



# INFORMATION BRIEF

## Using Individual Budget Allocations to Support People with Intellectual and Developmental Disabilities

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From every quarter, policy makers are being challenged to restructure service systems for people with intellectual and other developmental disabilities (I&DD). Increasing service demand, budget shortfalls, workforce shortages, reliance on legacy and often inefficient services, and mounting preferences for services that promote community integration and self-direction are among the factors pressing on public service systems. Working within this context, policy makers are seeking to redesign systems to make better use of available funding now and for the future.

Human Services Research Institute (HSRI) is currently assisting several states to design more rational and politically defensible reimbursement levels and/or individual budgets for service participants. Drawing on this experience, we describe below a process for moving from current inequitable and inefficient resource allocation systems to ones that simultaneously foster greater individual control and utilize limited resources more effectively. The core concept is an *individual budget allocation* built on a standardized assessment of individual support needs. The three sections below describe: (a) how we define an “individual budget allocation” in relation to this work; (b) essential considerations for developing assessment-informed allocation models and individual budgets; and (c) the benefits states can realize from undertaking such a reform of their resource allocation systems.

### Defining Individual Budget Allocations

Without question, appropriately supporting people with I&DD requires a substantial financial commitment on the part of a state. Individuals with I&DD have disabilities that are life-long and result in significant functional impairments that often require day-to-day services and supports

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*Centers for Medicare and Medicaid Services*

throughout their lives. I&DD services are among the most costly long-term services. The federal Medicaid program plays a major role in assisting states to finance long-term services and supports to people with I&DD. It offers states alternative pathways to apply state matching funds to secure federal dollars for services. While states make varying choices in their utilization of Medicaid dollars, they nonetheless increasingly rely on the §1915(c) waiver authority to furnish

services. These “Medicaid waivers” allow states to provide an array of home and community-based services (HCBS) for people with I&DD.

Yet, *how* services are delivered is just as important as *what* is offered. People with I&DD want to live their lives in the community, just like everyone else. They also want control over their lives. Based in great measure on these demands, the changes that are emerging in systems of support for people with I&DD are part of a continuing evolution that began decades ago. Along the way, words like *normalization*, *dignity of risk*, *inclusion*, *participation* and *natural supports* served as rallying points to push along further change. More recently, the concept of *self-determination* has taken root, carrying great implications for reforming how I&DD systems are run and to what ends. In “self-directed” systems, individual service recipients have considerable authority over what supports they receive, how they are received and from whom. Fundamental to self-direction is the budget that each individual is allocated to secure needed services.

In this era of self-direction, policy makers wanting to restructure resource allocation practices must act consistently with Medicaid policies, while they simultaneously seek to embed opportunity for “self-direction” within the new payment practices. At the center of a system promoting self-direction is a personal budget allocation that the individual may apply within the bounds of an approved service plan to secure needed supports. In the HCBS waiver application instructions, the Centers for Medicare and Medicaid Services (CMS) define the term *individual budget amount* as “a prospectively-determined amount of funds that the state makes available for the provision of waiver services to a participant.”<sup>1</sup> Implicit in this definition are two key concepts: the *state* determines the budget amount for each individual, and that information is provided to the participant *prospectively*, i.e. the individual is told what amount is allocated *before* developing a service plan, rather than after the plan is completed. Often the allocated amount is fixed, though a range may be specified.

To determine individual budget levels, states must have previously established appropriate infrastructure to support the practice, beginning with a formal and standardized means to assess personal support needs, and extending to include service planning protocols, reasonable reimbursement rates for providers, processes for providers to be reimbursed for services rendered, and quality assurance. The individual budget allocation is the foundation upon which is built a participant-directed plan, that maximizes the use of available funds to advance the personal goals and preferences of the person with I&DD.

### **Essential Considerations for Developing Resource Allocation Models and IBAs**

Reforming resource allocation practices under most circumstances is a complex task requiring planning and patience with a process that can unfold over years, not months. Six essential considerations are described below.<sup>2</sup>

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<sup>1</sup> Centers for Medicare and Medicaid Services (2008). *Application for a § 1915(c) home and community-based waiver CMS instrument for reviewing HCBS waiver applications instructions: Technical guide and review criteria resource attachments* (page 298). Bethesda, MD: Disabled and Elderly Health programs Group, CMS.

<sup>2</sup> See: Kimmich, M., Agosta, J., Fortune, J., Smith, D., Melda, K., Auerbach, K., and Taub, S. (2009). *Developing individual budgets and reimbursement levels using the Supports Intensity Scale*. Houston, TX: Independent Living Research Utilization (ILRU); Community Living Partnership.

**1. Establish policy goals and leadership**

**commitment.** While the overarching intent may be to improve the efficiency and effectiveness of resource allocation, under that umbrella may fall other potentially compatible policy goals:

- Assuring that resources are authorized to individuals equitably and in ways that accurately and reliably account for personal support needs.
- Assuring that resources are managed effectively and efficiently.
- Assuring that services are reimbursed in ways that service providers are compensated with fair/adequate and reasonable rates.
- Introducing participant direction into the delivery of services.
- Assuring provider reimbursement rates reflect underlying system values and preferred outcomes.
- Complying with the governmental requirements set by administering agencies and, for Medicaid-reimbursable services, Federal statute and regulations.

**Six Essential Considerations**

1. Policy goals and leadership commitment
2. Meaningful dialogue among stakeholders
3. Reliable and accurate information on support needs & expenditures
4. Choice between “Level-Based Budget Allocations” or “Individual Budget Allocations”
5. Reconciliation of assessment information and rates
6. Implementation with minimal system disruption

At the project’s outset, policy makers need to consider these and/or other policy goals, and indicate those that most drive the effort. These decisions will come into play later to help address various issues that arise and judge the outcome of the effort.

**2. Assure meaningful dialogue among stakeholders and transparency in system**

**development.** Stakeholders include service recipients, family members, service providers and others concerned with the outcome. Through a “Stakeholders Committee” broad input and feedback can be continually gathered to help ensure that the envisioned changes and their implementation are consistent with service system values and principles. This is particularly important when designing the individual budget allocation process, because the individual budget is the point at which individuals and their support people experience the impact of any systemic changes – the methodological changes to the resource allocation algorithm become real. The continuing involvement of the stakeholder committee also will contribute to ensuring the long-term feasibility and practicality of the changes made.

**3. Compile reliable and accurate assessment information on individual support needs and expenditures per person.**

Essential to reforming the resource allocation system is choosing an assessment tool that will provide sufficient information to accurately and appropriately differentiate among service participants with respect to their supports needs. This measure of support needs is used in combination with other information to generate a prospective individual budget. The IBA then can be used in the service planning process in the context of individual goals and preferences.

The Supports Intensity Scale (SIS) is an assessment tool that is being used by at least fourteen states. The SIS, developed in 2004 by the American Association on Intellectual and Developmental Disabilities (AAIDD), provides a standardized assessment of individual support needs. Other tools are available (e.g., the Inventory for Client and Agency Planning) and states may find it preferable to use legacy tools that have been in use for years. However, it is essential that the instrument selected be capable of reliably assessing support needs as well as measuring the relationship between these needs and dollars expended.

Information must also be collected on the amount of money that is expended annually for each participant's support. These data can be difficult to generate. State leaders may have precise information to describe what amount they are paying per person, but may have little idea of what each person actually costs to support. For instance, if four individuals live in the same community residence, a service provider may receive a flat rate payment per person without regard to the support need differences among the residents. Likewise, providers may receive a flat rate payment for offering day services to individuals regardless of differences in individual support needs. Such "blended" or "flat" rates make it difficult to develop strong statistical relationships between measures of support need and historical expenditures across service recipients because individuals equally share the expenditure figure regardless of their support needs.

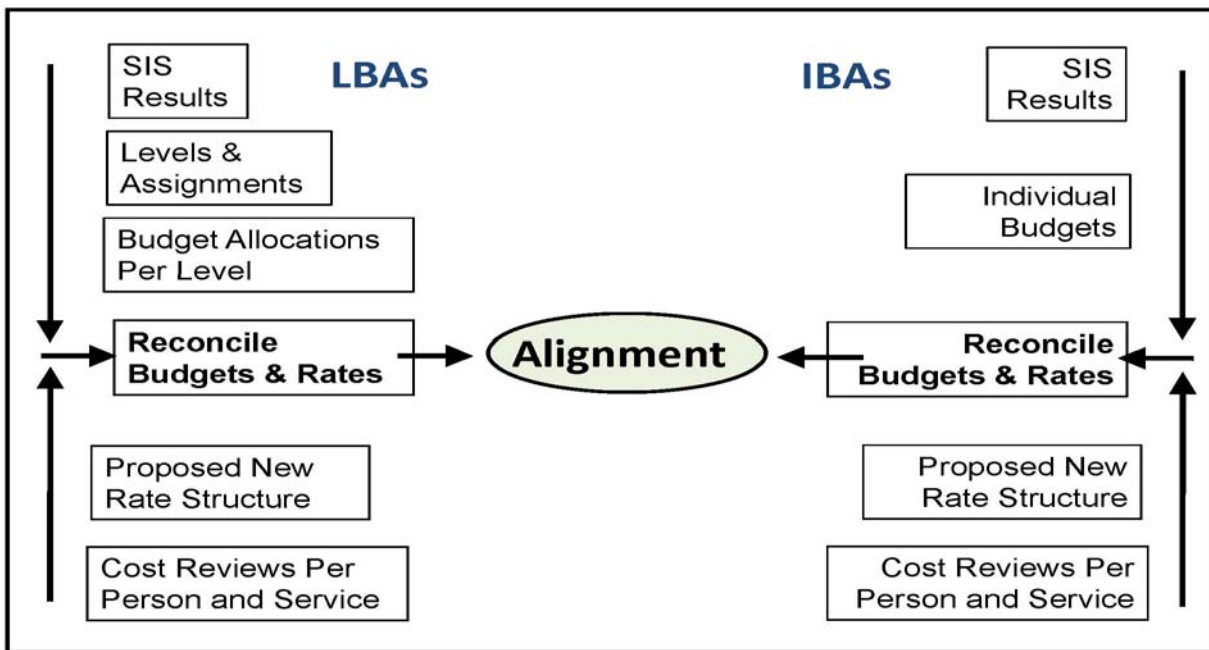
The value of the cost data may be enhanced by a measure of the direct service hours delivered to each participant over a specified time period. Other proxy measures or factors may be utilized as well, though until the expenditure side of the equation can be clarified it is difficult to draw relationships between support needs and costs.

- 4. Decide whether to develop "Level-Based Budget Allocations" or "Individual Budget Allocations."** Information on individual support needs can be used either to set broad allocation *levels* or to establish individual budget allocations. The choice hinges on the comprehensiveness of the data on individual needs and costs, and on the policy intentions of the state. In either case, the process is basically the same. The support needs of individuals are systematically analyzed in relation to costs (and perhaps direct service *hours*). Items in the assessment tool are examined in a variety of ways to determine what combinations of variables can best explain variance associated with targeted dependent variables (e.g., annual costs and/or a measure of services hours). The analysis is used to separate individuals into a reasonable number of "assessment" levels where there is meaningful separation between the levels. Typically, these levels depict low to high support needs, with other categories becoming apparent that are related to complex behavioral or medical needs. Ideally, total waiver expenditures and hours of support change in relation to changes in assessment level. In Level-Based Budget Allocations (LBA), the number of levels and their composition are dictated by the data set. The levels are tested against two major service categories: residential services and day services. It is worth noting that this process results in defined levels composed of individuals who are assigned to each level. All individuals falling within a level are assigned the same allocation (unless finer distinctions are made within levels, such as by creating sub-levels). In Individual Budget Allocations (IBA), each individual claims his own unique level; but achieving this degree of precision is

difficult initially. IBAs are calculated by computer through systematic analysis (as described above), but each individual is granted their own “level” or allocation.

Either way, care must be taken to set LBAs or IBAs in ways to achieve stated policy goals, but in a way to minimize dislocation for individuals. Most likely, as new allocations are set, some individuals will have increases or reductions in the amount they are assigned. As a result, states should take steps to inform individuals of their budget allocation and the means they could take to request that their allocated amount be reconsidered (e.g., informal review, fair hearing).

- 5. Reconcile assessment information and costs with respect to current payment rates and available state resources.** Regardless of whether LBAs or IBAs are used, individual allocations must be aligned with reimbursement rates. In addition to per person expenditure data, comprehensive provider cost information may be needed to guide the development of provider rates. States may decide either to utilize the existing rate structure or to take the opportunity to adjust reimbursement rates, perhaps encouraging certain service types over others.



Our approach to rate determination stresses the application of a standard rate-determination framework that bases rates on the level of direct staff effort necessary to deliver a particular service to people according to each person’s measured level of support need. Other components of the rate are based on observed usual and customary provider costs, but policy makers may also take into account a variety of factors (e.g., preferences pertaining to allowed indirect expenses, allowed expenditures for staff training or health insurance for staff, or differences in costs of living across the state). As a result, some service rates may be standardized so that each provider is reimbursed the same per unit of service. Rates

may also be graduated to take into account support needs per waiver participant and other factors. The goal here is to yield payment rates that are directly related to support needs while ensuring ample and equitable levels of provider compensation.

Initial prototype service rates are reviewed and must be reconciled with individual support needs to finalize the personal budget allocations. The budgets people are awarded must be adequate to purchase needed services while providers must likewise be reimbursed sufficiently for the services they deliver. Taken together, the complementary play between individual budgets and services rates must work within the overall aggregate system budget.

- 6. Implement the new resource allocation model (LBAs or IBAs) in a way that minimizes disruption to the existing service system.** With assessment levels established and payment rates associated with each level or individual budget, it is time to step back and carefully consider the upcoming implementation process. Altering payments for services obviously has ramifications for people with I&DD and for service providers. Policy makers must act cautiously to ensure that the revised rates and budget allocations do not result in major disruptions of the services and supports upon which people with I&DD and their families rely day-by-day. The state must develop the capacity to anticipate and analyze the effects of proposed changes. States may, for example, simulate the results of the new payment structure to study how funding patterns will change, or they may obtain feedback from stakeholders about the real-world implications any potential changes. Generally, states find it useful to phase in a new resource allocation model gradually while studying the impacts and making adjustments as warranted.

Overall, the process is a challenging one, dealing with the uncertainty of what the data will present as well as the sensitive dynamics of the situation on the ground. It is not a process which can be rushed. Each state is different. The basic approach must be to follow the data and actively engage all stakeholders.

### **Benefits of IBAs for Federal and State Waiver Operations**

Applying assessment-informed resource allocation practices to create individual budgets promises to yield distinct improvements in waiver programs. We describe below seven direct benefits:

- **Resource allocation can become more efficient and equitable.** Policymakers are seeking to restructure service delivery systems to achieve greater efficiency and equity – getting the most from each dollar spent and assuring that everyone is treated fairly, commensurate with their differing needs for support (and in a way that is impartial, free from biases or favoritism, or past uneven patterns of resource distribution).

#### **Seven Benefits of IBAs**

- More efficient and equitable resource allocation
- Increased opportunity for individual self-direction
- Quality improvement for waiver programs
- Values-driven systems reforms
- Development of new service approaches
- Realistic estimate of financial impact of wait lists
- Cross-state knowledge and understanding of support needs related to service costs

- *Efficiency* gains derive from having a better understanding of the costs required to provide a service at a given level of quality to a particular type of recipient. Efficiency demands that each recipient of service is allocated precisely the amount needed, no more and no less; similarly, a provider is reimbursed at a rate which covers the full costs of delivering a particular service to a particular type of individual, no more and no less. In redesigning the resource allocation process, a state not only studies the needs of its waiver population but also the true costs incurred by the provider community. On both sides of the equation one can expect to find opportunities to be more efficient. Ideally, the individual budget allocation reflects efficiencies in estimating providers' costs and in calculating the cost of the individual's support needs.

In the sphere of I&DD services, some residential service options are much less costly (per hour of support) than others, largely due to differing levels of intensity of supervision and support by staff. Some individuals may be capable of residing in these less expensive living arrangements that provide minimal support, such as supervised apartments. For them to live in a highly supervised setting would be inefficient – and likely also less appropriate given their capacity for independence and self-direction. An individual budget allocation would accurately reflect the hours of support the individual needs *but* would use hourly rates appropriate to the more independent settings.

- *Equity* requires a full, well-rounded understanding of a person's support needs, and the amount and intensity of support required to meet these needs. Few state I&DD service systems, however, presently use protocols that reliably assess individual support needs and translate such findings into equitable resource allocations. Very often, individual allocations are related to such “legacy effects” as when the person began services, whether and when he or she was relocated from a state facility, the fiscal arrangement made previously between the state and provider, or the relative tenacity of local case managers. As a result, over time and across geographic areas, decisions made about service awards often appear idiosyncratic and unfair. Equity means being fair – people with the same constellation of support needs receive the same budget allocation. Equity also means that uniform rates are established for all waiver services (with variations in accordance with the intensity of individuals' needs), such that providers receive the same rate for providing a given service to individuals with similar needs. Use of assessment-informed resource allocation models to create individual budgets guarantees that like individuals will receive like allocations; and that there is a rational, transparent justification for the decision.
- **Individuals can more definitively lead self-directed lives.** Policy makers may also apply individual budgets to position service recipients more favorably to direct their own lives. Emerging service practice for people with I&DD supports the belief that individuals and their family members must play leading roles in determining the substance of their lives, and that the relevant and preferred supports should be provided in accordance with need.<sup>3</sup> The

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<sup>3</sup> Kimmich, M., Agosta, J., Fortune, J., Smith, D., Melda, K., Auerbach, K., and Taub, S. (2009). *Developing individual budgets and reimbursement levels using the Supports Intensity Scale*. Houston, TX: Independent Living Research Utilization (ILRU); Community Living Partnership

Independence Plus Waiver and state-level initiatives to foster the use of “Support Brokerages” have done much to give individuals more choice among service providers and more control over their support plans. But self-direction means more than that.

- Individuals need to have ample authority over how their budget is applied to meet their needs. Having an individual budget will mean little if it can only be applied to a narrow or traditional group of providers. Systems grow more demand-driven when individuals can more freely exercise their preferences for varying providers, including new or alternative providers. Likewise, self-direction is enhanced when the range of services that individuals can choose from is broader. For instance, a program may allow for self-direction related to a few services (e.g., personal assistance, respite) and yet may not satisfy an individual's service needs. Overall, the wider the array of services the individual can direct, the greater the capacity for true self-direction.
- Individuals need support to participate effectively – for example, giving them information about service options, training for playing a self-directed role, and assistance to manage and pay staff or keep track of expenditures. This is especially crucial because many participants with I&DD have an intellectual disability that requires assistance and guidance from others. It cannot be presumed that such individuals can play an empowered role within the new system without training and support. Support may come from family members, friends, case managers and others. Policy makers must work with individuals and other in their lives to ensure that the individual exercises self-direction to the extent possible, even when the individual has (and needs) an extensive “support network”.
- Policy makers need to design service management practices that are simple to understand and have requirements that are straightforward to satisfy, if people with I&DD are to be able to participate effectively without significant intervention from others. For example, managing staff can be broken down into tasks the individual can handle (describing the supports needed and how they should be done; supervising the work) and ones that a fiscal intermediary could do (paying staff, tracking expenditures and other paperwork responsibilities), without undercutting the individual's desire and ability to direct his own life.

With this understanding of self-direction as a foundation, a state can adopt an assessment-based resource allocation model with individual budget allocations and thereby greatly enhance self-direction for people served through the HCBS waivers. There are two principle ways in which self-direction can be improved. First, an individual budget allocation means portability, that is, the individual can choose to change the specific provider of a service, or even the service s/he purchases, within a somewhat limited set of similarly-priced options. Because rates are set for a particular service to a particular type of individual (see “efficiency” benefit #1 above), moving to another provider becomes not a cost consideration but rather a question of quality and preference. And moving to another service type (such as from a family home to a supervised apartment) is similarly economically feasible since the individual budget allocation is based on the level of support needs of the person.

Second, an individual budget allocation sets the stage for a more meaningful support planning process. Knowing the allocation amount *prior* to the planning meeting means that more informed choices can be made – the individual can see immediately how a preference for a particular support means less of another desired support. It creates transparency, and leads the individual to clarify the relative value s/he places on particular types or methods of support. When the individual budget allocation is coupled with a standardized assessment measure of support needs, the process becomes even clearer. The Supports Intensity Scale, for example, was designed originally as a means of informing service planning; it covers a range of topics related to daily living skills, community life, employment, medical needs and behavior. The findings can spur discussion of various life topics. In addition, with a personal budget based on the assessment, individuals can better consider their needs in relation to the size of the budget and the supports available to make well planned decisions about what services to choose.

- **The quality of waiver programs and services can be improved.** Adopting an assessment-based resource allocation approach and building individual budget allocations are an integral part of a strong quality improvement process. As states pursue greater equity and efficiency in their resource allocation architecture, quality improvement is implicit in every step of the process. For example:(a) participant access to services is improved when an adequate and equitable budget allocation is established for each person; (b) participant-centered planning builds from knowledge of individual support needs, and the process is more effective when it occurs in the presence of a specific individual budget allocation, as discussed above; (c) provider capacity is enhanced by establishing appropriate service rates, which arise as part of increased efficiency and equity in resource allocation; and (d) participant safeguards are established in direct response to the nature of an individual's support needs.

Further, the quality of services can be improved by analyzing the impact of resource allocations on service outcomes. Policy makers are concerned about the health and well-being of service recipients, as well as whether or not the services they receive are having the desired effects. Little has been done, however, to assess systematically the relationship between individual budget allocations, the services delivered as a result of the allocation, and achievement of desired outcomes. The outcomes may be tied specifically to the individual (e.g., safety, gaining employment, having friendships) or to the system (e.g., reduced costs, increased staff tenure). By exploring such links, policy makers will begin to learn what services provide the best outcomes for the money spent and begin, over time, to improve system cost-effectiveness.

- **Values-driven systems reform can be encouraged and guided.** As state I&DD policy makers increasingly focus on long-range goals such as efficiency, equity and self-direction, service rates and individual budgets can be structured to promote the core system values. For decades, policy makers have given clear voice to the values and have worked to establish a wide array of services for people with I&DD. Unfortunately, however, they have not completely divested from “high cost but low value” services, nor have they ideally positioned systems to shed services that few want while developing others that are more

consistent with preferences for integration and self-direction. The issue arises with regard to both where waiver participants live and what they do during the day.

Certainly, not all high cost services have low value. For example, individuals with extraordinary medical conditions or behavioral challenges may cost a lot to support, but that expenditure may be highly cost-effective, yielding enhanced levels of health and well-being. In contrast, some services or practices with high costs may have low value to both individuals and policy makers. For example, large congregate care facilities have substantial fixed costs and high staff-to-resident ratios, making the per-hour or per-resident price much higher than other residential options -- yet many individuals would prefer to live elsewhere, closer to home or in smaller residences alone or with friends.

Likewise, training centers and sheltered workshops are mainstay day-time service options. Yet individuals with I&DD are often critical of such options, and consistently indicate preference for services that result in community employment -- the less-costly options. This point was poignantly made by a young self-advocate speaking at a professional gathering: she thanked her audience for all their efforts over the years, but added that “what you built, we don’t want.” She implored all to divest from costly and/or unwanted services, and offer services that help individuals live the life they want in their communities.

Providing individuals with authority over their own personal budget allocation can help reshape a state’s service supply over time. In addition, to encourage such shifts policy makers may adjust service reimbursement rates to make certain services more attractive than others.

- **Policy makers can use redesign of resource allocation models to develop or strengthen new service approaches.** States are increasingly emphasizing “in-home” supports where individuals live on their own, with family or with another support-giver. Research shows that in 2007, nearly 56% of those receiving I&DD services nationally were living at home with a family member.<sup>4</sup> Consistent with this finding, in recent years, a growing number of states have launched what have commonly come to be termed HCBS “supports waivers” for people with I&DD. These waivers are characterized by a relatively low dollar cap on total HCBS waiver services, flexibility in the selection of services within the dollar cap, and *the expectation that unpaid caregivers (e.g. family members) will provide significant support to waiver participants.*<sup>5</sup>

However, although family households are the mainstay of the service system, little is done to link these families together for mutual support. Working together, individuals with I&DD and their families can share information, pool their resources to achieve common goals, or work together to find and utilize informal supports in their communities. Such “human service cooperatives” are already taking form in several states, including Wisconsin, Illinois and

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<sup>4</sup> Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2008). *Residential services for people with developmental disabilities: Status and trends through 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

<sup>5</sup> Smith, G., Agosta, J. & Fortune, J. (2007). *Gauging the use of HCBS support waivers for people with intellectual and developmental disabilities*. Washington, DC: Office of Disability, Aging, and Long-Term Care Policy; Office of the Assistant Secretary for Planning and Evaluation; U.S. Department of Health and Human Services (Contract #HHS 100-03-0025).

Arizona. Going forward, policy makers may choose to nest within individual budgets sufficient resources for new services to link households together, and, accordingly, establish rates for services directed at such outcomes.

- **Costs for building capacity to address wait lists can be anticipated** by assessing those on the lists and projecting the potential cost to serve them appropriately. Demand for publicly-funded I&DD services is growing nationwide and, generally, has been increasing at a rate greater than population growth alone. It is not uncommon to observe year-to-year increases in the expressed demand for services of four percent<sup>6</sup> or more. Despite this reality, states generally operate their I&DD service systems under fixed capacity limits. Capped system capacity, coupled with rising demand for services, has resulted in individuals spilling over onto “waitlists.” How to address and plan for unmet service need is a major issue in most states.

To respond effectively, state policy makers must have reliable and accurate information pertaining to the number of people who have requested services and need them presently and others who would likely seek services in the near future. Doing so requires diligent data collection over several years to examine how demand trends behave over time.

At issue, always, is the accuracy of the information collected and the biases that may be inherent within the data. For example, in systems where resources are scarce, individuals may rush to express a service need whether or not it is presently needed, simply to “get on the list.” Such behavior tends to overstate numbers on a waitlist. In addition, states can confound their findings by establishing waitlists for a limited set of pre-defined services that individuals may or may not want; individuals who do not really want the particular service may sign up nonetheless, either because their desired option is not listed or as a safeguard against the possibility that their own needs will change by the time the service becomes available. The service-specific waitlist may thus overstate the need for that service.

States approach issues like these differently and with varying success. Colorado, for example, compiles a registry to track demand for services throughout the state. Likewise, Pennsylvania and Illinois gather information on service demand through the systematic use of a standardized protocol called the Prioritization of Urgency of Need for Services (PUNS). PUNS classifies individuals based on an assessment of how soon services must be provided. Individuals are classified as to whether the service need is an “emergency” (i.e., services are needed right away), “critical” (supports are needed within one year) or “planning” (services are needed within a 1-5 year time frame).

Building on this process, if states were to add to such data an assessment of support needs, they could make projections regarding the budget allocations individuals would require *if they were immediately enrolled* in the system and began receiving services. Such information would provide legislators and governors with more reliable estimates of the costs associated with reducing wait lists over time, and enable agency staff to more purposively plan for building system capacity.

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<sup>6</sup> Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2008). *Residential services for people with developmental disabilities: Status and trends through 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

- **A common understanding of support needs and associated service costs can be developed across states.** In the past, each state has developed its own I&DD service system largely on its own. Certainly, state policy makers share ideas and experiences across jurisdictions, and systems have common characteristics and offer comparable, though not identical, service arrays. Still, each system operates independently of others, with unique service populations, service protocols, provider networks, reimbursement mechanisms, quality assurance systems and so forth.

Developing cross-state data bases tied to a common assessment measure, such as the SIS, provides a valuable opportunity to change the situation significantly. Presently, HSRI maintains a data base of over 21,000 completed SIS surveys across seven states, including full state service populations in two of these states. The SIS data base allows comparison of waiver populations across states so that policy makers can observe whether the level of the support needs of individuals they serve in their own state differs markedly from other states. When individual-level expenditure data is added to the mix, comparisons between states are enriched.

In the future, as the data base grows, the performance of contrasting resource allocation models can be systematically compared. Which service models offer the greatest stability? Which result in the best fit for the service population with the least number of exceptions? Which are most efficient? Which are best at encouraging self-direction or nudging a system to incorporate more progressive practices? With time, these data may also be studied to assess trends in service demand or supply related to particular models. Eventually, models showing the greatest promise can be systematically applied, with appropriate modifications, to other jurisdictions with similar service populations.

## **Conclusion**

The past few years have witnessed substantial growth in the commitment among policy makers to improve the equity and efficiency of I&DD service systems, especially regarding resource allocation processes. Budget shortfalls, increased demand for supports – not just more service hours but also more person-directed supports – and other factors have coincided to lend support to this policy trend. In addition, advances in technical knowledge and capacity to assess individual support needs and develop more informed resource allocation protocols are making it increasingly possible for policy makers to restructure their allocation systems. The emergence of the Supports Intensity Scale (SIS) as a standardized, reliable tool for assessing individual needs also has been a crucial development. Several states (e.g., Colorado, Oregon, Georgia, and Louisiana) are already using the SIS to inform individual budget allocations.

This paper has highlighted the benefits of state reform initiatives, but not without clarifying the complex array of steps involved in the process. For each state, the question is not whether to follow this path but how urgently the change is needed and how steep the reform curve is likely to be. Urgency takes many forms. Some states face greater difficulties than others, from waiting lists or budget shortfalls or both. Yet, even where an I&DD system is facing significant challenges, redesign of the resource allocation protocol may be a necessary part of the solution.

On the other hand, the I&DD system need not be in crisis to undertake serious restructuring. Political will may favor staying ahead of full-blown crisis.

Going forward, policy makers have at least these two options to choose from:

- **Continue on the current path while taking small steps to explore the parameters of the needed re-design.** This option keeps the present ways of allocating resources intact, minimizing the resistance from stakeholders who are happy with the status quo but risking acrimony from parties eager to redress systemic inequities and inefficiencies. This approach buys time to line up political support and perhaps corral needed funds, but the time lag before serious reform begins may equally serve to dissipate commitment to change.
- **Press forward to restructure the resource allocation system and to establish level-based or individual budget allocations.** This option allows states to rally stakeholders around a desired reform process with specific products and time frames, and would position the state to reap the benefits sooner rather than later.

In HSRI's work across ten states, we have assisted policy makers in widely varying ways to embark on redesign of their resource allocation models and budgeting practices. Many of those that began slowly and with limited scope have eventually stepped up to a full-population endeavor. Some of those who chose to tackle the full effort from the start have moved on to refine their resource allocation algorithms or to expand to other waiver populations. Clearly, the decision rests on many factors. At a minimum, it would be prudent for state policy makers to explore the advantages and disadvantages of acting now rather than later, developing a rough work plan with estimated costs and timelines, so that a larger set of stakeholders – state government policy makers, legislators, advocates, service providers, and individuals and their families -- can weigh in and enable leaders to make an informed decision about how best to proceed.