Massachusetts, the first state to enter into a contract with the Federal Coordinated Health Care Office for a demonstration to provide services to people eligible for both Medicare and Medicaid, often referred to as dual eligibles, carved intellectual/developmental disabilities (I/DD) services out of their proposal even though all the demonstrations are supposed to cover all acute and long-term care services for everyone who is dually eligible.

Kansas' KanCare, a managed care proposal intended to cover all acute care and long-term care services for everyone eligible for Medicaid, has responded to ardent protest from the developmental disability community by carving I/DD services out for the first year of operation.

Additional states developing managed care proposals for the population eligible for Medicaid only as well as those eligible for both Medicare and Medicaid have also decided to, or are deliberating whether to, carve developmental disabilities services out.

Why are states carving out I/DD services? One view is that self-advocates, families, advocates and providers in the I/DD system are simply resistant to change; they want to hold on to the status quo and their resources; they are afraid of the rigorous accountability requirements in managed care and that perhaps providers won't survive.

Is this presumption true? Or might there be something substantive behind the resistance? And if we understand what is behind the resistance to managed care, might states have the information they need to develop managed care proposals that are responsive to stakeholders' concerns and do not meet with such resistance?

One way to analyze the resistance is to look at what is important to self-advocates and families in I/DD systems and the extent to which managed care proposals speak to their interests.

First and foremost for self-advocates is the desire to have a good everyday life: living in a place they like with people they like, working at a job that gives them an income and the prestige of playing their part in the economy; friendship and maybe romance; doing all those...
everyday things that make up life like shopping, working out, saying hello to a neighbor, worshipping, and having fun. Simple and fair expectations.

Families want the same things for their family member, but they also need support themselves so they can continue as the primary support for their family member. Families worry about the future, wondering if supports will continue, and often ask, "Who will be there when I am gone?" Families of children who are in school want something to be there after graduation and what they want is not group homes and "day activities." They want their kids to be working and moving toward independence. The families of those on waiting lists, which exist in at least 40 states, want help. They are looking for the services enjoyed by others and they don't want to have to wait for 10 years to receive those services.

Do managed care proposals speak to these expectations — and, in many cases, desperate needs? Do the proposals commit to using savings to serve unserved and underserved people on the waiting list? Do the words "care coordination" translate into a good everyday life? Does "community integration" mean going the distance to get someone a competitive job even if it costs more than an alternative day supports program the first two years?

Family support, a concept developed in the 1970s, has been very effective at helping families stay in it for the long run. But what assurance is there that family supports services will not erode in managed care when the words family support are not part of the discussion or in any written proposal? During the current recession, family support services have been the first service to suffer cuts, a pattern repeated from earlier recessions. Families are aware that service agencies know that even without support, they will do everything they can to keep their family member at home….where 90 percent of people with I/DD now live. What will be the basis for determining that family supports are necessary? Does "service substitution" translate into family responsibility and therefore reduced support to families?

Is it possible to structure a managed care program that is oriented to families, that accounts for the fact that services are life long and are not likely to be reduced over time, that imbeds a shared vision and set of values in the program and has a strong role for self-advocates and families in the development of policy? Well, we have a few examples in states that were the earliest adopters of managed care for long-term supports.

Arizona has been operating their I/DD program through an 1115 managed care waiver for some 20 years. It is an entitlement program without waiting lists, supports to families and services in the home and community are the bulk of the services delivered, self-advocates and families are active at the policy table, average service costs are among the lowest in the country, and system outcomes are well within the norm of other states (see www.nationalcoreindicators.com).

Michigan moved to managed care in 1998 through a 1915(b)(c) combination waiver. As part of that transformation, the waiting list was fully addressed. The system was designed with an eye to improving services and managing costs. The system's focus has continued to be on creating a
good everyday life for people with disabilities. Most recently, the program has focused on employment and the promulgation of positive behavioral practices. The costs in this fully entitled managed care system have been controlled over the decade and a half, and the system has survived the many state budget cuts.

With these examples, we have to conclude that yes, it is possible to design a managed care approach that not only meets the needs of people with developmental disabilities and their families, but also has the potential to do it more fully and creatively than in the traditional fee-for-service system. Success requires a focus on what is important to people, a process that engages them directly to build trust and a good design, a focus on planning for a transition that allows them time to prepare for the change, and good communication throughout the process.

Time is a factor. Thoughtful planning and participation require time: time to meet, time to draft and get comments, time to negotiate, time to test, and time to roll out the design responsibly; however, the pressures of budget cuts and legislative demands do not tolerate long time lines. But a negotiated time line with a solid target date can sharpen focus while allowing time to "do the thing right," avoiding mistakes that compromise the success of the program.

### Question...
#### Is Resource Allocation the Same as Capitation?

There are many questions about the difference between resource allocation and capitation in managed long-term services and supports. Do the two terms mean the same thing?

The answer is no, resource allocation is not the same as capitation.

Resource allocation is the funding amount, tier or rate band determined necessary to meet the needs of a specific individual.

Capitation, however, is the overall payment that the Managed Care Organization (generally per member per month) receives to provide for the services and supports for each and every person enrolled in the managed care program, along with all other managerial and quality functions to run the program.

**Resource allocation** has grown increasingly popular as state government systems have worked to increase equity in funding for people with I/DD, be cost effective with available dollars, and find new ways to support consumer directed budgets.

The calculation of resource allocation amounts are typically based on two categories of information while factoring in additional factors related to program and fiscal objectives.

- Information about the person that includes demographic information and an assessment of the person's functional and support needs.
• Information on the cost of services.
• Polices related to the types of services the state wishes to incentive (i.e. support people in their own homes, employment, community inclusion).
• The availability of funds.

The methodology to determine an allocation amount typically involves the use of statistical tools that effectively correlate need to service costs in order to determine the "right" amount of funding to meet the needs of each person relative to their characteristics and support needs.

The funding amount determined may be provided to the individual/family/support coordinator as the basis for developing an individual plan and budget and then purchasing services or the amount may be used as the basis for contracting with providers to serve specific individuals.

Can a resource allocation methodology be used in a capitated managed care environment? Yes. A managed care entity, once entered into a capitated contract with a state agency, could use a resource allocation methodology to determine an amount of funding needed to meet the needs of an individual. The managed care entity can provide the funding amount determined to the individual/family/support coordinator as the basis for developing an individual plan and budget and then purchasing services or the amount may be used as the basis for contracting with providers to serve specific individuals.

Capitation is the overall payment that the managed care organization (MCO) receives to provide for the services and supports for each and every person enrolled in the managed care program. Capitation includes more than just the sum of service dollars for all people receiving services and their individual support needs and must include all other contract components for administration, case management, quality management, billing, data management and other functions outlined in the MCO contract. And, each person's needs must be met according to the services outlined in the contract, regardless of the capitation rate received by the managed care organization.

There is a variety of methods used to set capitation rates and for people with intellectual/developmental disabilities involved in managed care long-term services and supports. Based on actuarial analysis, these factors should include, at a minimum, the following elements:

• Known policies or legislative changes.
• Demographics of people served and new people coming into program (where people live, work, spend their days).
Policies and programs to incentivize more in home services, employment services, and community-based supports.

Regional factors such as cost of living differences, and the network of providers and services available to meet people's needs.

Utilization, encounters, and expenditure data.

Specific costs and rate models for building provider rates.

Supporting people in new and better ways in the community, e.g., increasing the number of people with significant behavior needs receiving community support and working in community jobs, shared living, more children with autism receiving intensive services to intervene early.

If managed care contracts are all-inclusive, providing primary/acute health care, behavioral health services and long-term services and supports, these components are analyzed for each portion of the capitation, even if the final capitation is "rolled up" into one per member per month rate. There may be adjustments for specific circumstances such as transplants, hemophilia, or people with extraordinary support needs, such as helping children dependent on ventilator equipment to live in the family home and participate in community life.

As can be seen, capitation includes many more elements than resource allocation, which mainly focuses on services costs for a specific individual. ✺

Medical Necessity in the Context of Managed Long-Term Care Services and Support for People with Intellectual/Developmental Disabilities

Many stakeholders in I/DD have raised concerns about the "medicalization" of services if/when supports are provided through managed care systems due to requirements that services and supports meet medical necessity criteria. In contrast to medical managed care services, the vast majority of services for people with I/DD are long-term in nature and focus on people receiving supports to lead quality lives in the community, learning and growing throughout the lifespan. As such, a different approach to medical necessity needs to be taken when being applied to long-term services and supports rather than physical health services.

Certainly, access to quality health services is vital; indeed, health disparities for people with intellectual/developmental disabilities is a well-known issue, but medical/health services are only one facet of services.

Medical clinical guidelines exist in state and federal regulations, along with nationally recognized evidence-based standards for physical health. There are clinical practice guidelines for medically
appropriate interventions for specific medical conditions, diagnoses and recognized treatment plans (as well as those approved through specific waivers, especially for adults). For health related services, the concept of medical necessity is clearly established.

These kinds of evidence based and clear medical necessity criteria are largely unavailable for long-term, home and community-based supports for people with intellectual/developmental disabilities. This is because home and community-based services are not clinical in nature and focus instead on "initiating strong support for keeping members integrated with their families, communities, and other support systems."

There can be commonalities in necessity criteria between medically necessary services in acute care and medically necessary long-term services and supports, in that services and supports are:

1. Based on assessed need;
2. The most cost effective and efficient option to meet the person's needs;
3. Provided in the most integrated environment (often referred to as the least restrictive environment in current managed care contracts);
4. Not based primarily based on convenience of the person, caretaker, family or clinician; and,
5. Documented in the individual plan of services (or care plan for acute services).

From there, however, the criteria need to diverge. Services and supports to achieve quality lives in the community, such as employment, hourly habilitation for community living, learning new skills, respite, positive behavior support and newer, relationship-based models for out of home care (shared living) are not classically "medically necessary" through a primary care provider's script.

These services, instead, are based on each person's assessed needs, goals, and preferences in the context of the whole person. In addition, as more people with I/DD receiving services live within the family home (exceeding 55 percent nationally and much higher in several states), the person and their family situation are considered in service plan development.

For example, a person recently transitioned from high school may have many disability "labels," such as "significant cognitive disabilities" and "does not communicate through words." He may live in a family home with four siblings of similar ages that want to help provide supports and a relative with a family business who has expressed interest in employing the person if supported employment services were provided. The assessed need of employment services is considered the primary goal of the service plan.

The service plan for another man with similar support needs may differ considerably if he lives with a single, working parent and three younger siblings. The family moved to the city and has few community connections. The assessed needs and service plan would be tailored to this person's and family's situation and goals.
In summary, when looking at appropriate necessity criteria for long-term services and supports within managed care programs, it is important to carefully analyze two components:

1. Ensure the necessary criteria include the construct of the whole person (and, as appropriate, their family), the community and the person's desired outcomes; and

2. Add the more commonly known necessity criteria of managed care in order to meet regulations: covered services that are the most cost effective, integrated, and effective to meet the person assessed needs.

The analysis and design of necessity criteria is one key factor to begin the creation of services and supports that are value added for people with I/DD in managed care.

### Update on Dual Demonstration Projects

The following chart provides an update on the CMS Dual Demonstration Projects and Financial Alignment Initiative, including which states have included people with I/DD for acute, behavioral health and/or long-term services and supports in their proposals. As the state proposals continue to receive state and federal public comment from stakeholders and fine-tune their proposals, the following is composed of the most recent information available at this time.

<table>
<thead>
<tr>
<th>STATE</th>
<th>FINANCING MODEL</th>
<th>STATUS OF I/DD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arizona</td>
<td>Capitated</td>
<td>The I/DD population is fully carved out of this demonstration.</td>
</tr>
<tr>
<td>California</td>
<td>Capitated</td>
<td>People with I/DD receiving services from the Department of Developmental Services and regional centers are carved out from the demonstration. There are some people with developmental disabilities receiving services through the state's in-home supportive services (IHSS) and community-based adult services (CBAS) that will be included in the demonstration.</td>
</tr>
<tr>
<td>Colorado</td>
<td>Managed Fee for Service</td>
<td>The demonstration will include Colorado's entire dual eligible population, including those with I/DD with enhanced coordination between acute and long-term care.</td>
</tr>
<tr>
<td>Connecticut</td>
<td>Managed Fee for Service</td>
<td>People with I/DD are included with increased coordination focused on acute health care.</td>
</tr>
<tr>
<td>Hawaii</td>
<td>Capitated</td>
<td>The demonstration &quot;excludes approximately 1,200 individuals enrolled in the DD/DD 1915(c) home and community-based services (HCBS) waiver program.&quot;</td>
</tr>
<tr>
<td>Idaho</td>
<td>Capitated</td>
<td>The I/DD dual eligible population will be fully included in the demonstration.</td>
</tr>
<tr>
<td>STATE</td>
<td>FINANCING MODEL</td>
<td>STATUS OF I/DD</td>
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</tr>
<tr>
<td>Illinois</td>
<td>Capitated</td>
<td>The I/DD population is fully carved out of this demonstration.</td>
</tr>
<tr>
<td>Iowa</td>
<td>Managed Fee for Service</td>
<td>The demonstration will include Colorado’s entire dual eligible population, including those with I/DD, and has a heavy focus on acute care and health homes, although long-term supports and services (LTSS) and home and community-based services (HCBS) will be included.</td>
</tr>
<tr>
<td>Massachusets</td>
<td>Capitated</td>
<td>HCBS waiver services are carved out of the demonstration for now. There will be intersection with the I/DD population, however, on acute and behavioral health care at this time.</td>
</tr>
<tr>
<td>Michigan</td>
<td>Capitated</td>
<td>The demonstration will include the I/DD dual eligible population through a carve-in. Already existing pre-paid inpatient health plans (PIHPs) will remain in place, but if individuals with I/DD opt out of the demonstration they will not receive the enhanced care coordination and linkages with acute care envisioned in the new program design.</td>
</tr>
<tr>
<td>Minnesota</td>
<td>Capitated</td>
<td>The demonstration will include I/DD 1915(c) waivers.</td>
</tr>
<tr>
<td>Missouri</td>
<td>Managed Fee for Service</td>
<td>Dual eligible in I/DD waivers will have access to health home services &quot;for the coordination of all Medicare and Medicaid covered services, including Medicare and Medicaid long-term care services outside of primary care and behavioral health such as home and community-based (HCBS) services, developmental disabilities services, and waiver case management. Individuals receiving additional waiver services through a home and community-based services (HCBS) waiver or other state waiver program will continue to receive these services as usual but the Health Home will take responsibility for coordinating such services as appropriate.&quot;</td>
</tr>
<tr>
<td>New Mexico</td>
<td>Capitated</td>
<td>I/DD waiver participants are carved out for LTSS, and carved in for acute care.</td>
</tr>
<tr>
<td>New York</td>
<td>Capitated</td>
<td>The I/DD population will be part of a pilot in 2014, in fully integrated duals advantage (FIDA) Plans developed by OPWDD, including acute and long-term care.</td>
</tr>
<tr>
<td>North Carolina</td>
<td>Managed Fee for Service</td>
<td>The I/DD population is excluded from the three year demonstration.</td>
</tr>
<tr>
<td>STATE</td>
<td>FINANCING MODEL</td>
<td>STATUS OF I/DD</td>
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<tr>
<td>Ohio</td>
<td>Capitated</td>
<td>Individuals receiving service through Ohio's I/DD waiver are excluded. Those not in the I/DD waiver have the opportunity to opt in to the duals project.</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>Managed Fee for Service</td>
<td>Dual eligible individuals in waivers, including those with I/DD, will receive care coordination through the demonstration, but it will wrap around the existing service structure. A care coordinator monitoring a dual enrolled in a waiver or long-term care program may offer services complementary to existing services with the added benefit of disease management, but no services will be added beyond care coordination. Those members not in a waiver or HCBS will receive the full services of care coordination encompassing both Medicare and Medicaid.</td>
</tr>
<tr>
<td>Oregon</td>
<td>Capitated</td>
<td>Oregon's two home and community-based 1915(c) waivers for support services for people with developmental disabilities are excluded from the Coordinated Care Organization (CCO) global budgets; CCOs are still responsible for the health care needs for individuals receiving these excluded 1915(c) waiver services.</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>Capitated</td>
<td>The I/DD population is initially carved out of the demonstration, although Rhode Island intends to study possible future inclusion.</td>
</tr>
<tr>
<td>South Carolina</td>
<td>Capitated</td>
<td>South Carolina's demonstration is focused on dual eligibles over 65 and does not include the I/DD population.</td>
</tr>
<tr>
<td>Tennessee</td>
<td>Capitated</td>
<td>LTSS for persons with intellectual disabilities will remain carved out of the demonstration, but dual eligible members receiving these services will be part of the demonstration for all other services.</td>
</tr>
<tr>
<td>Texas</td>
<td>Capitated</td>
<td>The I/DD population is fully carved out of this demonstration.</td>
</tr>
<tr>
<td>Vermont</td>
<td>Capitated</td>
<td>The demonstration will include Vermont's entire dual eligible population, including those with I/DD for all services.</td>
</tr>
<tr>
<td>Virginia</td>
<td>Capitated</td>
<td>The I/DD population is fully carved out of this demonstration.</td>
</tr>
<tr>
<td>Washington</td>
<td>Capitated and Fee for Service</td>
<td>Washington's demonstration is divided into three &quot;strategies;&quot; strategy two, which involves a full financially integrated model purchased through health plans, will include...</td>
</tr>
</tbody>
</table>
Other New I/DD Managed Long-Term Care Service and Support Developments

NEW HAMPSHIRE

CMS has approved the New Hampshire Department of Health and Human Services Department state plan amendment to implement a statewide managed care program in late March 2012. Care management will include both acute and long-term supports and services for all Medicaid beneficiaries, including individuals with developmental disabilities. Enrollment for all populations is mandatory, beginning in Phase 2 of implementation when LTSS come on line.

Three contractors have been selected as MCOs; Boston Medical Center Health Plan, Granite Care-Meridian Health Plan of New Hampshire, and Granite State Health Plan (Centene Corporation).

The managed care system, care management, will be implemented in three phases. In the first year, Phase 1, all Medicaid enrollees will enroll in one of the MCO plans, starting with medical services, mental health, home health, private duty nursing, durable medical equipment, and related services. Phase 2 will incorporate long-term supports and services with a target date of January 2014. This includes people with I/DD. Phase 3 will include individuals eligible through the Affordable Care Act.

FMI [www.dhhs.state.nh.us/ocom/care-management.htm](http://www.dhhs.state.nh.us/ocom/care-management.htm).

NEW JERSEY

New Jersey's 1115 Comprehensive Care Waiver was approved on October 1, 2012. While this comprehensive waiver includes all aging and disabled populations, several components are
targeted specifically for people with intellectual and developmental disabilities (I/DD). A brief summary of the major elements affecting people with I/DD:

All Medicaid beneficiaries, including people with I/DD, will receive physical and behavioral health services in a managed care arrangement. Behavioral health services will be managed — separately from physical health services — in an administrative services organization (ASO).

Children between 6 and 21 years of age with I/DD and mental illness who meet ICF/MR institutional level of care will be provided "certain home and community-based services," which will be managed by the Department of Children and Families; their behavioral health services will be managed by the children's ASO for behavioral health.

Children up to age 13 with pervasive developmental disorders will receive select HCBS services managed by the Department of Children and Families.

All individuals with developmental disabilities living on their own or with families will be eligible to enroll in a new waiver program — the Supports Program — which will provide employment and day services, as well as funding for an array of community-based individual and family supports, administered by the Division of Developmental Disabilities.

FMI [www.state.nj.us/humanservices/dmahs/home/waiver.html](http://www.state.nj.us/humanservices/dmahs/home/waiver.html).

1 Arizona long-term care services definition for attendant care.