified in an individualized educational plan. No student can be denied an education based on their severity of disability, nor on the cost of their education. Of course, a free public education is available to all students in the United States. Thus, providing a free education to students with disabilities is not providing these children with anything above and beyond what is provided to the general population of students.

Because the amount of funding per child is not capped, and all children who are eligible under IDEA are entitled to receive educational supports judged necessary for an appropriate education, in one sense, special education funding in the United States can be considered to be unlimited. The legal context of IDEA, with its burden of implementation on states and their school systems, does not require the development of individual educational budgets for children. Schools are legally obligated to comply with the federal mandate of providing whatever supports are necessary for a child to receive an appropriate education.

In contrast to IDEA and educational services to children, there is no federal law that compels states to ensure that adults with IDD have access to the free and appropriate supports they need to participate in adult life activities. There is, however, a finite

amount of funding available to support adults with IDD in community settings and activities. The Home and Community-Based Services (HCBS) waiver is the major Medicaid program mechanism that pays for community-based long-term services and supports for people with IDD. The HCBS waiver program was introduced in the 1980s and was originally intended as a waiver of state plan requirements for funding institutional care in order to promote the establishment of community-based residential alternatives. Prior to the implementation of the waiver mechanism, the bulk of Medicaid spending for people with IDD was managed through the Medicaid Intermediate Care Facility for Intellectual Disability (ICF/ID) program for large congregate residential options. Braddock et al. (2015) reported that, nationwide, the HCBS waiver program surpassed ICF/ID spending in 2000 and, by 2013, funding for HCBS waivers had grown to approximately 2.5 times greater than ICF/ID. “Clearly the HCBS Waiver is an essential part of community services funding in the states, especially for supported living and personal assistance, family support, and supported employment. In 2013, 685,828 participants were supported by the HCBS Waiver across the nation” (p. 38).

Allocating Finite Resources

If funding for the HCBS waiver program was expanded tremendously and/or there were legal mandates in place to fully address each person’s support needs, determining the best means to distribute resources would not be an issue. Despite its expansion over the past 30 years, the HCBS waiver program does not provide sufficient funds to serve everyone who requests services (let alone those who would seek services if they thought there was a good chance they would receive funding and not be placed on a waiting list). Because of limited HCBS waiver funding, there are extensive waiting lists for HCBS services. Larson et al. (2015) reported that 639,000 people with IDD received publicly financed residential supports in 2013, but an estimated 117,000 people were on waiting lists for these supports. Moreover, while an additional 366,000 people receive funding for supports while living with a family member under the Medicaid waiver program, 108,000 were on waiting lists for in-home supports.

There are three potential responses to the reality that funding for the HCBS waiver is finite. One response is to tighten eligibility criteria so that the target population aligns with the available funding. The downside of this solution is obvious. Many people who have traditionally depended on HCBS waiver funding, as well as many people who would like to access HCBS funding in the future, would be denied participation. An alternative response is to provide everyone who meets eligibility requirements with some funding and never relegate anyone to a waiting list. Such action, if no more funding were provided, would mean that, for residential supports, the 639,000 who are currently funded would see their funding reduced by an average of a little over 15% to accommodate the introduction of the 117,000 currently on a waiting list. Similarly, for in-home supports, the 366,000 receiving services would see their funding reduced by 23% if the 108,000 on the waiting list were added to the program. As alluded to earlier, there would likely be many more people not currently on waiting lists who would “come out of the woodwork” seeking funding. The downside to this path of extending funding to a larger group of people without increasing the funding pool is that everyone would

likely experience a reduction in funding, and people with certain support needs (e.g., medical vulnerabilities) could face special risks.

The third way to respond is to attempt to allocate finite resources equitably; that is, allocate resources in a way that most fairly maximizes the number of people who have access to the services and supports they need to lead self-directed and dignified lives. An example of this approach that uses the *SIS—A* is provided in the next section.

Before moving on, it is important to recognize that algorithms to guide decision making for allocating resources can be developed around any assessment tool that distinguishes differences in relative need. *SIS—A* is not the only assessment instrument that has been used in the past for purposes of informing resource allocation decisions, nor is it currently the only tool being used. It is essential, however, that some type of accurate and reliable assessment be completed if a jurisdiction's goal is to differentiate funding eligibility based on support needs. Assessments can range in complexity from informal clinical judgments to fully validated, standardized assessment instruments, but some type of assessment must be completed to provide a basis for making determinations of relative need and relative funding. Moreover, when an assessment is used, in part, by a jurisdiction to allocate resources, the assessment results must be defensible. Results that come from assessment tools that have been shown to be reliable (consistent across administrations and assessors), valid (accurately measure the construct of interest), and standardized (uniform administration that allows meaningful comparisons to be made) are more defensible than those that don't have these characteristics. An unsound assessment will lead to indefensible funding decisions; therefore, it is in the best interests of jurisdictions to start with a sound assessment.

An honest critique of any funding approach requires one to separate criticism of the assessment tool that is used from both the jurisdictional limitations and the uneasiness with the prospect of conducting a “high-stakes” assessment that contributes to a division of resources. Unhappiness with the total amount of funding a jurisdiction has allocated for human services and/or frustration with the amount of funding an individual receives from a service system is unrelated to the quality or value of the assessment tool. Assessment, which involves human judgement, is intrinsic to any process where the goal is to differentially distribute resources based on ways in which people's support needs differ from one another.

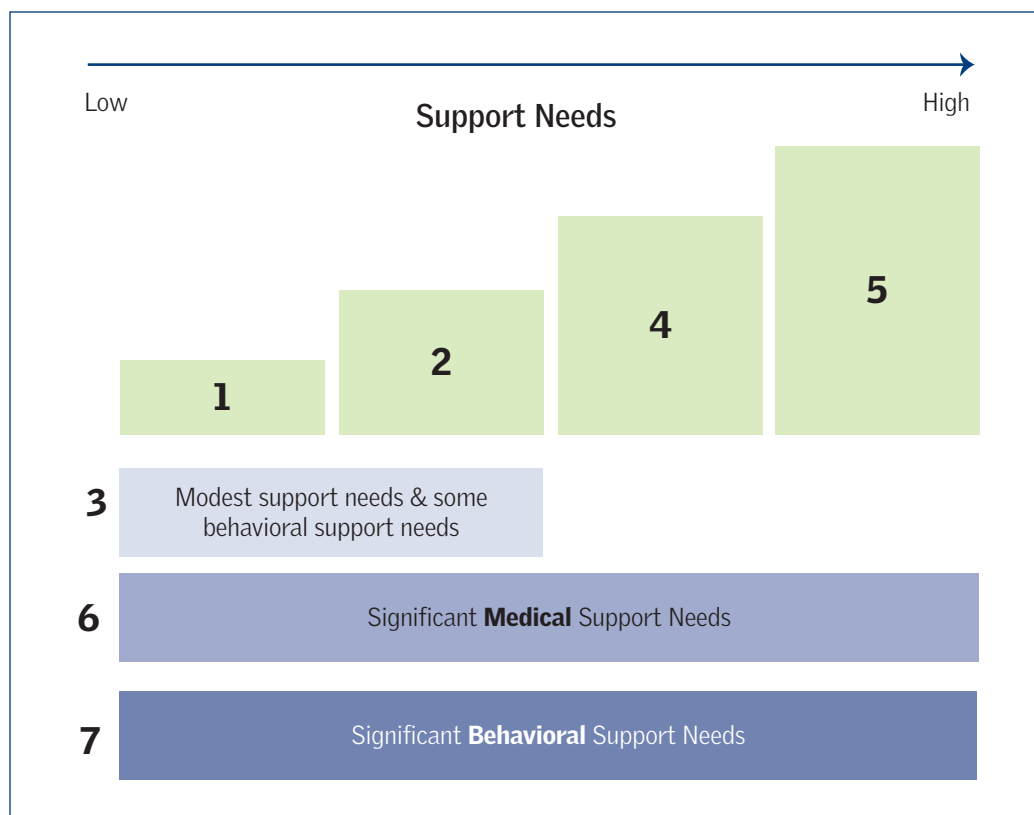
Using Support Needs as One Variable in Determining How to Allocate Resources

John Agosta and his colleagues at the Human Services Research Institute (HSRI) defined a supports budget as “a targeted amount of money, or allocation, that is available to individual service recipients to acquire the service they need and prefer” (2015, p. 2). Jurisdictions must consider several factors when allocating finite resources to people with IDD, including where people live (some geographical areas have a higher cost of living than others), their living situations (e.g., community residence, family), age differences, and differences in support needs. According to Agosta et al. (2016) “an objective assessment, such as the Supports Intensity Scale™ (SIS) is an important part of the budgeting process because it provides information about a person's support needs”

(2015, p. 3). HSRI has consulted with numerous jurisdictions in North America and around the world to use *SIS—A* results to identify *support levels* based on the intensity of support needs.

HSRI reported that jurisdictions with whom they have consulted have favored a seven-level framework for organizing funding levels (Agosta, Petner-Arrey et al., 2016). Figure 1 provides a graphic illustration of their framework, with descriptions of the support needs of the people who are assigned to each level.

FIGURE 1
Human Services Research Institute Seven-Level Support Intensity Framework (Agosta, Petner-Arrey et al., 2016).



Level 1: Adults in this level need supports that most others in society do not need to fully participate in daily life activities, but their support needs are less intense than most other people with IDD. People in Level 1 experience little to no need for extra support to address medical and behavioral challenges.

Level 2: Adults in this level have more intense support needs than those in Level 1. Like their counterparts in Level 1, they have little to no support need for medical conditions and behavioral challenges.

Level 3: Adults in this level have similar support needs to those in Levels 1 and 2, but require extra support due to the behavioral challenges they experience.

Level 4: Adults in this level need more intense supports to participate in daily life activities compared to people in the prior three levels. They may also need positive behavioral supports, but the support needed to manage challenging behavior is not as intense as Level 7.

Level 5: Adults in this level have more intense support needs to participate in daily life activities than those in Level 4. They may also have needs for positive behavioral supports, but the support needed to manage challenging behavior is not as intense as Level 7.

Level 6: Adults in this level have relatively intense support needs due to their significant need for supports to manage medical conditions. Their health and safety is at risk if medical supports are not in place.

Level 7: Adults in Level 7 have significant behavioral challenges that permeate all aspects of their lives. These adults need positive behavioral supports that are carefully developed and monitored. Without positive behavioral supports, they will be a risk to themselves and/or to others.

Developing Individual Budgets That Are Informed By Support Levels Assigned By a Jurisdiction

Given a support-level framework, individualized budgets may be established for each level. To complete this process, four steps must be completed—settling on the service array, establishing service reimbursement rates, creating anticipated service mixes, and ensuring a satisfactory exceptions process.

1. **Settling on the service array.** Given information on the intensity and nature of a person's support needs, policy makers must decide what services should be offered in response. To begin, it is essential that policy makers take a hard look at the services presently offered. Often these services were established years ago and do not always align with the services people prefer today. For example, service recipients increasingly want to work, but many jurisdictions offer mostly center-based day options rather than employment services. Likewise, individuals increasingly choose to live with their families, but the support offered to individuals and their families may be quite meager. In addition, legacy services may do little to encourage discovery and use of resources outside the public sector, and so encourage exclusive reliance on public services. Such services may include peer support or exchange networks where participants offer mutual support to one another, even forming alliances to purchase or negotiate for discounts for particular goods or services, or where support is sought from local businesses or community serving organizations.

Thought of this way, adjustments to services are nearly always needed. This often includes residential and day options, in-home and family supports, and capacity-building services. In addition, aside from these core services, other services must be made available for individuals to utilize due to their particular needs. These may include remote or assistive technologies, therapies, preventative and immediate responses for challenging behavior, or environmental adaptations.

The *definitions* used to describe each service are as important as the type of services that are available (Agosta, Taylor, & Vazquez, 2016). Clear definitions ensure that a jurisdiction is securing (and paying for) the type and quality of services that it seeks. Care should be taken to ensure that:

Policy intentions are embedded within the definition so that service providers, families, and others may easily grasp its purpose and objective;

- The expectations for service providers delivering the service is concisely stated, including the qualification of those who may deliver the service;
- The unit by which the service will be delivered is specified (e.g., 15, 30, or 60 minutes; daily; monthly); and
- The rate of reimbursement per unit of service is indicated, including any limitations on how often a service can be accessed.

2. **Establishing service reimbursement rates.** Once a service array is determined, policy makers must decide on the rates of reimbursement for delivering these services. Often, legacy services need to be redressed and new services will need to have first rates established. There are many ways to set rates and, in the United States, federal regulations and guidelines must be abided regarding fee-for-service Medicaid-funded services (e.g., see Federal Policy Guidance for Medicaid at <https://www.medicaid.gov/federal-policy-guidance/federal-policy-guidance.html>).

One means, an *independent rate-setting approach* (e.g., see Burns and Associates, 2016), makes use of historical cost data, but makes use of other information as well. Other factors may include benchmarks of cross-industry wage and benefit data, as well as assumptions pertaining to various costs associated with delivering each service, including direct care worker wages, benefits, and “staff productivity” (i.e., billable time), staffing ratios, mileage associated with staff travel, facility expenses, agency program support and administration, feedback from service providers, and alignment with policy intentions.

3. **Creating service mixes and individualized budgets.** With a service array and rates schedule in place, policy makers may discuss the average or typical service use, including type and amount of service, that should be associated with each support level. Historical service use patterns may be consulted, but the assumptions made for each level should be based on the policy intentions going forward. These budgets are adjusted based on the residence types available (e.g., supported or shared living, family home, paid residence or group home), age of the service recipient (e.g., youth or adults), and overarching policy intentions.

After thorough discussion, a preliminary service mix for each support level by residence type and age group is established. The mix only includes those services that everyone in the support level will likely use. For people living at home with families, for instance, this may include a combination of in-home supports and day services. Likewise, those living on their own may have access to some amount of drop-in assistance and day support. Services outside the primary mix (e.g., language therapy, equipment purchase) that are utilized on an individual or as needed basis are set aside

and accounted for separately. If the cost per unit of service delivered is known, an individualized budget may be computed for each service mix. The budget may be a dollar amount or a number of support hours, and it can be a precise dollar amount or described as a range or band.

Finally, the resulting service mixes must be tested. First, a cost impact analysis may be completed by accounting for the number of people who will be assigned each service mix (i.e., by support level, type of residence, and age) and tallying the combined cost for applying the mixes. Such analysis often results in adjustments to the mixes. Second, feedback from stakeholders regarding each service mix will help policy makers sharpen the proposed mixes as appropriate.

4. **Ensuring a satisfactory exceptions process.** Building prospective service mixes in this way may well provide ample support for most people, but there will be some for whom it is insufficient. Policy makers must always offer means for people to request additional support if the supports budget cannot meet their needs. The process should be well articulated so that individuals may be reasonably able to seek out additional support, and their requests appropriately vetted and decided.

This process illustrates one particular method for computing individualized budgets; others are surely possible. Further, it should be understood that local service arrays, rate schedules, service mixes, and budgets are inevitably dependent on the resources available. Systems that are financially challenged will likely field lean service arrays with depressed rate schedules and modest, even anemic, individualized budgets. To contrast, well-financed systems are better positioned to field a more satisfactory service response.

Either way, however, the process we've described leads to deliberation, problem solving, and decision making, and provides the opportunity to re-imagine and re-shape the service system. Where modest resources are available, policy makers have opportunities to divest from outdated or inefficient service responses, and focus resources instead on preferred "next generation" responses. Likewise, in well-funded systems, policy makers also have opportunities to make transformational, progressive-minded changes. Inevitably, building an individualized budgeting framework is not exclusively about the SIS, support levels, or eventual budgets. Rather, the driving intent of an individualized budgeting framework is to reshape systems overall to improve their efficiency and fairness, while enhancing opportunities for people to direct their lives within their communities.

Applying Individualized Budgets to Supports Planning

Earlier in this white paper, the reality of having access to finite funding was discussed. Decision makers within a jurisdiction are obligated to allocate limited resources as equitably, efficaciously, efficiently, transparently, and flexibly as possible. Based on information from a support needs assessment in concert with other relevant information, people can be categorized into different funding levels (see Figure 1). Once the amount of available funding is determined, an individualized budget, or "supports budget" can be created. According to Agosta, Taylor, & Vazquez (2016), "A supports budget is a targeted amount of money or allocation that is available to individual service recipients to acquire the services they need and prefer" (p. 2.).

There are some who may caution that introducing budget restrictions into a planning process can restrict the type of creative problem solving that can lead to imaginative planning. Having access to unlimited resources would seem to have the effect of offering people a planning context with no restrictions, whereas the reality of finite resources creates an inevitable tension between what one individual may want in terms of resources and what the system has available to meet the needs of everyone. The downside of planning processes that are premised on resources that people believe they should have access to without any constraints is the distinct possibility that many people could become sorely disappointed when they find they cannot access the resources they were counting on receiving. Also, such an approach risks the possibility that public funding will be distributed on the basis of the strength of people's advocacy skills and the robustness of their advocacy networks. In such a context, people with equal levels of need end up receiving unequal levels of resources to address their needs (Nerney, 2001). We believe that team planning will be more creative and more meaningful, and a jurisdiction's system of allocating resources will be more equitable, if people commence their planning processes with an understanding of the resources that are available to them for services and supports.

Although Agosta and colleagues (2015) fully embrace the importance of creative problem solving and developing personalized support plans driven by the service recipient's life goals and preferences, they argue for considering budget allocations during the planning process. They contend that such knowledge is empowering: "Supports budgets assure that individuals know what their allocation is in advance of planning, so that they can choose the type and amount of services in their plan. Knowing one's budget promotes self-determination by putting people in charge of the services they receive from the outset" (pp. 3-4). Additionally, "knowing the supports budget ahead of time creates the space for a productive discussion between the individual and the planning team about the full range of supports, paid and unpaid, that are available to address the person's needs" (p. 4).

Supports Budget: A Case Study

The case of Howard provides an example of how a supports budget provides a foundation for a planning to meet individual needs. Howard lived at home with his family and wanted to remain with family members for the foreseeable future. Howard was assessed using the *SIS—A*, and in conjunction with other variables used by his jurisdiction, was assigned to a supports level reflecting his assessed need. Then, given his type of residence and age group, he was allocated a prospective budget; the amount was the same as that which was allocated to others with similar circumstances.

In advance of his supports planning meeting, Howard received notification of his support level and prospective budget allocation as well as information to illustrate how he might apply the budget to secure the services and supports he needs. Because Howard lived at home with his family, he could apply his assigned budget to select a combination of in-home supports and day services.

During the planning meeting, Howard and his team discussed his overall needs. This began with a discussion about Howard's strengths and interests, what he could do

without specialized supports, and when and where specialized supports were needed. It also featured discussion about the natural supports that he had in place and how friends and family might support him. Furthermore, there was discussion about community resources with which Howard could routinely engage that could provide needed supports (for examples of community supports, see *LifeCourse Tools* by University of Missouri at Kansas City Institute on Human Development, 2017). Finally, the team discussed the paid services that Howard needed and how his individualized budget will be applied. Howard and the team decided to use his funding to:

- Retain direct support professionals (e.g., personal care attendants) to provide periodic support in his home for part of the week, totaling 10 hours a week.
- Retain a community guide to assist Howard to join, without paid staff, a community health club he likes, as well as to participate in a peer support network that he values.
- Receive support to keep his part-time job at a hardware store for 20 hours per week.
- Participate in an art-oriented day program for 5 hours a week.
- Receive support to volunteer at a museum for 5 hours a week.

In addition, Howard added a few other needed services. These included physical therapy twice a month and a transportation service so that he could safely and reliably get to and from work.

The mix of services and their associated annual cost fell within the budget which his jurisdiction had allocated, and so the final plan was authorized. If, however, the planning process had yielded a plan that exceeded the budget, the team would have been encouraged to: (a) identify alternative resources that could be used to make up the difference, or (b) adjust the preferred mix of services in ways to bring down their total cost. After taking these steps, if additional paid resources were still required, Howard would request these resources through an exceptions process. In contrast, if the process yielded a budget under the assigned amount, Howard would keep these funds in reserve, pending decisions later to enrich his plan. Throughout the process, because Medicaid has strict rules concerning how funds can be used, the budget allocation could only be applied to obtain services for which Medicaid is willing to pay. The team could not plan on applying his budget, including reserves, to purchase goods and services outside of Medicaid's guidelines (e.g., food, vacation expenses). As a result, Howard's team, like any other planning team seeking to build a plan that involves supports in excess of the budget allocation or outside of what Medicaid might pay, would need to integrate alternative resources into their strategy.

Howard's story illustrates the advantages of an individualized supports budget. Howard and his team knew in advance what amount of public funding would be available. To begin, the team was encouraged first to identify and arrange supports outside this funding, reinforcing an overall policy intention for individuals to develop stronger connections to their communities. Next, Howard exercised authority over building his own personal service mix, and an exceptions process was available for him to ask for additional resources if needed. If Howard decides to move out of his family home in the future, he will have a different budget associated with his choice to be supported in

independent living that will provide sufficient funding for the support that he needs in this new setting.

From a systems perspective, this process, when enacted over thousands of service recipients, allows policy makers to manage resources more purposively, efficiently, and fairly. Further, with time and evaluation, policy makers should be able to make informed decisions over how to sharpen the funding framework, including service array, rates, service mixes, and budgets by support level.

The Road Forward

A theme throughout this paper has been that the issue of how to distribute finite resources among deserving individuals is different from the adequacy of the size of the finite resources that are available for distribution. Jurisdictions differ in regard to the amount of resources that are available for services to people with disabilities. For instance, within the United States, there are profound differences among states in terms of fiscal effort to support services to people with developmental disabilities (Braddock et al., 2015). The strength of any society's commitment to its citizens with developmental disabilities is partially reflected in its allocation of resources. Periods of increased commitment coincide with the expansion of resources, and periods of decreased commitment are evidenced by fiscal retrenchment.

We have attempted to show how the assessment of support needs can inform the work of people who are striving to establish a rational basis for distributing public funds that have been set aside for services and supports for people with IDD. However, the quality of guidance from the SIS scales, as well as any other assessment for that matter, will begin to diminish as a jurisdiction's overall fiscal effort becomes increasingly inadequate. In terms of this white paper, it is not our purpose to analyze the overall adequacy of funding to support people with disabilities in the United States or other countries. However, those committed to a social contract, where society makes a commitment to address the needs of its most vulnerable citizens, must remain vigilant in demanding that an adequate fiscal effort be made. When the finite pot of funds becomes woefully insufficient, there is essentially nothing to divide up among people.

References

- American Association on Intellectual and Developmental Disabilities. (2017). *International SIS use*. Retrieved from [http://aaidd.org/sis/international#
UsWhcPaSKW4](http://aaidd.org/sis/international#.UsWhcPaSKW4)
- Agosta, J., Petner-Arrey, J., Karedell, Y., Vazquez, A., Rojas, R., Taylor, B., & Villwok, M. (2016). *Information brief: Supports Intensity Scale and assessment levels*. Tualatin, OR: Human Research Institute.
- Agosta, J., Petner-Arrey, J., Aiken, F., Kardell, Y., Vazquez, A., Rojas, R., . . . Villwock, M. (2015). *Information brief: Person-centered planning and supports budgets*. Retrieved from <http://www.hsri.org/publication/information-brief-person-centered-planning-and-supports-budgets>
- Agosta, J., Taylor, B., & Vazquez, A. (2016). *Information brief: Service definition best practice standards and emerging innovative services*. Tualatin, OR: Human Services Research Institute.
- Burns and Associates (2016). *HCBS waiver programs*. Retrieved from <https://www.burnshealthpolicy.com/services/>
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Individuals With Disabilities Education Act, 20 U.S.C. §§ 1400 *et seq.* (2006 & Supp. V. 2011).
- Lakin, K. C., & Stancliffe, R. J. (2007). Residential supports for persons with intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 151–159. <http://dx.doi.org/10.1002/mrdd.20148>
- Larson, S. A., Faykin, F., Muchow-Hallis, L., Pettingel, S., Taylor, B., Hewitt, A., Sowers, M., Fay, M. L. (2015). *In-Home and residential long-term supports and services for people with intellectual or developmental disabilities: Status and trends through 2013*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Residential Information Systems Project.
- Nerney, T. (2001). *Filthy lucre: Creating better value in long term supports*. Wayne, MI: Center for Self Determination.
- Stancliffe, R. J., & Lakin, K. C. (2005). Context and issues in research. In R. J. Stancliffe and K. C. Lakin (Eds.), *Cost and outcomes of community services for people with intellectual disabilities* (pp. 1–22). Baltimore, MD: Paul H. Brookes.
- The Arc. (2015). *WIOA: What it means for people with intellectual and/or developmental disabilities (I/DD)*. Retrieved from <http://www.thearc.org/document.doc?id=5183>

- Thompson, J. R., Bradley, V., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., Wehmeyer, M. L., et al. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, 47(2), 135–146. <http://dx.doi.org/10.1352/1934-9556-47.2.135>
- Thompson, J. R., Wehmeyer, M. L., Hughes, C., Shogren, K. A., Little, T. D., Copeland, S. R., . . . Tassé, M. J. (2016). *Supports Intensity Scale—Children’s version: User’s manual*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Thompson, J. R., Bryant, B., Schalock, R. L., Shogren, K. A., Tassé, M.J., Wehmeyer, M. L., . . . Rotholz, D. A. (2015). *Supports Intensity Scale—Adult Version: User’s manual*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- University of Missouri at Kansas City (UMKC) Institute for Human Development. (2017). *Life course tools*. Retrieved from <http://www.lifecoursetools.com/>.
- Workforce Innovation and Opportunity Act, Pub. L. No. 113-128, to be codified at 29 U.S.C. §§ 3101 *et seq.* (2014)