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Challenges Posed by Waiver Waiting Lists

Roger Auerbach
Susan C. Reinhard

This document was prepared by Roger Auerbach of Auerbach Consulting, Inc. and Susan C. Reinhard of Rutgers Center for State Health Policy (CSHP).

Prepared for:

Rutgers Center for State Health Policy

Susan C. Reinhard & Marlene A. Walsh

Robert Mollica

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Rutgers Center for State Health Policy
55 Commercial Avenue, 3rd Floor
New Brunswick, NJ 08901-1340
Voice: 732-932-3105 - Fax: 732-932-0069
Website: www.cshp.rutgers.edu/cle

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Summary

More states are using "money follows the person" and institutional transition programs to rebalance their long-term care systems. One major challenge they face is the decision to give certain individuals priority access to services when there are home and community-based services (HCBS) waiver waiting lists.

This State *Policy in Practice* brief describes how selected states develop and maintain waiting lists and whether they are giving service priority to certain groups of people on a waiting list, such as those transitioning from institutional services.

Major Points

- States have a variety of lists, known as waiting lists, planning lists, interest lists or registries.

- The process for adding individuals to a list varies, from a telephone call to an authorized entity to an eligibility assessment for waiver services; some place individuals on a list and only require an assessment when there are waiver slots available.

- Some states develop and administer a single centralized list for each waiver, while others delegate responsibility for maintaining a list to county or regional entities and require a data reporting process to periodically adjust waiver service and slot allocation.

- Some states have adopted laws and policies that require new waiver services be allocated to people on a list based on date of application (Iowa) or the date clients have their name placed on a list (Maryland); both of these states have exceptions for some individuals who are transitioning to HCBS from existing Medicaid-funded institutional services.

- All states interviewed consider the date of application, but most also prioritize services by some form of "needs" test.

- All states interviewed give priority either to an established number of individuals moving from institutional to community-based services (i.e. 100 a year) or all individuals transitioning from institutions.

- States vary on how individuals move from a list to receiving services.

Background

States have developed a variety of lists for individuals who want and need home and community-based services (HCBS) offered through Medicaid waiver programs when the State does not have resources available to serve them. A review of HCBS waiting lists by the University of California San Francisco for the Kaiser Commission on Medicaid and the Uninsured found that 206,427 individuals were on waiting lists for 102 waivers in 2004.[1]

When waiver slots and financing are not available to all who need them, states address a number of policy issues in developing and maintaining waiting lists:

- Do we assess individuals' need for services or simply maintain a list of individuals who express interest in waiver services?
- If we do an assessment, do we assess both need for services and financial eligibility for Medicaid?
- If we do a care assessment, how often do we reassess care needs?
- Do we maintain a centralized waiting list or delegate responsibility to local administrative entities?
- When funding becomes available for additional waiver slots, how do we allocate those new slots? Are the slots allocated centrally? Are the slots and/or funding allocated to local administrative entities?
- Are there certain criteria to be used to give service priority for individuals in certain categories, such as those transitioning from institutions or at risk of institutionalization?

These are some of the questions states address as they attempt to balance the fairness of first-come, first-served with their desires to implement "money follows the person" and institutional transition programs, and serve people most in need of HCBS waiver services.

States considering developing or modifying priority criteria for waiver services should be aware of federal policy developed by the Centers for Medicare & Medicaid (CMS). The new HCBS Waiver Application, Version 3.3, Appendix B-3-c clearly requires a state filing a new or renewal application to specify whether any waiver capacity is being reserved (prioritized) for certain groups of eligible individuals. CMS

[1] Kitchener, Ng, Harrington: *Medicaid 1915(c) Home and Community-Based Service Programs: Data Update.* The Kaiser Commission on Medicaid and the Uninsured, 2005.

requires that the purpose for the reservation be specified and how the state determined the amount reserved for each group that it prioritized. The CMS instructions for the completing this subsection state that if there are not CMS-approved categories and reserved capacity (slots), all waiver openings are considered available to all who apply and are eligible. CMS lists the following as examples of appropriate purposes for reserving waiver capacity:

- community transition of institutionalized individuals
- individuals transitioning from other waivers
- individuals requiring services due to a crisis or emergency
- individuals who age out of another waiver or other services

As discussed below, these examples reflect criteria states have been using in prioritizing access to waiver services.

Program Practices

To explore these issues, we interviewed officials from selected states. States were chosen from the Kaiser report based on waiting list size, type of waiver and geography. Representatives from 6 states operating 20 waivers with waiting lists were interviewed by telephone. The states include: Georgia, Iowa, Kansas, Maryland, Minnesota, and Michigan.

To gain an understanding of the relationship between "money follows the person" and other rebalancing programs and existing waiver waiting lists, we used a semi-structured interview guide and reviewed state policies and procedures.

Descriptions from these six states are summarized in three major areas: developing the waiting list, maintaining the waiting list, and moving from waiting lists to services.

Developing the Waiting List

Georgia Community Care Services Program (Elderly/Disabled Waiver)

Individuals receive a telephone screening by an Area Agency on Aging (AAA) specialist to determine eligibility for waiver services, and to establish priority for a face-to-face assessment for an initial plan of care. During the telephone call, specialists explain the eligibility criteria, screen for functional eligibility using a Determination of Need Functional Assessment (DON) and use Medicaid criteria to assess financial eligibility. The DON screening results in a score that determines an applicant's priority for initial assessment and eventual eligibility for waiver services. Individuals who receive a high score are referred for a face-to-face assessment if funds may be available for waiver services. Individuals are placed on a waiting list based on their score if the

DON is low or financing is not available. Applicants are advised of all non-waiver community resources which may meet their needs.

Georgia Waiver for Individuals with Mental Retardation/Developmental Disability (MR/DD)[2]

Individuals apply for services through a regional single point-of-entry system and receive a face-to-face assessment of their need and eligibility for services within 14 working days. If individuals are eligible for waiver services, but the resources are not available to fund the services, they are placed either on a short-term or long-term planning list. Some of the services offered through the waiver, such as day and residential services, may also be available through state-funded programs and may be accessed while individuals are on a planning list. However, the planning lists are maintained for eligible individuals needing and desiring the full array of waiver services. In cases of emergency, there can be immediate access to services, but not necessarily to all services.

Individuals are placed on the short-term planning list based on the determination that:

1. The consumer lost placement because of death or abandonment by caretaker;
2. The consumer is in immediate danger of losing home/care supports because of a terminally ill caretaker;
3. Current placement imminently is harmful to the consumer (children or adult protective services involvement or abusive/neglectful home environment) or the consumer becomes a danger to others;
4. The consumer is gravely disabled and needs intensive supervision and care and the parents/guardians are elderly or incapacitated;
5. The consumer is in need of more restrictive/intensive care after lesser care placement has failed;
6. The consumer/family needs can best be served in a community placement instead of the more restricted, institutional environment (MHMRSA Policy on Planning Lists No. 7.101).

Long-term planning lists are "working waiting lists" that are more flexible. They provide opportunities to explore options and help keep regional boards connected to consumers and families. Some examples given for individuals who may need services in the future include:

1. Consumers whose placement is in danger due to long term illness of a caretaker;

[2] Georgia is in the process of revising its policies on "planning" lists. The summary provided here reflects procedures in effect in June 2006.

2. Consumers whose parent/caretakers are aging and desire placement and there is no other responsible person who can provide needed care;

3. Consumers who have a severe medical or behavioral problem which is progressive or warrants a more structured placement over time (MHMRSA Policy on Planning Lists No. 7.101).

Iowa HCBS Waivers

Iowa administers a uniform policy for all five of its waivers that have waiting lists. Individuals can apply for waiver services, but only receive a full assessment if there are available waiver slots. They can be placed on a waiting list through contact with a Department of Human Services' income maintenance worker. Individuals can apply for Medicaid and are screened for financial eligibility. If they are found eligible, they can receive Medicaid State Plan services. They can also receive available state-funded services.

Kansas HCBS Waiver for Individuals with Developmental Disabilities (DD) and HCBS Waiver for Individuals with Physical Disabilities (PD)

Individuals are assessed to determine whether they have an institutional level-of-care using different assessment tools for the two waiver populations. The assessments are completed by the Community Development Disability Organizations (CDDOs) for the DD Waiver and the Independent Living Centers for the PD Waiver. If individuals meet the appropriate institutional level-of-care and there are no available waiver slots, they are placed on a waiver waiting list. For individuals with developmental disabilities, state-funded day and residential services may be available through the CDDOs. For individuals with physical disabilities, non-waiver services may be available through the Independent Living Center.

Maryland Older Adults Waiver (Elderly), Living At Home Waiver (Physically Disabled) and Waiver for Children with Autism Spectrum Disorder

When a waiver is closed to new applicants, an individual may call a toll-free telephone number if they are interested in pursuing waiver services. A Waiver Services Registry contractor informs them about the registry process. If they are interested in "registering" for waiver services, the contractor collects information and adds them to the appropriate registry based on the date of the request. No eligibility screening is performed. The contractor sends a letter to the individual and their representative, if applicable, telling them that they are on the Registry. A fact sheet on the applicable waiver and a Registry rights and responsibilities fact sheet are included. The rights and responsibilities fact sheet includes information on: the right to appeal eligibility decisions; that individuals will be treated with dignity and respect; that disclosed

information will be kept confidential; the responsibility to notify the Registry of contact information changes; the need for timely response to requests for information; understanding that there are eligibility requirements for the waiver which must be met in order to receive waiver services (DHMH Waiver Services Registry Policy).

However, if individuals desire waiver services, have been in an institution where Medicaid has paid for their services for at least 30 days, and are eligible for waiver services, their applications can be processed and they can receive waiver services without going on the Registry (DHMH Policy).

Minnesota Nursing Facility Level-of-Care Waivers for Individuals under age 65 (CADI, TBI)

Individuals are screened for eligibility by the county. If the person is eligible for waiver services, the county then determines if it has a waiver slot to immediately begin services. If it does not have an available slot, the individual is placed on a waiting list. The State allocates resources to the counties every six months, but reserves some resources to ensure service to people wishing to leave nursing homes and hospitals.

Counties are required to have a state-approved "Resource Management Policy and Procedure" including a waiting list for individuals who are eligible for and choose waiver services, but are unable to access them. The policy must include a prioritization for allocation of waiver slots following state requirements for serving:

1. Persons relocating from nursing facilities, long-term care hospitals or acute hospitals (depending on specific waiver);
2. Persons relocating from regional treatment centers, institutions for mental diseases (IMDs) and other institutions; and
3. Persons at imminent risk (within 30 days) of admission to nursing facilities, regional treatment centers, long-term care hospitals, IMDs, and other institutions.

A second level priority is other persons living in the community eligible for and choosing waiver services and need services that would otherwise be provided in a nursing facility or hospital. Counties must periodically reevaluate the needs, choices and options for those individuals waiting for waiver services and make individuals aware of available Medicaid State Plan services which could meet their needs. It should be noted that the State and CMS are engaged in ongoing discussion about the operation of some of these policies.

Michigan MI Choice Program (Elderly/Disabled Waiver)

Waiting lists are developed and maintained by each waiver program agent for the area it serves when the number of individuals applying for services exceeds program capacity. Any person who expresses interest in the program must be evaluated by the waiver agent using the Telephone Intake Guidelines (TIG) at the time of request. If people are determined ineligible by the TIG, they may request a face-to-face evaluation using the Medicaid Nursing Facility Level of Care Determination and financial eligibility criteria. If they appear to meet the level of care criteria, but do not appear to meet the financial criteria, they may be placed on a waiting list if they may be eligible within 60 days.

If individuals are determined presumptively eligible based on financial information and the TIG, but new participants are not being accepted, they are placed on the waiting list chronologically by priority category. Applicants determined ineligible based on the telephonic screen may request a face-to-face evaluation using the regular Medicaid functional and financial criteria (Michigan DCH Bulletin, 2005). The priority categories in order of priority are:

1. Persons no longer eligible for Children's Special Health Care Services because of age;
2. Nursing Facility Transition participants;
3. Current Adult Protective Services clients;
4. All others by date of request

MI Choice program agents advise applicants on waiting lists of all alternative options for assistance.

Maintaining the Waiting List

Georgia Community Care Services Program (Elderly/Disabled Waiver)

Waiting lists are developed and maintained separately at the local level by the twelve (12) Area Agencies on Aging (AAA) according to uniform procedures established by the state Division of Aging Services. The Division tracks the lists at the state level. Individuals on a waiting list must be re-screened every four (4) months to determine if an applicant's priority or need for services has changed. If the level of need has changed, an individual's placement on the waiting list may also change.

Georgia Waiver for Individuals with Mental Retardation/Developmental Disability (MR/DD)

Both short-term and long-term planning lists are developed and maintained at the regional level in accordance with policies developed by the state agency. Individuals on the short-term planning list are reassessed every quarter by their support coordinator to determine their need for services. Individuals on the long-term planning list are reassessed annually. If there is a change in need for services, individuals can move from one planning list to the other, although allocation of overall slots and resources continue to be made at the state agency level.

Iowa HCBS Waivers

The waiting lists for all waivers, except the waiver serving people with mental retardation, are maintained by the state Department of Human Services. Individual counties maintain the waiting lists for the MR Waiver and report to the State on the waiting list status every six months. Individuals are not assessed or reassessed for waiver services while on the waiting list.

Kansas HCBS Waiver for Individuals with Developmental Disabilities (DD) and HCBS Waiver for Individuals with Physical Disabilities (PD)

Individuals on the DD Waiver waiting list are reassessed each year as many are receiving other services. If they are not receiving services, they are generally not reassessed. Individuals on the PD Waiver waiting list are reassessed if they have been on the waiting list for over a year and they become eligible for a waiver slot.

Maryland Older Adults Waiver (Elderly), Living At Home Waiver (Physically Disabled) and Waiver for Children with Autism Spectrum Disorder

The Department of Health and Mental Hygiene (Medicaid) is responsible for the Waiver Services Registry which is managed by a contractor. Individuals are not assessed or reassessed for services while on the Registry. Quarterly, the State matches the Registry information against State vital statistics records of deceased residents to remove deceased individuals from the Registry.

Minnesota Nursing Facility Level-of-Care Waivers for Individuals under age 65 (CADI, TBI)

Waiting lists are developed and maintained by each county based on state policy guidelines . The State uses a waiver management system to track the counties' waiting

lists and allocates new waiver slots every six months. Individuals on the lists are periodically re-evaluated for their needs, choices and options.

Michigan MI Choice Program (Elderly/Disabled Waiver)

Waiting lists are developed and maintained by each waiver program agent for the area it serves. The MI Choice program agents must submit a quarterly report to the state program development office which includes information of the number of persons waiting in each category by number of months, new persons enrolled in the program from each category in the last quarter, and the number of persons eliminated from the waiting list for any reason, except program enrollment, and the reason for removal.

Moving from Waiting List to Services

Georgia Community Care Services Program (Elderly/Disabled Waiver)

The state Division of Aging Services allocates funds to each AAA for the waiver program. The AAA determines the number of people it can serve with the funds available including any new people from the waiting list. When it determines that there may be enough funding to admit new individuals from the waiting list, it contacts waiting list individuals, based on DON score and length of time on the list, to determine if they still need services. If they continue to need services, they are referred for a face-to-face assessment and an initial plan of care. The Division monitors the utilization of allocated funds and can transfer allocations among AAAs based on need.

In a recent legislative session, the Legislature specifically allocated waiver funding for individuals transitioning from a nursing facility. Other than this program, new waiver services are delivered to those eligible individuals based on assessment of need and length of time on a waiting list.

Georgia Waiver for Individuals with Mental Retardation/Developmental Disability (MR/DD)

Available money and waiver slots are allocated to the regions on an annual basis. The State normally holds back some of the slots for emergencies which occur during the year. For example, in 2006 the State reserved 17% of the available slots as a reserve to distribute to regions for emergencies. The regional boards decide who can be served from the short-term list. Boards often phase-in people from the list during the course of the year.

Iowa HCBS Waivers

State law requires that any new waiver slots be distributed on a first come, first served basis, based on the date of application. However, there are some slots in the MR/DD waiver specifically reserved for individuals transitioning out of an Intermediate Care Facility for Individuals with Mental Retardation (ICF/MR). Generally, letters go to individuals on the waiting lists as soon as a waiver slot is available. For the MR/DD Waiver, counties are allocated new waiver slots, if available, every six months. Statewide waiting list data, including numbers of slots approved and numbers of individuals on a specific waiting list, is available on the DHS website.

Kansas HCBS Waiver for Individuals with Developmental Disabilities (DD) and HCBS Waiver for Individuals with Physical Disabilities (PD)

Available waiver slots for the DD Waiver are allocated at the beginning of each budget period. Some funding is held in reserve in order to serve individuals who meet "crisis" criteria (discussed below). The PD Waiver slots are allocated from a centralized waiting list and people are moved into waiver services as soon as a slot becomes available. Kansas representatives report that there are terminations from and additions to waiver services on a regular basis.

Generally, individuals get waiver services on a first come, first served basis. However, individuals can receive waiver services through a "crisis exception" if there is a waiting list in place. The criteria for both waivers include, but are not limited to persons who:

1. Are at significant, imminent risk of serious harm because the primary caregiver(s) is/are not able to provide the level of support necessary to meet the person's basic needs;
2. Require protection from confirmed abuse, neglect, or exploitation;
3. Are at risk of family unit dissolution (break-up), involving minor dependent child or dependent spouse; or
4. Are at the end stages of a terminal illness, and life expectancy is documented by a physician to be less than six (6) months.

In addition, for individuals with MR/DD would be given an exception to the waiting list and would begin services immediately when:

1. Support is needed to support a child or family when that child has been determined by the state agency to be at imminent risk of coming into custody of the agency; and
2. Support is needed for an individual who is being released from state agency custody as part of a permanency plan in transitioning to adult services at age 18 or thereafter.

Finally, state statute provides that if an individual moves from the state ICF/MR, money will follow that person and waiver services are available. Similarly, eighty (80) individuals a year can move from institutional services and receive PD Waiver services.

Maryland Older Adults Waiver (Elderly), Living At Home Waiver (Physically Disabled) and Waiver for Children with Autism Spectrum Disorder

For the Living at Home Waiver and the Waiver for Children with Autism Spectrum Disorder, waiver slots are generally available at the beginning of a waiver year given budget support. Waiver slots for the Older Adults Waiver are filled monthly as individuals leave the Waiver. Medicaid notifies the contractor when waiver slots become available and the contractor notifies individuals on the Registry in numerical order by mailing the individuals a waiver application and application materials.

Medicaid mails the waiver's Administering State Agency Waiver a list of individuals who have been given the opportunity to apply for waiver services. The Administering State Agency then contacts the individuals by telephone to offer assistance in completing the application and to answer questions. Individuals have one month to respond. If there is no response, the Registry contractor mails a second letter and application. If there is no response after the second letter and month, the individual's name is removed from the Registry.

Minnesota Nursing Facility Level-of-Care Waivers for Individuals under age 65 (CADI, TBI)

Each county decides which individuals get access to services based on its allocation from the State and its state-approved Resource Management Policy and Procedure. The policy and procedure include a state-required prioritization of services for individuals relocating from institutions and those at imminent risk of institutional admission (see above discussion in Development).

Michigan MI Choice Program (Elderly/Disabled Waiver)

MI Choice Program agents receive a budget from the state and are expected to manage the program within that budget. They must decide whether they can add new participants to the program within the allocated budget and slots. When they decide that new participants can be added, they must make those opportunities available to people based on priority category on a first come/first served basis with first priority to individuals "aging out" of Children's Special Health Care Services, next to Nursing Facility Transition participants, then to adult protective services clients (see Development above).

Conclusion

Most states are actively implementing programs to rebalance their long-term services and supports systems, many utilizing money follows the person principles and institutional transition programs. When states do not have sufficient resources to meet the needs of individuals requiring home and community-based services and choose to maintain some form of waiting list, they must make certain decisions on how to develop and maintain the lists and whether to give certain groups priority for newly-available services. These decisions become more important when trying to encourage individuals to transition for institutional to community-based services. Decisions about whether an individual transitioning from an institution should receive services before an individual on a waiting list, living at home and losing parental caregiver support, are very challenging.

This survey of state policy revealed that states use different methods to establish and maintain waiting lists, interest lists or registries when resources are not available to serve all who need assistance. Some states require assessments prior to being placed on a list; others only assess when there is likelihood that resources will soon be available; others only require a telephone call. Almost all states manage access to services on a statewide, centralized basis, although many states delegate major responsibility to regional entities to administer the waiting list process. All states interviewed consider date of application in determining priority for services, but most also prioritize by some form of "needs" test. While Georgia's elderly/disabled waiver uses a functional needs based assessment, other states use criteria which include: loss of primary caregiver; confirmed abuse, neglect or exploitation; grave illness; and children transitioning to adult services. All states interviewed give priority either to an established number of individuals moving from institutional to community-based services (i.e. 100 a year) or all individuals transitioning from institutions.

States will continue to analyze whether their policies make sense as sufficient resources will to be a challenge for almost all states in the near future. While there is a sense that it is the "fairest" to meet the needs by serving people by date of application, states committed to avoiding unnecessary institutionalization realize that some "need-based" priority system must be adopted. The challenge to balance competing principles will continue to confront states for years to come.

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Appendix 1.

Interview Questions

1. Do you have a waiting list, interest list or both? (need to distinguish)

2. If you have a waiting list, how are individuals' names placed on a waiting list (telephone to local or central number; e-mail)? Are they screened or assessed for Medicaid financial eligibility and/or institutional level-of-care? Do they have to have both financial and functional eligibility established before being placed on the waiting list?

3. If they are screened, what process and what tools are used to do the screening? Are people offered any services while on the waiting list?

4. Do they have to be reassessed or continue to verify need for waiver services (phone or otherwise) in order to remain on the list? If so, how often? Is this a state requirement through regulation or some other policy?

5. Is the waiting list prioritized with any criteria including "avoiding institutionalization" or "loss of informal supports"? Are there different criteria for different waivers? Can you share those criteria? How are they made public? If circumstances change, can a person be reassessed for movement up the list?

6. Are there circumstances where a person could move directly into the waiver without going on a waiting list? For example, if a person is leaving a nursing home, can they move to the top of the list?

7. Is the waiting list maintained centrally by the state? Do you have uniform guidelines? Are there separate local waiting lists? Are there uniform guidelines?

8. How do individuals move from the waiting list to waiver services? Are waiver slots allocated on an annual basis or more frequently?

9. Are waiver slots allocated to specific individuals on the central list? Are they allocated by priority, geography or other means? If there are extra slots one local area, can they be re-distributed to another area? How does that happen?

10. How do you track the data so you know about the availability of a waiver slot?

11. Under what circumstances have you stopped adding names to the waiting list?

12. Does the size of the list impact services expansion?

13. Is there anything else you want to share with us that I have not asked?

14. Is there anything you would like to know about how other states deal with this issue?